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Parkinson's disease: A study to examine, develop and feasibility test behaviour change techniques to improve physical activity and exercise self-efficacy (PD Active)

Thesis presented by

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for the degree of

Doctor of Philosophy

University College Cork

Discipline of Physiotherapy, School of Clinical Therapies

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2024

Abstract

Background: Parkinson's disease (PD) is a common progressive neurological condition characterised by motor and non-motor deficits. Physical activity and exercise can improve health outcomes but many people fail to reach or maintain the recommended physical activity guidelines. This was further exacerbated with the onset of COVID-19, where people were unable to attend exercise classes or support groups, resulting in deteriorating health, well-being, and social isolation. Virtual exercise classes were developed in an attempt to overcome those challenges. However, these online classes are not accessible to everyone, and many people are dependent on (face-to-face) organised commitment in order to maintain physical activity and exercise. This emphasised the importance of behaviour change techniques to support self-efficacy and independent physical activity. This in turn requires an in-depth exploration of the reasons why people engage in physical activity, the motivators and barriers to exercise, and how we can promote self-management rather than creating dependence on services.

Objectives: To review the existing literature regarding behaviour change techniques and exercise among people with Parkinson's disease (PwPD), and to qualitatively explore beliefs about exercise and exercise accessibility among PwPD, their family members/carers, and physiotherapists, and to then develop and test the feasibility of a tailored exercise intervention incorporating behaviour change techniques to improve self-management, exercise accessibility and adherence in PwPD.

Methods: Initially, a systematic review (SR) was conducted to determine behaviour change techniques used to promote exercise adherence and exercise self-efficacy among PwPD, and the findings were mapped to the Theoretical Domains Framework. Following this, a qualitative study was completed involving one-to-one interviews with PwPD and group interviews with family members, and with physiotherapists, to discuss the findings of the review and to explore

motivation, support, and self-managements of exercise in PwPD. These studies together informed how exercise and behaviour change can be tailored, explicitly including behaviour self-management strategies. The resulting intervention was tested for feasibility, and measurements of quality of life, self-efficacy, physical activity, and exercise adherence were collected.

Results: The SR showed that the five most important domains when implementing a behaviour change intervention were *behaviour regulation*, *belief about capabilities*, *social influences*, r*einforcement* and *goals*. The qualitative interviews highlighted differences in exercise preferences between men and women. Individuals expressed a strong desire to manage their own exercise prescription more; to be involved in the development and progression of exercise programmes, and they believed a shared responsibility (between the physiotherapist and the person) would encourage self-management. Therefore, the resulting intervention included the addition of four behaviour change techniques: activity diary (*behaviour regulation*), peer support (*social influences, reinforcement, belief about capabilities*), exercise specific education (*goals, belief about capabilities*), goals setting (*goals, reinforcement*) and barrier identification (*belief about capabilities, behaviour regulation*) to an existing 12-week PD exercise and education program. The feasibility study showed that exercise and behaviour change techniques were feasible and acceptable to participants, and the group dynamic was universally enjoyed.

Conclusion: Overall, this intervention could transform the health outcome for PwPD, by improving their self-efficacy, exercise adherence and empowering them with skills to self-manage their condition, potentially reducing healthcare burden. Clinicians should profile the individual's motivation type and their baseline understanding of exercise to select the appropriate behaviour change technique. Future pilot studies will include tailoring of the intervention based on the participants' qualitative feedback; adaptations to the exercise diary

(encompassing goal setting), providing videos of the exercises, involving family members more for home exercise programmes, reducing the number of education sessions, and including information about available support services (for family members).

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Poster Presentations

Phase 1: Systematic Review

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Ahern L, Timmons S, Lamb SE, McCullagh R. Can behaviour change interventions improve self-efficacy and exercise adherence among people with Parkinson's. Online Poster presented at European Geriatric Medicine Society 18th International Congress “Better Together: Multidisciplinary Team Working", London 28th-30th of September 2023.

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Phase 2: Qualitative Research

Ahern L, Timmons S, Lamb SE, McCullagh R. Exploring Perceptions and Understandings of the Role of Physical Activity and Exercise in the Management of Parkinson's: A Qualitative Study. Online poster presented at Futures Research Conference, University College Cork September 2023.

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Ahern L, Timmons S, Lamb SE, McCullagh R. ‘I knew nothing about Parkinson’s’: Insights into Receiving a Diagnosis of Parkinson's Disease from Patients' Perspectives: A Qualitative Study. Online Poster presented at European Geriatric Medicine Society 20th International Congress "Health Aging in the Changing World", Valencia 19th-21st of September 2024. DOI: 10.13140/RG.2.2.32039.15526

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Oral Presentations

Phase 2: Qualitative Research

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Phase 3: Feasibility Study

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Publications

1) Ahern L, Timmons S, Lamb S, McCullagh R. Can behavioural change interventions improve self-efficacy and exercise adherence among people with Parkinson's? A systematic review protocol [version 2; peer review: 2 approved]. *HRB Open Research*. 2022;5(15) https://doi.org/10.12688/hrbopenres.13474.2

2) Ahern L, Timmons S, Lamb SE, McCullagh R. A systematic review of behaviour change interventions to improve exercise self-efficacy and adherence in people with Parkinson's disease using the Theoretical Domains Framework. *Journal of Frailty, Sarcopenia and Falls*. 2024;9(1):2459-4148. https://doi.org/10.22540/JFSF-09-066

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4) Ahern L, Curtin C, Timmons S, Lamb SE, McCullagh R. 'I Knew Nothing About Parkinson's': Insights into Receiving a Diagnosis of Parkinson's Disease and the

Impact of Self-Management, Self-Care, and Exercise Engagement, from People with Parkinson's and Family Members' Perspectives: Qualitative Study. *Geriatrics*. 2025; 10(73). https://doi.org/10.3390/geriatrics10030073

5) Ahern L, Timmons S, Lamb S, McCullagh R. Behaviour change for Parkinson's disease: A randomised controlled feasibility study to promote physical activity and exercise adherence among people with Parkinson's: study protocol [version 1; peer review: 2 approved]. *HRB Open Research*. 2024;7(7) doi:10.12688/hrbopenres.13843.1

Published data sets

1) Ahern L. Data from: Extended Data for Behavioural change for Parkinson's disease: A randomised controlled feasibility study to promote physical activity and exercise adherence among people with Parkinson's: study protocol. 2023. *Dryad*. doi:https://doi.org/10.5061/dryad.5tb2rbpb9

2) Ahern L. Data from: Extended data for behavioural change for Parkinson's disease: A randomised controlled feasibility study to promote physical activity and exercise adherence among people with Parkinson's, study protocol. 2024. *Zenodo*. doi:https://doi.org/10.5281/zenodo.10407626

Declaration

This is to certify that the work I am submitting is my own and has not been submitted for another degree, either at University College Cork or elsewhere. All external references and sources are clearly acknowledged and identified within the contents. I have read and understood the regulations of University College Cork concerning plagiarism and intellectual property.

Signed



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Leanne Ahern

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D4: Publication 4: Ahern L, Curtin C, Timmons S, Lamb SE, McCullagh R. ‘I Knew Nothing About Parkinson’s’: Insights into Receiving a Diagnosis of Parkinson’s Disease and the Impact of Self-Management, Self-Care, and Exercise Engagement, from People with Parkinson’s and Family Members’ Perspectives: Qualitative Study. *Geriatrics.* 2025; 10(73).

D5: Publication 5: Ahern L, Timmons S, Lamb S, McCullagh R. Behaviour change for Parkinson's Disease: A randomised controlled feasibility study to promote physical activity and exercise adherence among people with Parkinson’s: study protocol [version 1; peer review: 2 approved]. *HRB Open Research*. 2024;7(7)doi:10.12688/hrbopenres.13843.1

Glossary of Abbreviations

ADL: Activity of Daily Living

BC: Behaviour Change

BCW: Behaviour Change Wheel

CI: Confidence Interval

COM-B: Capability, Opportunity, Motivation - Behaviour

CONSORT: Consolidated Standards of Reporting Trials

COREQ: Consolidated criteria for reporting qualitative research

ESES: Exercise Self-Efficacy Scale

EQ5D: EuroQoL – five dimensions

GRADE: Grades of Recommendation, Assessment, Development and Evaluation

H&Y: Hoehn and Yahr

JBI: Joanna Briggs Institute

MCID: Minimal Clinically Important Difference

MDC: Minimal Detectable Change

n-RCT: non-randomised controlled trial

PD: Parkinson's disease

PDQ: Parkinson's disease Questionnaire

PEEP: Parkinson's Exercise and Education Programme

PPI: Patient and Public Involvement

PRISMA: Preferred Reporting Items for Systematic reviews and Meta-Analyses

PwPD: People with Parkinson's disease

QoL: Quality of life

RCT: Randomised controlled trial

SAM: Step Activity Monitor

SPPB: Short Physical Performance Battery

SR: Systematic review

SSI: Semi structured interviews

TDF: Theoretical Domains Framework

TIDieR: Template for Intervention Description and Replication

TUG: Timed Up and Go

UPDRS: United Parkinson's disease Rating Scale

WHO: World Health Organisation

5TSTS: Five-time sit to stand

6MWT: Six-minute walk test

Chapter 1

Introduction and Background

1.1 Introduction

Parkinson's disease is the second-most common neurodegenerative disease after Alzheimer's Disease.[1] The incidence of Parkinson's disease is approximately 1.5 times higher in men compared with women[1], with an estimated 6.1 million people worldwide living with Parkinson's disease.[2] In Ireland, the incidence is 1–2 per 1000 in the general population and 1 per 100 in those over eighty years. With a population of 5,089,478 there is an estimated 15,000 people living with Parkinson's disease in Ireland.[3,4]

Parkinson's disease is a progressive neurological condition with cardinal features (tremors, bradykinesia, rigidity, festination of gait) and non-motor features (mood, pain, sleep, fatigue, etc). Deteriorating motor symptoms can lead to a sedentary lifestyle, which worsens with disease progression[5], subsequently leading to increased functional dependence[6] and declined physical condition.[6] The severity of the disease is quantified using the Hoehn and Yahr scale.[7] The scale originally was described in 1967 and included stages 1 through 5.[7] It has since been modified with the addition of stages 1.5 and 2.5 to account for the intermediate course of Parkinson disease, known as the modified Hoehn and Yahr scale.[8] As shown, people who are in Stages 1-3 are independently able to walk, with some postural instability. (see Figure 1.1).

Stage 0: No signs of disease
Stage 1.0: Symptoms are very mild; unilateral involvement only
Stage 1.5: Unilateral and axial involvement
Stage 2: Bilateral involvement without impairment of balance
Stage 2.5: Mild bilateral disease with recovery on pull test
Stage 3: Mild to moderate bilateral disease; some postural instability; physically independent
Stage 4: Severe disability; still able to walk or stand unassisted
Stage 5: Wheelchair bound or bedridden unless aided

Figure 1.1: Modified Hoehn and Yahr Scale[8]

The importance of exercise in the management of Parkinson's disease has been well researched.[9,10] Exercise is essential for people with Parkinson's disease (PwPD) to relieve symptoms[11], as well as improve strength, balance, gait speed, physical function and motor control[10], with emerging evidence suggesting it may have a neuroprotective effect, possibly decelerating disease progression.[12,13] Recent research has shown that many types of physical exercise (dance[9,14], tai chi[14], pilates[14], Nordic walking[14], boxing[14], rope sport[14], aqua-aerobic[9], gait-balance-function training[9], mind-body training[9], LSVT BIG[9], gaming, endurance training[9], strength and flexibility training[9]) worked well for PwPD compared to no physical exercise.[9,14] However, the evidence is scant regarding the more effective type of exercise.[9] Therefore, the personal preferences of PwPD should be given special consideration to help motivate them to adhere to an exercise programme. Any exercise counts! In spite of this emerging evidence, as few as 30% of PwPD meet the recommended activity guidelines[1,7] with most being one-third less active than age-matched peers.[15,16]

1.1.1 Issues with motivation to exercise

Stronger motivation is highly correlated with exercise participation.[17] Intrinsic motivation involves accomplishing an action for the pleasure and satisfaction gained from performing the behaviour.[18-20] Extrinsic motivation to perform an action refers to the completing of a behaviour for reasons other than the actual action, such as gaining praise from others or avoiding negative evaluations.[18-20] Both intrinsic and extrinsic motivation are believed to involve brain regions that are innervated by the dopaminergic pathway.[21] Although, it is known that dopamine transmission subserves motivational processes, some evidence suggests that it is particularly important for intrinsic motivation.[22]

PwPD often report that lack of motivation prevents regular physical activity (22% (43/201 surveys)).[23] Parkinson's disease is characterised by the depletion of the neurotransmitter

dopamine. Dopamine function plays a vital role in motivated behaviour[24] and as a result reward processing can be compromised in PwPD.[25,26] Dopamine contributes to exploration for the sake of interest[27,28], with dopamine projections resulting in increased subjective interest in, and motivational energy for, previously enjoyable activities[29] and dopamine has also been associated with intrinsically motivated flow states.[30,31] As Parkinson's disease progresses, the dopaminergic neurons related to intrinsic motivational functions are highly affected.[32] Dopamine depletion associated with the disease progression may result in lack of motivation, loss of interest in pleasurable activities, and pessimistic views of exercise capability.[33,34] This may affect PwPD's well-being, compliance and participation in treatment, physical activity or exercise.[35]

One of the main factors reported by PwPD who do not participate in any regular physical activity (compared to PwPD who engage in regular physical activity) is lack of motivation, although this could be cause or effect.[23] If intrinsic motivation is lowered by disease progression, this poses the question of whether strong extrinsic motivation could encourage people to engage in regular physical activity and exercise or not.

In older adults, extrinsic motivation has a positive relationship with exercise behaviour[36], while intrinsic motivation shows a strong positive relationship with physical activity levels.[37,38] Adult men reported higher intrinsic motivation for exercise compared to adult women.[20] Further, women are more likely than men to report exercising for the extrinsic reasons of losing weight and improving physical appearance.[39-41] Motivation is also related to exercise behaviour change. Specifically, people who begin to exercise report higher levels of extrinsic motivation i.e. they are exercising for a purpose[42], while those who maintain exercise regimens over time report higher levels of intrinsic motivation, i.e. "enjoying" it.[17,37] Additionally, expectations of enjoyable and valuable exercise can drive motivation.[43,44] Therefore, reasons and motivation type should be examined to help people engage with exercising long term.

There are many factors that could affect one's motivation to exercise including cognitive issues (difficulty understanding the instructions or value of exercise)[45], general health barriers[46], lack of social support[23], poor accessibility of the exercise location and lack of transportation to the location[23] and low previous physical activity level or sport participation.[23] One factor that has not been widely discussed in the research is the emotional challenge that comes with a diagnosis of Parkinson's disease, and the lack of exercise specific education at or near the time of diagnosis. Research conducted among people with Multiple Sclerosis found that general practitioners often support patients to manage comorbidities, which has been related to a delayed diagnosis of Multiple Sclerosis, progression of disability, lower health-related quality of life, and increased mortality due to the condition.[47-49] Another aspect is the emotional burden placed on the caregivers. If the individual with Parkinson's disease rely on others for transport to exercise classes or requires supervision during at home exercises, they may be reluctant to enrol. Therefore, leading to the question, does a delayed diagnosis and/or emotional burden indirectly impact one's motivation to exercise?

1.1.2 Behaviour change

Adapting from a sedentary lifestyle to a more physically active lifestyle is a complex process.[50] Research is limited regarding the optimal strategy to encourage this change (among PwPD) and its success in promoting long term adherence to physical activity. Previous research has implemented barrier identification[51], problem solving[51] and goal setting[52] as the main behaviour strategies. To promote motivation and encourage healthy behaviour change in PwPD, the effective strategies need to be identified, in order to develop a model that includes all the essential components for this change process. While behaviour change techniques offer structured approaches to support engagement and adherence, it is important to recognise that these techniques do not operate in isolation. Their effectiveness depends on how they interact with each other, as well as with the individual's personal context, including physical, cognitive,

and emotional capacity, and broader environmental factors such as social support, accessibility, and cultural norms. In Parkinson's disease—where symptoms, motivation, and support needs can fluctuate over time—tailoring BCTs to the dynamic and individualised lived experience is essential. Therefore, this project considered not only which techniques were used, but also how they functioned collectively within the participant's own social and environmental context.

1.1.3 Theoretical Domains Framework

The Theoretical Domains Framework (TDF)[53] was originally illustrated in 2005 and has since been revised in 2012. The TDF is an integrative framework remodelled from a combination of psychological theories as a tool to help implement theoretical approaches to interventions aimed at behaviour change.[53] The framework consists of 14 domains generated from 128 constructs, which were developed from 33 theories of behaviour change.[54] It provides a high level of explanation for constructs related to individual level change while it also contains combined (e.g., organization) level constructs.[55] The domains include knowledge (e.g., of condition/scientific rationale, procedural knowledge); skills (e.g., competence/ability, assessment); social/professional role and identity (e.g., group/social identify, social/group norms); beliefs about capabilities (e.g., self-efficacy, perceived competence); optimism (unrealistic optimism, pessimism); beliefs about consequences (e.g., outcome expectancies, anticipated regret); reinforcement (reward, incentives); intentions (e.g., stability of intentions, stages of change model); goals (e.g., goal priority, goal/target setting); memory, attention, and decision processes (e.g., attention control, decision making); environmental context and resources (e.g., environmental stressors, barriers and facilitators); social influences (e.g., social pressures, social norms); emotion (e.g., fear, anxiety) and behaviour regulation (e.g., self-monitoring, breaking the habit).[53] Therefore, these domains will help identify the most important intrinsic and extrinsic components of behaviour change that may influence self-management and exercise adherence. However, while the TDF offers a comprehensive

framework to identify behavioural determinants, its static structure does not adapt to the dynamic and evolving nature of behaviour, particularly in progressive conditions like Parkinson's disease, nor explain behaviours. These limitations highlight the need for adaptive approaches that can capture changes in individual aspirations, needs, and capacities over time.

1.2 Aims and objectives.

The overall aim of my project was to design, develop and test the feasibility of a tailored exercise intervention incorporating behaviour change techniques to improve exercise self-management, exercise accessibility and adherence in people with Parkinson's disease.

The objectives were

- To systematically identify the common behaviour changes techniques used to promote exercise among PwPD and examine their effectiveness.
- To qualitatively explore motivation to exercise, support, and self-management needs among people with Parkinson's disease, their family members and physiotherapists.
- To design a novel exercise programme with behaviour, change techniques to improve self-efficacy, and physical activity.
- To test the feasibility of a novel exercise programme, measuring recruitment, study procedures, resource needs, participant adherence and safety.
- To explore qualitatively the experience and perceptions of the programme.

1.3 Project structure

This project was conducted in line with the Medical Research Council (MRC) Framework for intervention development[56] and follows Eldrige *et al*[57]. The MRC guidelines suggest four important phases when developing and evaluating complex interventions; 1. Developing a complex intervention, referring to the entire process of designing and planning an intervention, from initial conception through to the feasibility study.[56] This involved adapting an existing

intervention for a new context, based on research evidence and theory of the problem.[56] 2. Feasibility, assessing the feasibility and acceptability of the intervention and evaluating the design, to make decisions about the progress to the next stage of evaluations.[56] 3. Evaluation, assessing an intervention using the most appropriate method to address the research questions.[56] 4. Implementation, considering the efforts to increase the impact and uptake of successfully tested health improvements.[56]

In order to achieve this, the project was divided into three phases (Figure 1.2; Systematic review, qualitative research and feasibility study). From the literature, behaviour change techniques included a wide range of different methods including videos, role-playing, education sessions, and self-monitoring (symptom diaries) which led to improvements in both quality of life and mobility[51,52], as well as improved self-efficacy and depression.[51,58] However, it remained unanswered as to whether these techniques led to better exercise adherence and more physical activity, indicating that a comprehensive systematic review of exercise behaviour strategies was needed.

Therefore, the aim of the first phase was to systematically identify the most common types of behaviour changes techniques used to promote exercise and physical activity among PwPD (Figure 1.2, Phase 1). A systematic review was conducted (Chapter 4) to determine the effects of behaviour change (BC) techniques to improve exercise self-efficacy and adherence in PwPD. The BC interventions were mapped to the Theoretical Domains Framework[53], which helped identify effective core components across the interventions. Most were small exploratory studies, and interventions were multi-component, including education, behaviour techniques, and support groups. Exercise self-efficacy remained unchanged, while small improvements in exercise adherence, quality of life and physical function were seen.[59] It was determined that the most effective TDF domains were *behaviour regulation*, *belief about*

capabilities, *social influences*, *reinforcement*, and *goals*. Heterogeneity between studies prevented a meta-analysis, highlighting the novelty of the topic and need for further exploration. These five domains were used to frame the topic guides for the Phase 2 interviews with PwPD, the family members and physiotherapists to explore their lived experience and motivation to exercise.

Previous literature exploring barriers and facilitators to exercise for PwPD, has highlighted the importance of family[60-62] and social supports.[60,61] However, these studies did not provide insight into self-management and support needs from the individuals, family members and physiotherapists' perspectives. Therefore, the aim of the second phase of the project was to explore PwPDs' motivations for exercise, support, and self-management needs among people with Parkinson's disease (PwPD), their family members and physiotherapists (Figure 1.2, Phase 2). A sequential qualitative interview study was conducted (Chapter 6) with the first stage informing the subsequent stages. In Stage 1, through semi-structured one-to-one interviews with PwPD, their motivation to exercise, and the challenges that arise, the main supports and motivation needs of the PwPD were identified. These findings were brought to the subsequent Stage 2 group interview with their family members, and Stage 3 group interview with the physiotherapists.

The systematic review showed the effective behaviour change domains were *behaviour regulation, belief about capabilities, social influences*, *reinforcement* and *goals*. While the qualitative interviews highlighted that differences in exercise preferences existed between men and women, and individuals expressed a strong desire to be more involved in planning their own exercise programme. The findings from the systematic review and the qualitative research informed the behaviour change techniques aimed to improve exercise self-efficacy and exercise adherence and the self-management of exercise/physical activity in PwPD. Phase 3 aimed to

test the feasibility of additional behaviour change techniques (activity diary, peer support, exercise specific education, goals setting and barrier identification) to an existing 12-week Parkinson's exercise and education programme (Figure 1.2, Phase 3). The exercise and behaviour change techniques were ***feasible*** and ***acceptable*** by the participants, with most participants reporting the activity diary and goal-setting the most important BC technique and the WhatsApp peer support method the least important. Two outcome measures (the ESES and PDQ39 SI) showed floor/ceiling effects, potentially as the participants had low disability. Generic measures may detect improvements better, such as the Exercise Self-Regulation Questionnaire which can additionally indicate motivation type, and the EQ5D to measure health status. The results of the feasibility study are presented and discussed in relation to the project as an entirety and its implications for future research (Chapter 11).

Most of the findings of the thesis have been published, therefore this thesis takes the form of a publication-based thesis. The text of each paper, published or prepared for submission, is presented in a chapter, in conjunction with additional supporting text as needed in linking chapters. The PDF copies of the published papers are further presented in the appendices. Consent forms, participant information sheets and supplementary materials are also presented in the appendices.

*This work from this project was funded by the Irish Research Council Enterprise Partnership Scheme in conjunction with Parkinson's Ireland (*EPSPG/2021/77*) awarded to Leanne Ahern.*

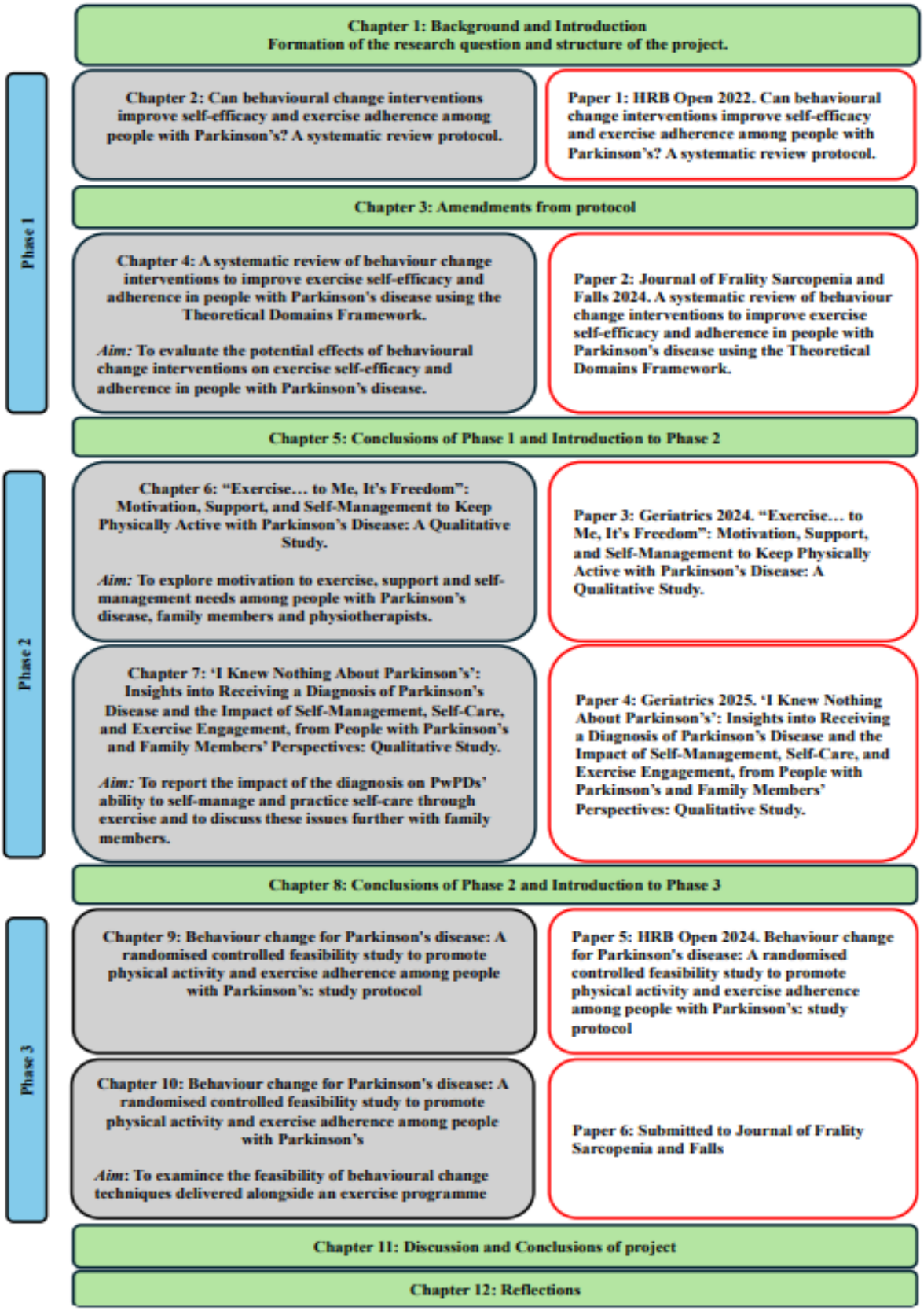


Figure 1.2: Project Structure

Chapter 2

Can behaviour change interventions improve self-efficacy and exercise adherence among people with Parkinson's disease? A systematic review protocol

Abstract

Background: People with Parkinson's disease (PwPD) have a higher tendency to adopt sedentary lifestyle behaviours and have lower physical activity levels compared to their healthy peers. Previous research has indicated that personal factors including outcome expectation and low self-efficacy are stronger predictors of exercise adherence than disease severity. ***Objective:*** The purpose of this review is to synthesise the best available evidence on interventions that encompass self-management strategies to overcome barriers to exercise and improve self-efficacy and exercise adherence among PwPD. ***Methods:*** The following databases will be searched using a comprehensive search strategy: EBSCO, Medline, CINAHL, Web of Science, PubMed, Embase, Scopus, Google Scholar and Cochrane Library from database inception to 2020. Interventional studies including behaviour change interventions will be included in this review. The title, abstract and full-text screening will be conducted by two independent reviewers. The Joanne Briggs Institute Checklist will be used to assess the quality of each included study. Data will be extracted by two independent reviewers. The outcomes of interest will be self-efficacy outcomes and measures of exercise adherence. A systematic narrative synthesis will be conducted using a framework analysis, applying the Theoretical Domains Framework and Behaviour Change Wheel, producing findings focusing on practice-orientated outcomes. Presentation of data will include tables and text summarizing the characteristics and findings of the eligible studies. Data synthesis and statistical analysis will be performed in

Review manager 5.3. The quality of evidence will be reviewed using the GRADE criteria. ***Discussion:*** The review will comprehensively synthesise the available evidence on interventions to enhance self-efficacy, improve quality of life, physical function, ultimately improving exercise adherence among PwPD and provide invaluable information for healthcare professionals. This review will make recommendations for appropriate self-management strategies for maximum effect and may have implications for policy and practice regarding enhancing self-efficacy and long-term exercise adherence among PwPD.

Keywords: Parkinson's disease, exercise self-efficacy, behaviour change interventions, quality of life, exercise adherence

Grant information: LA is funded under the Irish Research Council Enterprise Partnership Scheme (in conjunction with Parkinson's Ireland.)

The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

2.1 Introduction

Parkinson's disease is the second most common neurological condition globally. This neurodegenerative condition effects the basal ganglia, leading to progressive movement disorders which with time become more disabling.[63] Key motor features associated with Parkinson's disease are tremor, rigidity (muscle stiffness), akinesia (difficulty initiating movement), bradykinesia (slow movements) and postural instability.[64] There are also many non-motor features associated with Parkinson's disease including apathy, depression, pain, fatigue, sleep disorders, cognitive impairment, and autonomic dysfunction.[65] The combination of these motor and non-motor features can result in reduced mobility, reduction in quality of

life and loss of function.[5] As a result, people with Parkinson's disease (PwPD) have a higher tendence to adopt sedentary lifestyle behaviours and have lower levels of physical activity compared to their healthy peers.[5,66]

2.1.1 Exercise, physical activity, and Parkinson's disease

The advantages of regular physical activity are extensive with research suggesting that PwPD benefit from physical activity in multiple ways including improvements in general health, disease-specific improvements and potentially disease-modifying effects.[67]

Physical activity is characterised as any bodily movement produced by skeletal muscles resulting in energy expenditure[68] including unstructured or incidental movement. The term exercise often interchangeably used with physical activity.[69] However, exercise is a subcategory of physical activity.[68] Exercise is physical activity that is planned, structured, repetitive and purposeful with the aim to improve or maintain one or more components of physical fitness (cardiorespiratory endurance, muscular strength, muscular endurance, flexibility and body composition).[68]

The role of exercise in the management of Parkinson's disease is well-documented. The majority of exercise interventions for PwPD focus of resistance training, balance, aerobic exercise, and flexibility conducted in an exercise or rehabilitative setting.[70] A meta-analysis conducted by Choi *et al.*[10] investigated the effects of exercise therapies on PwPD. Exercise therapies including walking[71-73], strength and flexibility[74-77], balance[78,79], aerobic[80-83] and combined exercise[84-88] were shown to improve balance, walking speed, exercise tolerance, gait function, aerobic capacity, motor control, physical functioning, muscular strength and flexibility among PwPD.[10] However, exercise therapies did not show a significant effect on the non-motor symptoms. They concluded that exercise therapy is more effective for the motor symptoms rather than the non-motor symptoms of PwPD.[10]

However, Tennigkeit *et al.*[58] conducted a systematic review including 24 studies which discussed the benefits of exercise and self-management education for PwPD from Sweden and Germany. Self-management education interventions included interactive group sessions, educations sessions for PwPD and family members, educational video clips, role playing and handouts and self-monitoring techniques (using diaries for fluctuation in symptoms). They reported positive outcomes for health-related and general quality of life (QoL)[89-99], depression[89,90,92,94-98,100], self-efficacy[94,100-102], and functional mobility[92,102,103], suggesting the benefit of behaviour change interventions for improving the non-motor symptoms of PwPD.

Despite the clear benefits of exercise and physical activity for PwPD, only 30% achieve recommended activity levels, some are inactive for 70% of the day and most are less active than their age-matched peers.[15] Recently, studies have shown that exercise may have protective effects associated with the basal ganglia (known as neurogenesis) which results in improvement in dopamine transmission, increased cerebral blood flow and new formation of neuronal synapses which in turn can improve motor function.[104] Neurogenesis can result in a slowed progression of Parkinson's disease and improvements in motor control, particularly when exercise is carried out at vigorous intensities.[104-106]

In addition to this, a study conducted by Sajatovic *et al.*[100] investigated the changes in depression in PwPD (with depression) between a combined group exercise and self-management programme and a self-directed individual exercise and self-management program. They reported no significant changes in apathy or anxiety in both groups. However, both groups displayed modest within group improvement in cognition, while the combined group showed additional significant improvements in depression.[100] There was no significant differences between groups. This indicates that behaviour self-management strategies such as

group education and peer support may improve non-motor features such as depression in PwPD.

2.1.2 Barriers to exercise in PwPD

While good compliance can be achieved with prescribed exercise programmes with supervision within a clinical trial this does not completely translate to similar compliance during everyday life. Schootemeijer *et al.*[46] conducted a comprehensive review discussing the various barriers to exercise faced by PwPD. They discussed barriers including non-motor factors (anxiety, depression, fatigue, and apathy), personal factors (low self-efficacy, fear of falling, low outcome expectation and lack of time) and environmental factors (lack of social support, lack of exercise partner, poor accessibility, bad weather, financial burden, cultural challenges, awareness of moving in a crowded environment, and discomfort of seeing advancing symptoms of peers).[46]

Although PwPD experience increasing difficulties engaging in exercise as the disease progresses, previous research has indicated that personal factors including poor outcome expectation and low self-efficacy are stronger predictors of exercise adherence than disease severity.[107]

In terms of exercise, self-efficacy is an individual's confidence or belief that they can successfully engage in physical activity or exercise.[61,108] Exercise self-efficacy can be categorised into performance self-efficacy (beliefs about performing exercises) or beliefs in overcoming barriers.[109,110] Exercise self-efficacy determines the type of exercise an individual partakes in, their effort level, and their long term exercise adherence when they face barriers to participation.[109,111] A meta – analysis conducted by Higgins *et al.*[110] reported that short-term exercise interventions (duration between two - eight weeks) were more effective for enhancing performance efficacy. In contrast interventions that included long term strategies providing

opportunities for individuals to experience and successfully conquer barriers over a longer period were more effective for enhancing confidence in overcoming barriers to exercise.[110] This indicates the potential benefits of integrating long term strategies into behaviour change interventions to promote long term adherence to physical activity and exercise among PwPD.

2.1.3 Behaviour change

Adapting health behaviour in terms of changing from a sedentary lifestyle to a more physically active lifestyle is a complex process.[50] Merely informing individuals about the benefits of physical activity has been shown as inadequate to maintaining behaviour change.[50,112] In order to assist behaviour change in PwPD disease-specific counselling and coaching may be required.[113] Behaviour change interventions are complex and involved many cooperating components.[114] These psychology-focused interventions try to facilitate more constructive health behaviours.[115] Particular strategies are utilised to promote behaviour change; some interventions are tailored to enhancing physical activity engagement by identifying barriers and problem solving.[116] While others prompt individuals to track their sedentary behaviour as a method of changing behaviour.[116] These interventions utilise theories of behaviour and behaviour change to inform particular therapeutic strategies.[117]

Speelman *et al.*[51] studied the long-term effect of including behaviour change interventions (coaching, goal setting, use of activity monitors) into a multi-component exercise programme for PwPD. They reported improvements in physical activity level for all subgroups of PwPD.[51] While Ellis *et al*.[52] investigated the effects of short daily interactions (five minutes/day) with a virtual exercise coach to encourage walking (monitored by a pedometer) among PwPD. The interactions discussed progression of short- and long-term goals, collaborative problem solving to overcome barriers and positive support.[52] They reported excellent retention rate in the walking programme and improvements in gait after one month. However, due to the short

duration of the intervention the long-term effects of adherence and occurrence of behaviour change are unknown.[52]

2.1.4 Theoretical Domains Framework (TDF)

The TDF is a combined theoretical framework which was created from 128 theoretical constructs and 33 behaviour theories.[53] The TDF has been used in implementation research[53] to perform a process evaluation of randomized trials to further understand the effect of implementing evidence[118], as guidance on identifying behaviour change techniques[117,119], to identify influences on behaviours[120-124], and systematic intervention design.[125-127].

The TDF consists of 14 domains subcategorised into personal factors, social factors and environmental factors (Table 1). The TDF has previously been correlated with a simpler model of behaviour known as the COM-B.[119,128] The main principle of this model is that capability, opportunity, and motivation interact to produce behaviour. Whereas the TDF provides a more in-depth insight of psychological capability and reflective motivational processes.[53]

Table 2.1: Theoretical Domains Framework domains and definitions.[53]

TDF Domain	Definition
Knowledge	Awareness of the existence of something
Skills	Ability or proficiency acquired through practice
Memory, attention, and decision processes	Ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives
Behaviour regulation	Anything aimed at managing or changing objectively observed or measured actions
Beliefs about capabilities	Acceptance of the truth, reality or validity about an ability, talent, or facility that a person can put to constructive use
Beliefs about consequences	Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation
Social/ professional role and identity	Behaviours and displayed personal qualities of an individual in a social or work setting
Emotion	A complex reaction pattern, involving experiential, behaviour, and physiological elements, by which the individual attempts to deal with a personally significant matter or event
Intentions	Conscious decision to perform a behaviour or a resolve to act in a certain way
Reinforcement	Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus

Goals	Mental representations of outcomes or end states that an individual wants to achieve
Optimism	Confidence that things will happen for the best or that desired goals will be attained
Environmental context resources	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour
Social Influences	Interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours

In order to motivate individuals with Parkinson's disease to remain physically active outside a clinical setting it is important to identify self-management strategies to overcome these barriers, improve self-efficacy and promote physical activity among PwPD. To the best of our knowledge this is the only review exploring the effectiveness of behaviour change interventions on self-efficacy and long-term exercise adherence among PwPD. The findings of this review will make recommendations for appropriate self-management strategies and may have implications for policy and practice.

2.1.5 Review objectives

The purpose of this review is to comprehensively synthesise the best available evidence on behaviour change interventions that encompass self-management strategies to over barriers to exercise and improve exercise adherence among PwPD.

Specifically, the objectives are to:

1. Examine self-management strategies to overcome barriers to exercise among PwPD.
2. Determine the effectiveness of behaviour change interventions aimed to improve exercise self-efficacy, QoL and physical function and exercise adherence among PwPD.
3. Identify strategies to promote long term exercise adherence among PwPD.

2.1.6 Research question

Specially, this review is aimed to answer the following questions:

1. Do behaviour change interventions improve exercise self-efficacy among PwPD?
2. Do behaviour change interventions improve QoL and/or physical function among PwPD?
3. Do behaviour change interventions improve exercise adherence/increase levels of physical activity among PwPD?

2.2 Methods

This protocol was designed in line with the methodological framework provided by the Joanna Briggs Institute (JBI) Reviewer's Manual[129] and reported in line with the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines.[130] This review is registered with PROSPERO (ID:CRD42021293057). [See Appendix A, Table A1] *Extended Data:* PRIMSA-P Checklist

2.2.1 Inclusion and exclusion criteria

Studies to be included in this review must satisfy the following inclusion criteria (Table 2.2).

Table 2.2: Eligibility Criteria

Inclusion Criteria	*Exclusion Criteria*
Population, or participants and conditions of interest **Community dwelling independently mobile people with Parkinson's disease (Hoehn and Yahr stage 1-4; i.e. mobile without assistance of another person when "on").**	**a) Diagnosis of Atypical Parkinson's disease (e.g. Progressive supranuclear palsy)** **b) Current inpatients orhad a recent hospital admission (< 6 weeks ago)** **c) Immobile or a wheelchair-user** **d) Severe visual or auditory impairment, serious medical conditions in major organs (heart, lung, or kidney) or other illnesses which prevented independent ambulation.** **e) Identified as a high falls risk (fallers)**
Intervention **Any form of behaviour change intervention (e.g. education, behaviour technology) or support strategy used in conjunction with exercise**	**The intervention;** **a) Did not include self-efficacy strategies or behaviour change strategies.** **b) Did not include an exercise component** **c) Focused solely on falls prevention**

Comparator: **Comparator groups must include people with a Parkinson's disease diagnosis.** **A specific intervention type was not defined for the purpose of inclusion (comparator groups including but not limited to exercise alone, usual care or waiting list were included)**	**Comparator group including non-Parkinson's disease individuals.**
Outcomes of interest **a) Exercise self-efficacy measures (e.g. Self-efficacy for exercise scale, Physical Activity Assessment Inventory)** **b) Quality of life (e.g. PDQ-39. PDQ-8, EQ5D)** **c) Physical function (e.g. 6MWT, gait velocity)** **d) Exercise adherence (e.g. self-log, activity monitors).**	**Other outcomes (e.g. medication adherence, changes in anxiety and depression) Self-efficacy outcomes related to the management of a chronic condition rather than exercise self-efficacy**
Setting **Community gyms/halls, community outpatient facilities, acute hospitals (if the intervention was conducted with community dwelling PwPD in hospital-based gyms or clinics), or the home environment**	**Study interventions carried out in acute hospitals with inpatients, or in long term care facilities**
Study design **Interventional studies:** **Randomised control trials, quasi-experimental trials, pilot interventional studies, pre- and post- interventional studies, and feasibility studies.**	**Qualitative studies, observational studies, or systematic reviews**

2.2.2 Search strategy

Two independent reviewers (LA and RMcC) will conduct a search using the following electronic databases: *EBSCO, Medline, CINAHL, Web of Science, PubMed, Embase, Scopus, Google Scholar, Cochrane Library.* Databases will be searched from inception to 2020. The search strategy was developed by the primary author (LA) and supported by a librarian with systematic review experience (VC). Two independent reviewers (LA and RMcC) will search the databases using the search terms showed in Table 2.3. Reference lists of related articles and relevant reviews will be checked to identify further eligible studies.

Table 2.3: Search strategy

Databases:
- **EBSCO (Academic search complete and PsycINFO)** - **Medline** - **CINAHL** - **Web of Science** - **PubMed** - **Embase** - **Scopus** - **Google Scholar** - **Cochrane Library**
Search keywords:
1. [“behaviour change intervention*” OR “behaviour change intervention*” OR “behaviour change technique*” OR “behaviour change technique*” OR “cognitive behaviour therapy” OR “cognitive behaviour therapy” OR psychology OR “psychological therapy” OR “health **a. behaviour*” OR “health behaviour*”]**
2. [self-efficacy OR “self efficacy” OR “physical activity self-efficacy” OR “physical activity self **a. efficacy” OR “exercise self-efficacy” OR “exercise self efficacy” OR self-management]**
3. 1 AND 2
4. [“physical activit*” OR recreation OR sport OR exercise OR training OR fitness OR “physical **a. therap*” OR rehabilitation]**
5. 3 AND 4
6. [“Parkinson’s disease” OR “Parkinsons Disease” OR “Parkinson Disease” OR Parkinson’s OR **b. Parkinson]**
7. 5 AND 6

2.2.3 Study records

Articles identified from the literature search will be uploaded to Endnote X8, a citation manager. Duplicates will be removed using the “remove duplicates” function, and manual screening of the results will be conducted to ensure accuracy (LA). Titles and abstracts of the identified articles will then be exported to Rayyan (LA), an electronic software designed to support article screening and allows collaboration between reviewers during the study selection process.

2.2.4 Study selection

Two independent reviewers (LA and RMcC) will be involved in the study selection process through each phase of the review. Following the removal of duplicates, LA and RMcC will independently screen all titles and abstracts of the articles identified by the literature search.

Studies not meeting the inclusion criteria will be excluded. Prior to the formal screening process, test screening questions will be developed based on the inclusion/exclusion criteria.

Subsequently, LA and RMcC will independently screen the full text articles identified from the previous stage to select the suitable studies. Reference lists of the included articles and previously conducted reviews in the area will be checked to identify any additional studies. Both LA and RMcC will independently screen any additional articles to determine their suitability. Any disagreement regarding inclusion will be resolved by a third reviewer (ST). A Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) flow diagram will display the study selection process and summarise the inclusion and exclusion of studies at each stage of the review by providing reason for exclusion.

2.2.5 Data collection and extraction

Two independent reviewers (LA and RMcC) will extract data from each eligible study and conduct the risk of bias assessment. Reviewers will perform practice extraction exercises prior to the formal extraction to ensure consistency. Any disagreement regarding extraction will be resolved by a third reviewer (ST) and a consensus achieved. If required, primary authors of studies will be contacted to provide further details. A data extraction template will be designed *a priori*. Data including study design, sample characteristics (size, sex, mean age) specific details about the intervention (type, duration and follow-up) and implementation methods, pre- and post-intervention outcome results, and theorical framework used (if applicable) will be extracted.

2.2.6 Methodological quality of studies

To assess the potential risk of bias The Joanne Briggs Institute Checklist[129] for the corresponding study designs will be used for each eligible study.

Two independent reviewers (LA and RMcC) will assess the potential risk of bias of each article. Any disagreements will be resolved by a third reviewer (ST). In the incidence where data is missing, or information is not clear the primary authors will be contacted for clarification. Following the assessment, studies will be classified as a high, medium, low, or unclear risk of bias.

2.2.7 Assessing the quality of evidence

The quality of evidence will be assessed using the Grades of Recommendation, Assessment, Development and Evaluation (GRADE) approach.[131] This involves assessing the quality of evidence using a specific points system to upgrade or downgrade the ratings for each quality characteristic. Evidence can be downgraded one level for serious limitations or two levels for very serious limitations depending on the assessment for five characteristics: limitation in study design and conduct, inconsistent results across studies, indirectness of evidence with respect to study design, populations, interventions, comparisons or outcomes, imprecision of the estimates of the effect and publication bias. Evidence can be upgraded depending on the assessment of the following three characteristics; large magnitude of effect, plausible confounding that would reduce the effect, and dose-response gradient.[131-134]

Two independent reviewers will assess the quality of each eligible articles (LA and RMcC). Any disagreement will be resolved by a third reviewer (ST) and a consensus achieved. In the incidence where information is not clear the primary authors will be contacted for clarification.

2.2.8 Narrative synthesis and analysis of the data

Initially, a narrative analysis will be completed. If data is missing or incomplete, we will contact the author by email for the information. Data will be presented using tables and text summarizing the characteristics and findings. A narrative synthesis of the findings will be

completed to investigate the association and findings between the included studies. Patterns demonstrating the effectiveness of the interventions will be discussed, including the participants, the intervention, and its impact on the outcomes. Outcomes will include subjective measures of impact including self-efficacy and quality of life, as well as objective measures of physical / functional gains (e.g. 6MWT, gait velocity), and measures of exercise adherence (e.g. self-log, activity monitors).

The interventions will be mapped to the Theoretical Domains Framework (TDF) and Behaviour Change Wheel (BCW), producing findings focusing on practice-orientated outcomes. The TDF includes fourteen domains related to the psychology of behaviour change.[135] While the BCW focuses on the success of implementing interventions by coordinating change interventions with behaviour barriers; a person's opportunity, capability and motivation interconnects and influence their behaviour (COM-B).[136] The effectiveness of the mapped interventions will be evaluated further in the context of the models.

The data will be assessed for eligibility for meta-analysis, exploring heterogeneity of populations, interventions, and outcome.

2.2.9 Meta-analytical approach

Statistical analysis will be performed by using the Cochrane Review Manager (RevMan 5.3) software. The mean difference and the 95% confidence interval (CI) will be used as an effective size for the combined analysis, with $p \leq 0.05$ considered as statistically significant.

Assessment of heterogeneity

If significant methodological, statistical, and clinical heterogeneity is detected, results will not be reported as the pooled effect estimate in a meta-analysis. Heterogeneity will be identified by visual inspection of the forest plots and by conducting a $\chi 2$ test with a significance level of

$\alpha = 0.1$. Heterogeneity will also be examined using the I^2 statistic as recommended by Higgins.[137,138] The I^2 statistic will quantify inconsistency across the included studies in order to assess the impact of heterogeneity on the meta-analysis. An I^2 statistic $\geq 75\%$ signifies a substantial level of inconsistency.[139] If heterogeneity is determined, individual studies and subgroup characteristics will be examined to identify potential reasons.

Data will be summarised by means of a random-effects model with due consideration of the whole distribution of effects by presenting a prediction interval. Analyses will be conducted according to the guidelines outlined in the Cochrane Handbook for Systematic Reviews of Interventions.[139]

Subgroup analysis

Subgroup analyses will be completed to determine the effectiveness of behaviour change strategies on quality of life based on the type of strategy.

Assessment of reporting biases

If ten or more of the included studies investigate the same outcome, funnel plots will be used to assess small study effects and evaluate potential publication bias using the Egger test in Stata 13.

Sensitivity analysis

A sensitivity analyses will be performed to explore the influence of the following factors (if applicable) on effect sizes.

- Restricting analysis to high-powered, larger studies
- Restricting analysis to low risk of bias studies
- Restricting analysis to studies including a control group.

To test the robustness of the results analysis will be repeated using different statistical models (random-effects and fixed-effect models) and different measures of effect size (odds ratio and relative risk).

2.2.10 Dissemination of results

The systematic review will be disseminated in a peer-reviewed journal and the results will be presented both locally to physiotherapy clinical colleagues, and at international conferences. The dataset created during the study will be available from the corresponding author upon request.

2.2.11 Amendments

Any amendments to this protocol will be described in a table including the date of each amendment as well as a description of and rationale, this will be documented in a note to a later publication (section "Differences between protocol and review"). The PROSPERO register will remain updated with the protocol and any amendments made.

2.2.12 Ethics approval and consent to participate

Ethical approval is not required for this study as it will not involve conducting experimental research or include identifying personal data.

2.2.13 Study status

The systematic review protocol was finalised in November 2021 and the database search was conducted in December 2021. Full-text screening will be completed in January 2022. It is anticipated the review will be completed in September 2022

2.2.14 Data availability

No data are associated with this article.

2.3 Discussion

Self-efficacy and attitudes towards exercise are linked in a linear relationship.[111,140] Exercise self-efficacy increases with mastery experiences, as individual become more experienced with exercise. However, self-efficacy also plays an important role in maintaining motivation to exercise.[61] While the body of evidence supporting behaviour change interventions displays a positive effect of self-efficacy there is a need to pool evidence from trials to accurately determine the treatment effect of these different interventions.

The authors are unaware of other reviews of behaviour change interventions implemented to enhance self-efficacy and improve exercise adherence among PwPD. By exploring this, the findings of this review will provide invaluable information for healthcare professionals. Additionally, this review will make recommendations for appropriate self-management strategies for maximum effect and may have implications for future policy and practice regarding enhancing self-efficacy and long-term exercise adherence among PwPD.

Chapter 3

Amendments: Changes from protocol in systematic review

The following amendments were made to the SR process, after the publication of the review protocol.

Date: 15/11/2021

Amendment: The inclusion criteria outlined in the protocol stated that interventions would be included if they implemented "any form of behaviour change intervention, used in conjunction with exercise or alone". However, prior to conducting the database search this was amended to only include studies that implemented a behaviour change intervention in conjunction with exercise.

Rationale: This amendment ensured that the search was clearly focused to answer the specific research question

Date: 20/01/2022

Amendment: The protocol stated that the findings would be mapped to the Behaviour Change Wheel (BCW) and the Theoretical Domains Framework (TDF). However, during data synthesis it was determined that the findings would only be mapped to the TDF.

Rationale: The components of the BCW are embedded within the TDF and mapping to both would not provide any additional information.

Date: 06/04/2022

Amendment: The protocol outlined that the JBI risk of bias tool would be used to assess the risk of bias in the included studies. However, we used the Cochrane risk of bias Tool (Version 2) for randomised control trials and the ROBINS-I tool for non-randomised trials.

Rationale: These tools are the preferred method of assessing risk of bias.

Date: 25/05/2022

Amendment: The protocol outlined that the proposed sensitivity analysis would include "restricting analysis to studies including a control group"; this was further refined to "restricting analysis to studies including a control group with an exercise component."

Rationale: To ensure the specific research question was answered.

Date: 10/09/2023

As per the protocol, the database was from inception to 1st of September 2021. This was subsequently updated and searched to 10th January 2024, in preparing the thesis.

Chapter 4

A systematic review of behaviour change interventions to improve exercise self-efficacy and adherence in people with Parkinson's disease using the Theoretical Domains Framework.

Abstract

Background: Physical activity and exercise can limit the development of sarcopenia in Parkinson's disease. ***Objective:*** This review aims to evaluate the potential effects of behaviour change (BC) interventions on exercise self-efficacy and adherence in people with Parkinson's disease. ***Methods:*** We searched nine databases and included randomised and non-randomised studies reporting exercise self-efficacy, quality of life (QoL), physical function and/or exercise adherence. Two reviewers independently screened, data extracted and assessed risk of bias and certainty of evidence. The interventions were mapped to the Theoretical Domains Framework. ***Results:*** Eleven studies (n=901participants) were included. Four were randomised trials and risk of bias was mixed. Most interventions were multi-component, including education, behaviour techniques, and support groups. The most effective domains appear to be behaviour regulation, belief about capabilities, social influences, reinforcement and goals. ***Conclusion:*** Future research should examine multi-component BC interventions encompassing the five most effective TDF domains.

Keywords: Parkinson's disease, Physical Function, Behaviour Change Interventions, Quality of Life, Theoretical Domains Framework.

4.1 Clinical implications

- There is insufficient high-quality evidence to recommend the most effective BC intervention to promote exercise adherence among PwPD.
- Future research should examine multi-component BC interventions encompassing the five most effective TDF domains (behaviour regulation, belief about capabilities, social influences, reinforcement and goals).
- We recommend that trials are sufficiently powered, diverse populations are recruited, with sufficient follow-up periods to indicated sustainable exercise adherence.

4.2 Introduction

Parkinson's disease is a progressive neurodegenerative condition with motor and non-motor symptoms.[63,141] Disease progression leads to muscle atrophy, reduced physical capacity, and impacts vitality. People with Parkinson's disease (PwPD) are three times more likely to develop sarcopenia and fall twice as often compared to age-matched healthy controls.[141-144] PwPD have an annual falls incidence of 60%[145], highlighting falls are a serious concern.

Maintaining an active lifestyle is essential to reduce sarcopenia and fall risk in PwPD.[146] However, PwPD are 30% less active than healthy age-matched controls[5,15], keeping active for only 30% of the day.[15] Only 30% of PwPD meet the World Health Organisation's recommended activity guidelines.[15] "Physical activity" is described as any bodily movement produced by skeletal muscles resulting in energy expenditure[68], including unstructured or incidental movement while "exercise" is planned, structured, and purposeful, with the aim to improve or maintain one or more components of physical fitness.[68]

Exercises can improve muscle strength, aerobic fitness, and balance in PwPD.[70] A recent pilot study12 (n=30) showed that a 24-week high intensity interval training significantly increased leg lean mass, appendicular muscle mass, walking endurance and physical performance.[147] While a systematic review conducted Chung *et al*.[148] (7 studies, n=401 participants) demonstrates that intensive progressive resistance training, 2-3 times per week over 8-10 weeks can result in significant strength, balance and motor symptoms improvements in people with early to moderate Parkinson's disease.[148] Further to this, a large scale randomised controlled trial (n=231)[149] compared PwPD who exercised 40 to 60 minutes, 3 times weekly to usual care for 6 months.[149] They found that an exercise programme targeting balance, leg strength, and freezing of gait improved physical and psychological health.[149] Falls were reduced in people with milder disease but not in those with more severe Parkinson's disease.[149] These studies show that exercise can improve muscle strength and physical function and in turn reduce the risk of developing sarcopenia and falls in those with early to moderate Parkinson's disease.

From these studies, we can see that interventions require adherence to intensive exercise lasting over three months. It is established that non-motor features are a considerable barrier to exercise among PwPD. Apathy may be defined simply as a loss of motivation, appearing as though the person is lazy or uncaring.[150] A recent meta-analysis (18 studies; n=1,144 participants)[58] would suggest that exercise alone fails to improve non-motor symptoms. However, Tennigkeit *et al*.[58] found that when exercise is combined with behaviour strategies to help disease management, the results were more promising.

Strategies including videos, role-playing, education sessions, and self-monitoring (symptom diaries) led not only to improved mobility and QoL, but also improved self-efficacy and depression, suggesting behaviour change (BC) approaches may help non-motor symptoms.[58] However, it remains unknown whether these techniques further led to better exercise adherence

and more physical activity, suggesting that a comprehensive review of exercise behaviour strategies is indicated.

Exercise self-efficacy is positively correlated to more exercise behaviour and adherence.[151,152] Speelman *et al*.[51] has shown that BC approaches (coaching, goal setting, activity monitors) are widely accepted by participants, and perceived as effective[51], with the activity monitor being identified as the most useful tool.[51] Ellis *et al*.[52] has shown that short daily interactions (five minutes/day) with a virtual coach is also well accepted among participants.[52] However, their effects on adherence and physical activity remains unclear.

Behaviour change interventions aim to overcome barriers to behaviour. The Theoretical Domains Framework (TDF)[53] provides a structure to understanding the barriers and motivators to behaviour (in this case, exercise among PwPD), and can be used to classify BC interventions and their components. This may, in turn, explain the how interventions facilitate exercise adherence and help identify the effective core components across interventions.

In short, to motivate PwPD to remain active to help reduce the risks of sarcopenia, falls, and frailty, it is important to identify BC interventions that overcome barriers to exercise, to improve exercise self-efficacy and adherence, which in turn, lead to less falls, greater strength, fitness, and better quality of life (QoL). To the best of our knowledge, no previous review has explored the effects of BC interventions on exercise self-efficacy and adherence among PwPD. This review aims to address this evidence by providing recommendations for self-management approaches.

4.2.1 Review objectives

This review aimed to synthesise the available evidence on BC interventions to improve exercise adherence among PwPD.

Specifically, this review aimed to

1. Describe the most common behaviour change interventions to improve exercise adherence.
2. Map the identified intervention components to the Theoretical Domains Framework.
3. To determine the effects of the BC intervention on exercise self-efficacy, QoL, physical function, and exercise adherence.

4.3 Methods

This review was conducted guided by the Joanna Briggs Institute (JBI) Reviewer's Manual[129] and reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines[153]. The protocol was registered with PROSPERO (ID: CRD42021293057) and is published online[154] (https://doi.org/10.12688/hrbopenres.13474.2). We included randomised and non-randomised studies to provide evidence of effect, recognising that non-randomised studies provide less robust evidence.

4.3.1 Eligibility criteria

We included full-text studies reporting exercise self-efficacy, exercise uptake and adherence in PwPD and published in English. PwPD diagnosed with other comorbidities (e.g. anxiety, depression, and diabetes) were included. See Table 4.1 for eligibility criteria.

Table 4.1: Eligibility Criteria

Inclusion Criteria	*Exclusion Criteria*
Population, or participants and conditions of interest **Community dwelling independently mobile people with Parkinson's disease (Hoehn and Yahr stage 1-4; i.e. mobile without assistance of another person when "on").**	**a) Diagnosis of Atypical Parkinson's disease (e.g. Progressive supranuclear palsy)** **b) Current inpatients or had a recent hospital admission (< 6 weeks ago)** **c) Immobile or a wheelchair-user** **d) Severe visual or auditory impairment, serious medical conditions in major organs (heart, lung, or kidney) or other illnesses which prevented independent ambulation.** **e) Identified as a high falls risk (fallers)**
Intervention **Any form of behaviour change intervention (e.g. education, behaviour technology) or support strategy used in conjunction with exercise**	**The intervention;** **f) Did not include self-efficacy strategies or behaviour change strategies.** **g) Did not include an exercise component** **h) Focused solely on falls prevention**
Comparator: **Comparator groups must include people with a Parkinson's disease diagnosis.** **A specific intervention type was not defined for the purpose of inclusion (comparator groups including but not limited to exercise alone, usual care or waiting list were included)**	**Comparator group including non-Parkinson's disease individuals.**
Outcomes of interest **e) Exercise self-efficacy measures (e.g. Self-efficacy for exercise scale, Physical Activity Assessment Inventory)** **f) Quality of life (e.g. PDQ-39. PDQ-8, EQ5D)** **g) Physical function (e.g. 6MWT, gait velocity)** **h) Exercise adherence (e.g. self-log, activity monitors).**	**Other outcomes (e.g. medication adherence, changes in anxiety and depression) Self-efficacy outcomes related to the management of a chronic condition rather than exercise self-efficacy**
Setting **Community gyms/halls, community outpatient facilities, acute hospitals (if the intervention was conducted with community dwelling PwPD in hospital-based gyms or clinics), or the home environment**	**Study interventions carried out in acute hospitals with inpatients, or in long term care facilities**
Study design **Interventional studies:** **Randomised control trials, quasi-experimental trials, pilot interventional studies, pre- and post- interventional studies, and feasibility studies.**	**Qualitative studies, observational studies, or systematic reviews**

BC interventions are defined as complex coordinated sets of activities devised to change specified behaviour patterns.[136] Behaviour techniques are defined as complex, observable, and reproducible components of an intervention designed to alter behaviour[136], such as goal-setting, decision-making or problem solving. Finally, exercise self-efficacy was defined as an individual's confidence or belief that they can successfully engage in physical activity or exercise.[61,108]

The primary outcomes of interest were exercise self-efficacy, QoL, physical function and exercise adherence and every timepoint was considered.

Table 4.2: Search strategy

Databases:
- **EBSCO (Academic search complete and PsycINFO)** - **Medline** - **CINAHL** - **Web of Science** - **PubMed** - **Embase** - **Scopus** - **Google Scholar** - **Cochrane Library**
Search keywords:
1. **["behaviour change intervention*" OR "behaviour change intervention*" OR "behaviour change technique*" OR "behaviour change technique*" OR "cognitive behaviour therapy" OR "cognitive behaviour therapy" OR psychology OR "psychological therapy" OR "health behaviour*" OR "health behaviour*"]**
2. **[self-efficacy OR "self efficacy" OR "physical activity self-efficacy" OR "physical activity self efficacy" OR "exercise self-efficacy" OR "exercise self efficacy" OR self-management]**
3. **1 AND 2**
4. **["physical activit*" OR recreation OR sport OR exercise OR training OR fitness OR "physical therap*" OR rehabilitation]**
5. **3 AND 4**
6. **["Parkinson's disease" OR "Parkinsons Disease" OR "Parkinson Disease" OR Parkinson's OR Parkinson]**
7. **5 AND 6**

4.3.2 Database searching

The search strategy was developed by the primary author (LA) and supported by an experienced librarian (VC). A search of nine databases (See Table 4.2) from inception to 10th September 2023 was performed (LA).

4.3.3 Study selection and article screening

Identified articles were uploaded to Endnote X8. Following de-duplication, titles, abstracts, and full texts were independently screened by two reviewers (LA, RMcC), using the search terms displayed in Table 4.2. The reference lists of the included articles and topical reviews were hand-searched. Any disagreement regarding inclusion was discussed with a third reviewer (ST).

4.3.4 Data extraction

One reviewer (LA) extracted the data. A second reviewer (RMcC) randomly selected four studies to verify data extraction methods. Data extracted included author, year, country, study design and size, participant characteristics, disease severity, details of the exercise and BC interventions, results, and theoretical framework used.

4.3.5 Risk of bias assessment

Three independent reviewers (LA, RMcC and ST) assessed the risk of bias using the Cochrane Risk of Bias Tool (Version 2)[155] for randomised controlled trials (RCTs) and the ROBINS-I tool[156] for non-randomised trials, as recommended[157]. Any ambiguity was reviewed, and a consensus was achieved.

4.3.6 Mapping to the Theoretical Domains Framework (TDF)

The extracted intervention components were mapped to the Theoretical Domains Framework (TDF), using Atkins *et al*.[53] for guidance. Using the coding described by Atkins *et al*.[53], two researchers (LA, RMC) extracted the suitable codes, and assigned them to the TDF domains. Codes were re-reviewed by three researchers (LA, RMcC and ST) to confirm final allocation.

4.3.7 Data synthesis

We completed a narrative synthesis to examine the effects of BC interventions. Components of the effective BC interventions were mapped to the TDF, to identify which barriers and facilitators were addressed in the effective interventions. Negative effects were also recorded. We attempted a meta-analysis, but the heterogeneity between studies led to a very small number of studies being included in each model, with low/very low certainty in the evidence.

4.4 Results

4.4.1 Study selection

After completing the searches, 1032 articles were identified, 61 full-text articles were reviewed and finally eleven articles (2002-2020) (n=901) were included (Figure 4.1: PRISMA Flow diagram). Table 4.3 describes the characteristics of the included studies.

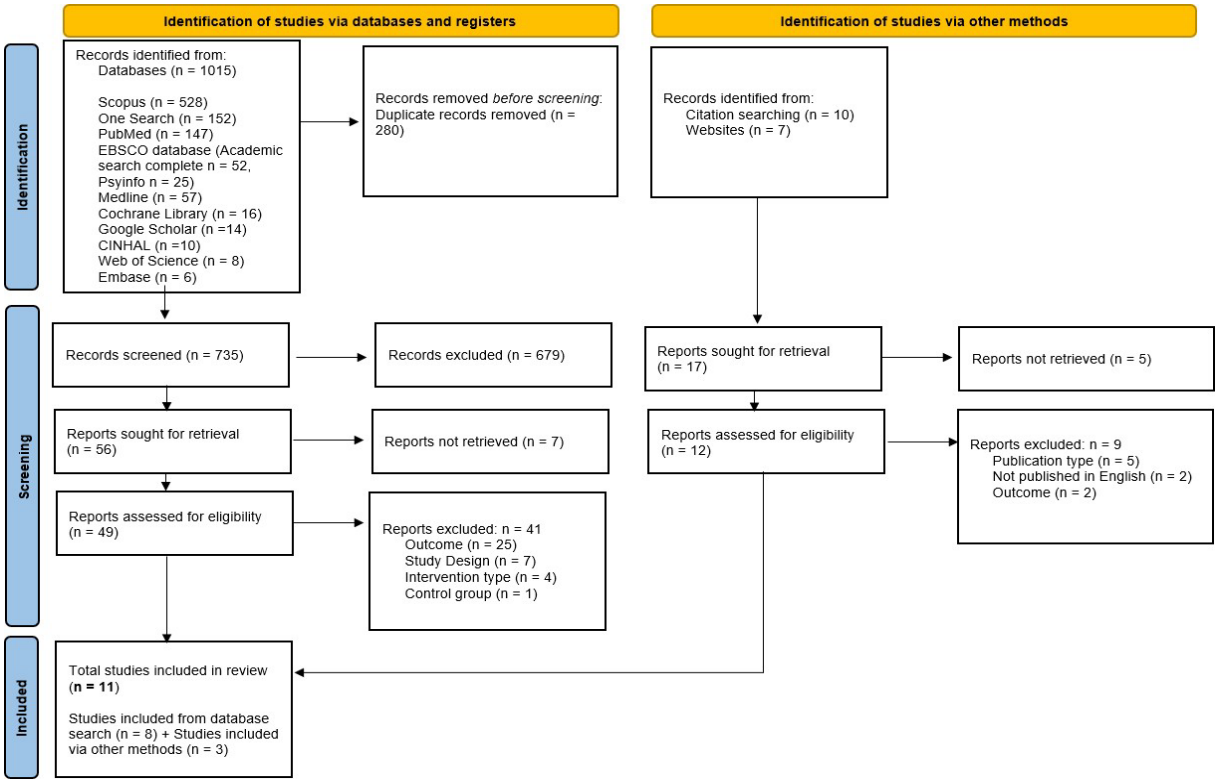


Figure 4.1: PRISMA flowchart

Table 4.3: Study characteristics and description of interventions of included trials.

First Author, Publication year, Country, Study design, Participants, Sample Size	Aim	Programme Facilitator/s	Behaviour Change		Exercise Intervention	Comparator intervention	Outcome Measures
			Behaviour change framework	Mode of delivery	Intervention type, FITT, Setting		
Colón-Semenza *et al.* (2018)[158] **USA** **Feasibility study (Mixed methods)** **Idiopathic Parkinson's disease (H&Y stage 1- 3)** **Total: n=10 (5 coaches; 5 mentees)** **Peer coaches: Age: 64.6 ± 4.04 Sex: 3/2 (M/F)** **Peer mentees: Age: 63.4 ± 2.06 Sex: 3/2 (M/F)**	**To develop a PD-specific peer coach training programme and a remote peer-mentored walking programme using mHealth technology with the goal of increasing physical activity in persons with PD.**	**Peer coaches** ***Training Program*** **1) Peer coaches were asked to review printed and Web-based educational materials independently over a 1- to 2-week period** **2) Peer coaches participated in two,4-hour, in-person training sessions**	**1) Self-determination theory** **2) Social Cognitive Theory**	***Multi-component Behaviour Change Components: Technology + Support Groups*** ***Peer-mentored walking program*** **1) The peer coaches and mentees were given a wireless activity tracker (FitBit Zip).** **2) Coaches were instructed on how to become friends on the Fitbit mobile app, so as to instruct mentees during their initial interaction.** **3) Within 1 week after training, peer coach scheduled initial conversation focusing on establishing rapport, jointly determining the 8-week walking goal for the mentee, and developing the initial action plan.** **4) Peer coach and mentee did not walk together, but in their own self-selected environment.** **5) Peer pairs viewed the steps they accumulated over the week using the FitBit friends' option. This feature allows remote interaction between the peer coach and peer mentee, allowing regular feedback (i.e., cheering with an emoji or instant messaging) on progress toward goals.** **6) Mentees could see the coach's step counts, providing a social comparison and vicarious experiences to improve self-efficacy.** ***Weekly Phone Calls*** **1) The peer coach and mentee engaged in phone conversations weekly** **2) Peer coaches had checklists to guide peer discussions to ensure that they were adhering to the recommended techniques for peer mentoring.** **3) These were: assessing the walking activity goal, progress made, problems encountered, strategies to overcome barriers, and resources available. Frequency: Self-selected** **Duration: 8 weeks** **Setting: Self-selected environment**	**Self-regulated exercise in self-selected environment** **Duration: 8 weeks**	**No control group**	**1) Activity tracker** **2) Self-efficacy for Walking Duration** **3) LLFDI**
Ellis *et al.* (2013)[52] **USA** **Single group pre-post study** **Idiopathic Parkinson's disease (H&Y stage 1.5-3)** **Total: n=20**	**To explore the feasibility, acceptability, and preliminary evidence of the effectiveness of a virtual exercise coach to promote daily walking in community-dwelling persons with Parkinson disease**	**N/A**	**None**	***Multi-component Behaviour Change Components: Technology + Support Groups*** ***Activity monitor in conjunction with Virtual Coach (focused on promoting walking)*** **1) Participants instructed to wear a pedometer and walk daily for 1 month and to interact with the virtual exercise coach for 5 mins per day.** **Conversations with the virtual exercise coach were dialogue and other media designed to promote health behaviour change and**	**Participants were instructed to walk daily for 1 month (No specified exercise intervention)**	**No control group**	**1) Useability and Acceptability (Activity monitor steps)** **2) Safety** **3) Efficacy (6MWT; Gait speed; Self-selected walking speed)**

Age: 65.5 ± 5.6 **Sex: 9/11 (M/F)**				**conversational nonverbal behaviour designed to build a relationship and a therapeutic alliance** **3) A daily 5-min conversation typically, was a greeting, social chat, and well-being check-in to see whether the participant needed to progress or suspend their walking programme and to provide empathic opportunities.** **4) After this, participants plugged their pedometer into the system to upload their steps.** **5) The virtual coach reviewed their progress relative to short-term and long-term goals, provided positive reinforcement if warranted, identified barriers to walking, and engaged the participant in a problem-solving discussion for any barriers identified, then negotiated a new short-term goal, if warranted.** **6) The session closed with an exercise tip of the day. Each day's dialogue varied in content and structure and was augmented with additional media for participant engagement and retention.** **Frequency: Self-selected** **Duration: 1 month** **Setting: Self-selected environment**			
Ellis *et al*. (2019)[159] **USA** **RCT** **Idiopathic Parkinson's disease (H&Y stage 1-3)** **Total: n=51 Age: 64.1 ± 9.5 Sex: 28/23 (M/F)** **Intervention: 26** **Age: 64.8 ± 8.5** **Sex:15/11 (M/F)** **Control: 25** **Age: 63.3 ± 10.6** **Sex: 13/12 (M/F)**	**To explore the preliminary effectiveness, safety, and acceptability of a mobile health (mHealth)-mediated exercise programme designed to promote sustained physical activity in people with PD.**	**A licensed physical therapist with expertise in PD to develop an individualised exercise and walking program.** **Exercises were adapted remotely over time by the physical therapist in response to improvements or setbacks experienced by participants**	**None**	***Behaviour Change Component: Technology*** ***mHealth App*** **The mHealth condition was used in conjunction with the individualised exercise and walking programmes. It included:** **1) Remote monitoring,** **2) More accessible communication,** **3) More frequent programme adaptation by a physical therapist.** **4) Incremental walking and exercise goals were entered into the mHealth app.** **5) Action plans included what (which exercises, duration of walking), how (appropriate technique), when (time of day, days per week), and where (community, mall) for exercise.** **6) Notifications (i.e., automated prompts and reminders) were used to motivate participants** **7) Exercises were adapted remotely over time by the therapist in response to improvements or setbacks.** **8) Adherence and progress toward goals was graphically displayed to allow participants to track their own performance.** **9) Triggered contact between the physical therapist and participants during a change in the pattern of exercise adherence (i.e., unexplained lack of engagement > 1 week), a patient-reported acute health condition or a patient-initiated question about the program.** **Frequency: Daily interaction with mHealth app** **Duration: 12 months** **Setting: Self-selected environment**	**The programme was developed from a predetermined set of exercises based on the American Parkinson Disease Association "Be Active and Beyond" programme (included strengthening and stretching exercises)** ***Walking Component*** **Consisted of an individualised recommended range of steps per day (eg,5000-7500 or 7500-10,000) that was determined from each participant's baseline activity level** **Frequency:** **Exercise component 5 to 7 exercises for ≥ 3d/wk.** **Walking component Individualised recommended range of steps per day (e.g.,5000-7500 or 7500- 10,000)** **Duration: 12 months** **Setting: Self-selected environment**	**Stretching and strengthening exercises provided using printed photographs; walk daily using a pedometer; interact with a physical therapist at the beginning of the study only;** **no use of mobile technology**	**1) StepWatch Activity Monitor** **2) PDQ-39** **6MWT**

				Both exercise and control interventions of the programme included standard elements designed to promote behaviour change. These included **1) Participant goal setting,** **2) Tailoring the programme to participants' preferences, and** **3) The provision of feedback via activity trackers.**			
Hermanns *et al.* (2019)[160] **USA** **Feasibility pre-post-study** **Idiopathic Parkinson's disease (H&Y stage 1-4)** **Total: n=5** **Age: 73 ± 4.95** **Sex: 3/2 (M/F)**	**1) To assess the feasibility of an intervention that requires wearing a physical activity tracker and participating in an online support group, and** **2) To examine the effect of this intervention on the self-efficacy for physical activity and QOL of older adults with PD**	**Physical Therapist**	**Social Cognitive Theory**	***Multi-component Behaviour Change Component: Technology + Support Groups*** ***Activity Tracker*** **1) Participants were given physical activity tracker** ***Online Support*** **1) Participants were instructed to engage in a private online support group where they would engage in education session, share what exercises or other physical activity they performed, their overall perceived health, and other PD resources with the other study participants.** **Frequency: Minimum three times per week** **Duration: 12 weeks** **Setting: Self-selected environment**	**1) Participants were provided with an iPad.** **2) Three videos were preloaded and available for viewing: warm-up and two additional videos of specific exercises for balance, rigidity, and gait.** **3) Beginning with the seated warm-up video performed by therapist- included stretching.** **4) Instructed to select one of the two remaining videos for large muscle exercise.** **Frequency: Three times per week** **Duration: 12 weeks** **Setting: Self-selected environment**	**No control group**	**1) Physical Activity Assessment Inventory** **2) Functional Assessment of Cancer Therapy-General** **3) Physical activity tracker**
Lai *et al.* (2020)[161] **USA** **Preliminary Quasi-experimental (Mixed methods)** **Idiopathic Parkinson's disease (H&Y stage 1-3)** **Total: n=20** **Intervention: 10** **Age: 63.4 ± 10.4** **Sex: 7/3 (M/F)** **Control: 10** **Age: 70.8 ± 7.1** **Sex: 7/3 (M/F)**	**To inform future, large-scale trials that aim to implement Internet-exercise interventions in Parkinson's disease**	**Physical Therapist**	**Social Cognitive Theory**	***Behaviour Change Component: Technology*** ***Telecoach TAE*** **1) Participants received one-to-one exercise training through the telehealth system.** **2) The system allowed telecoaches to monitor vital signs remotely in real-time during the exercise sessions and communicate with participants through videoconferencing.** **3) A telecoach accompanied and observed the participant for all of each exercise session.** **4) In addition to ongoing verbal support during exercise training, participants received behaviour coaching at the initial home visit (20 min).** **5) Behaviour coaching aimed to: instruct participants on proper exercise technique to increase mastery; discuss barriers or issues with the participant's ability to attend the exercise sessions; help participants set achievable goals to complete the exercise prescription; provide verbal encouragement to achieve the desired exercise workload; answer questions related to exercise and discuss the benefits of exercise.** **Frequency: 3 sessions per week Duration: 8 weeks (Total: 24 sessions) Setting: Self-selected environment**	**1) Both the TAE and SRE group received a home visit prior to starting the intervention and the same exercise prescription of combined aerobic and strength exercises.** **2) Participants were told to perform moderate aerobic exercise within 40-60% of their heart rate reserve, using telehealth system & stationary recumbent cycle.** **3) For strength exercises, participants used adjustable ankle weights (1-5 lb.) to perform 2-3 sets of 10-20 repetitions for major lower-extremity muscle groups.** **4) Participants were informed that they could independently perform 'more or less exercise' than prescribed, as long as they were connected to the telehealth system.** **Frequency: 165 minutes per week Duration: 8 weeks (Total: 24 sessions) Setting: Self-selected environment**	***SRE group* (No telecoach)** **1) Participants independently managed their exercise training using the telehealth system** **2) The journal was used to record their progress and included written instructions on exercise techniques.** **3) Participants were told that exercise data during sessions were recorded for later inspection by a telecoach, on weekly basis.** **4) Participants were given the contact information of a telecoach to discuss exercise-related questions or technical issues with equipment.** **6) Similar to the TAE group, SRE participants received a behaviour coaching session at initial home visit** **Frequency: 3 sessions per week Duration: 8 weeks (Total: 24 sessions) Setting: Self-selected environment**	**1) Measures of adherence: (a) the total number of exercise sessions performed, (b) time in minutes exercising per week, (c) time exercising at a moderate aerobic intensity per week, and (d) attendance** **2) Walking Capacity (walking capacity (6MWT, and comfortable and fast walking speed)**

Landers and Ellis (2020)[162] **USA** **Single-arm pilot study** **People with Parkinson's disease (self-reported) who had downloaded the commercially available app** **Total: n=28** **Age: 62.1 ± 9.6 Sex: 6/14 (M/F) (8 unspecified)**	**To test the feasibility, safety, and signal of efficacy of a mobile app that facilitates exercise for people with Parkinson disease**	**The customised exercise regimen was constructed and developed by physical therapists**	**None**	**Behavioural Change Component: Technology: Online Mobile Exercise App:** **1) After registering on app and completing several self- report Likert scale questions and performance-based assessments, exercise regimen was made for participant's level of function.** **2) The customised exercise regimen was constructed and developed by physical therapists.** **3) The app chose the exercise programme based on the primary goal (i.e., mobility) and then used the responses from self-report questions and the data from performance-based tests to determine the severity of the PD.** **4) From this information, the app selected exercises consistent with the primary goal and at the appropriate level of function based on one's severity of Parkinson disease.** **5) At preset intervals (generally after 2 weeks), the app reassessed functional capacity (same self-report questions and performance-based measures). Type, duration, and intensity of each exercise was adjusted in the exercise regimen.** **Frequency: 150 mins per week** **Duration: 12 weeks** **Setting: Self-selected environment**	**Aerobic, strengthening, balance, yoga based, range of motion/stretching, meditation based, and speech therapy exercises.** **Frequency: At least 150 minutes per week.** **Duration: 12 weeks** **Setting: Self-selected environment**	**No control group**	**1) Feasibility** **2) Safety** **3) Efficacy (30- second STS; Timed Up and Go; PDQ-8)**
Lee *et al.* (2019)[163] **South Korea** **Quasi-experimental study (With a non-equivalent control group)** **Idiopathic Parkinson's disease (H&Y stage 1-3)** **Total: n=42** **Intervention group: 22** **Age: 62.73 ± 8.50** **Sex: 13/9 (M/F)** **Comparison group: 20** **Age: 62.20 ± 5.27** **Sex: 12/8 (M/F)**	**To test the effects of group exercise and telephone counselling on physical and psychosocial health in people with Parkinson's disease.**	**Classes were supervised by three experts who were doctoral students majoring in geriatric nursing or sports medicine and who had previously participated in exercise programmes for participants with chronic disease.** **Counselling-NR**	**Social Cognitive Theory**	**Behaviour Change Component: Support Groups** ***Motivational Telephone Counselling*** **1) Telephone counselling was delivered to motivate continuation of exercise and obtain feedback on the group exercise program.** **2) Counselling content included:** **(a) Have you lately experienced any health problems such as a fall or unpleasant symptoms?** **(b) Has any positive or pleasing change occurred since you began participating in the group exercise program? If so, what is it?** **(c) Has any negative or unpleasant change occurred since you began participating in the group exercise program? If so, what is it? Let's think about what we could do to solve the problem.** **(d) Are you willing to participate in the group exercise programme consistently? If not, what is the reason for your decision?** **(e) Is there anything more that you want to talk about or suggest?** **Frequency: Once every 2 weeks** **Duration: 12 weeks** **Setting: Sporting facility**	**The group programme consisted of 10 minutes of warm- up (range of motion exercise and stretching were conducted for relaxation of muscles and joints), 15 minutes of aerobic exercise (line dancing), 15 minutes of resistance exercise (upper limb theraband exercises; lower limb body weight exercises), and 10 minutes of cool down (stretching).** **Frequency: Twice a week** **Duration: 12 weeks** **Setting: Group classes in sporting facility**	**Usual Care-Pharmacological treatment from outpatient clinic.**	**1) The International Physical Activity Questionnaire-Short Form** **2) The Schwab and England Activities of Daily Living Scale** **3) Short Form Geriatric Depression Scale-Korean Version** **4) 30-second STS** **5) TUG** **6) Berg Balance Scale** **7) 6MWT** **8) PDQ-39**

Long (2020)[164] **USA** **Single arm feasibility study** **Idiopathic Parkinson's disease (H&Y stage 1-2)** **Total: n=13** **Age: 61.69 ± 9.14** **Sex: 9/4 (M/F)**	**To evaluate feasibility, acceptability and preliminary efficacy for PA levels, self- efficacy, motivation, and self-perception of performance**	**Occupational Therapist**	**1) Bandura's Self-Efficacy Theory** **2) Self-Determination Theory Further supported by** **3) The Transtheoretical Model of Behaviour Change and** **4) The Transformative Exercise Framework**	***Multi-component Behaviour Change Components: Technology + Support Groups + Education + Behaviour Techniques*** ***Activity monitor (tracking and feedback)*** **a Fitbit PA monitor with online monitoring platform** ***Therapist support (emphasizing stages of change)*** **1) Participant/therapist interaction (included discussing the stages of change, motivational interviewing: positive reinforcement, goal setting)** **2) Sessions that occurred over the following 14 weeks (week 1, 2, 3, 6, 10, and 14). The therapist checked-in with the participant via phone or email to provide additional support and feedback on the weeks when the participant did not have one-to-one sessions (week 4,5, 7, 8, 9, 11, 12, and 13).** ***Educational workbook (emphasizing self-management strategies and self-efficacy)*** **a PD-specific PA workbook (included information of physical activity and PD-specific exercise benefits, overcoming challenges, developing a physical activity plan, goals and targets, safety and monitoring and recording physical activity and progress)** **Frequency: Six one-to-one sessions** **Duration: 14 weeks** **Setting: Self-selected environment**	**No specific exercise component-Participants engaged in self-regulated exercise in self-selected environment**	**No control group**	**1) Activity tracker** **2) Brunel lifestyle inventory Physical Activity Questionnaire** **3) The Exercise Self-Efficacy scale** **4) The Behaviour Regulation in Exercise Questionnaire** **5) Modified Canadian Occupational Performance Measure**
Peteet (2002)[165] **USA** **Pilot RCT** **Idiopathic Parkinson's disease (H&Y stage 2-3)** **Total: n=19** **Age: 60.89 ± SD NR** **Sex: 12/7 (M/F)** **Intervention: 8** **Age: 58 ± 6.59** **Sex: 5/3 (M/F)** **Control: 11** **Age: 63 ± 9.52** **Sex: 7/4(M/F)**	**NR**	**Physical Therapist (exercise) Instructor (self-management program)**	**1) The Health Belief Model** **2) The Transtheoretical model (stages of change)** **3) Social Learning theory**	***Multi-component Behaviour Change Components: Behaviour Techniques + Education*** ***Self-management educational program*** **1) Instructor-led group discussion of topics including exercise barriers, fall prevention, strategies for relaxation, physical activity action planning and feedback, modelling of behaviour by participants for one another, reinterpretation of symptoms by giving many possible causes for each symptom, management strategies for symptoms, and individual decision making** **2) Informal group problem solving,** **3) Individualised self-management exercise plans for participants** **Frequency: 45 mins per session, once per week** **Duration: 6 weeks** **Setting: Group session (setting NR)**	**1) Warm-up (bicycle, upper-extremity ergometer, stretching exercises to the legs and arms, and mobility exercises to the neck, trunk, aims and legs** **2) Aerobic component using theraband and/or weights for strengthening. Treadmill and overground walking with varying speeds and frequencies was used along with external visual (e.g., stripes on the floor) and auditory (e.g., metronome or music).** **3) Functional activities like turning in bed, transferring to sitting & standing, and stairs.** **4) Introduction of recreational activities, such as ball games and aerobics.** **5) Relaxation exercises** **6) Cool down** **Frequency: 45 mins session, once/ week** **Duration: 6 weeks** **Setting: Group session (setting NR)**	**Control group engaged in exercise component only** **Both groups participated in the same standard exercises**	**1) The Physical Activity Scale for the Elderly** **2) The Self-Efficacy for Exercise scale** **3) the Geriatric Depression Scale** **4) Functional Reach Test** **5) Timed Up and Go Test** **6) Berg Balance Scale**

Tickle-Degnen *et al.* (2010)[91] **USA** **RCT** **Idiopathic Parkinson's disease (H&Y stage 2-3)** **Total: n=107** **Age: 66.3 ± 9.0** **Sex: 72/35 (M/F)** **Intervention:** **27 hours rehabilitation:37** **Age: 67.6 ± 10.3** **Sex: 26/11 (M/F)** **18 hours rehabilitation:33** **Age: 65.8 ± 8.3** **Sex: 22/11 (M/F)** **Control** **0 hours rehabilitation:** **37 Age: 65.6 ±** **8.3 Sex: 24/13** **(M/F)**	**1) To determine whether self-management rehabilitation promoted HRQOL beyond best medical therapy.** **2) To determine whether rehabilitation outcomes persisted at 2 and 6 months of follow-up.** **3) To determine whether rehabilitation-targeted domains of mobility, communication, and activities of daily living were more responsive to the intervention than were nontargeted areas such as emotions, stigma, social support, and cognitive ability**	**A physical therapist led all sessions and an occupational therapist and speech and language therapist each participated in half of the sessions, assisted by therapy students.**	**1) Theory of planned behaviour** **2) Social Cognitive Theory**	***Behaviour Change Component: Education Interdisciplinary Self-management Rehabilitation*** ***27 hours of rehabilitation, with 18 in clinic group rehabilitation and 9 hours of rehabilitation*** **1) Participants assigned to the 27-hour condition engaged in 4.5 hours of self-management rehabilitation per week in two 1.5-hour group clinic sessions and one 1.5-hour individual home or community session to transfer self- management skills to the locations of daily living.** **A physical therapist led all sessions and an occupational therapist and speech and language therapist each participated in half of the sessions, assisted by therapy students.** **3) Participants received manuals with detailed photographs of exercise routines. Each group clinic session involved physical exercises, speech exercises, functional training, and a discussion about self-management strategies (Barriers to exercise, communication, mobility, benefits of exercise, enhancing social communication, strategies to improve walking, mastering moving in bed, rising from chairs, coping with tremor, stiffness, self-management for life: moving forward, preventing falls, talking on the phone. strategies to improve dressing, relaxation, stress management, self- management for life: staying on track).** ***18 hours of clinic group rehabilitation plus 9 hours of attention control social sessions*** **1) Participants assigned to the 18-hour condition had 3 hours of self-management rehabilitation per week in two 1.5-hour group clinic sessions** **2) They did not receive weekly 1.5 hour of transfer-of- training session in the home or community.** **3) Instead, they received weekly 1.5-hour student-facilitated social group session in the clinic, which was intended to control for the extra attention.** **Duration: 6 weeks** **Setting: in clinic (group session), home environment (transfer training)**	**Motion, flexibility, and strength exercises (25 min)** **Active ranging/stretching to increase trunk extension/rotation** **Stretching hip flexors, hamstrings and gastrocnemius, Strengthening trunk/hip postural muscles, knee and ankle extensors** **Daily function training examples (15 min) Moving in bed** **Rising from chair** **Up and down from floor** **Social communication** **Dressing** **Handwriting** **Swallowing** **Social Communication** **Gait training (10 min)** **Walking with external auditory cues to optimise gait pattern and Speed** **Frequency: One a week (part of the group self- management rehabilitation sessions)** **Duration: 6 weeks** **Setting: In clinic**	**0 hours rehabilitation**	**PDQ-39**
van Nimwegen *et al.* (2013)[166] **Netherlands** **Multicentre RCT** **Idiopathic Parkinson's disease (H&Y stage 1- 3)** **Total: n=586** **Intervention: 299** **Age: 65.1 ± 7.9 Sex:**	**To evaluate whether a multifaceted behaviour change programme increases physical activities in participants with Parkinson's disease.**	**Physiotherapists**	**1) Social Cognitive Theory** **2)The transtheoretical model of health behaviour change.**	***Multi-component Behaviour Change Components: Support Groups + Education+ Behaviour Techniques + Technology*** ***ParkFit Activity Coach*** **1) Physiotherapists served as personal activity coaches who guided participants towards more active lifestyle during monthly coaching sessions.** **2) Physiotherapists educated participants about the beneficial effects of physical activity and about suitable activities.** **3) Additionally, participants were stimulated to participate in group exercise to experience beneficial effects of physical activity and to receive social**	***Physiotherapy*** **1) The ParkFit programme also included regular physiotherapy sessions.** **2) Based on individual disabilities, the therapist and participant jointly formulated individually tailored treatment aims, according to the evidence-based guideline of physiotherapy for PD** **Frequency: NR** **Duration: 24 weeks** **Setting: Community Hospital**	***ParkSafe*** **Regular physiotherapy aimed at promoting safety of movement. Received an education brochure (similar to ParkFit group) but provided information about benefits on physiotherapy and safety movements.** **Frequency: NR** **Duration: 24 weeks** **Setting: Community Hospital**	**Primary Outcome: LAPAQ** **Secondary Outcomes:** **1) 6MWT** **2) PDQ-39** **3) 7-day activity diary** **4) Ambulatory activity monitor**

194/105 (M/F) **Control: 287** **Age: 65.9 ± 7.2** **Sex: 188/99** **(M/F)**				**support from fellow participants.** ***Education Brochure and Health Contract*** **1) Participants received an educational workbook covering specific elements to promote a behaviour change.** **2) The workbook gave information about the benefits of physical activity, the risks of a sedentary lifestyle, suitable activities for PD participants, strategies to identify and overcome barriers to engage in physical activity, setting goals and recruiting social support.** **The workbook included a health contract (written agreement between participant and physiotherapist) to support initiating and maintaining physical activities by formulating long term activity goals.** **4) A logbook was included to monitor short term goals.** **Participants received a bi-annual newsletter accentuating the benefits of physical activity.** ***Goal setting*** **1) During the coaching sessions participants and physiotherapists formulated activity goals.** **2) These were created in order to obtain the long-term goals a formulated in the health contract.** **3) During the coaching sessions participant and therapists evaluated these goals as well as the experienced barriers.** **4) The formulated activity goals had to be realistic, concrete, and individualised and had to be formulated in a systematic way.** ***Activity Monitor*** **1) All participants got a personal ambulatory monitor.** **2) The accelerometer showed the amount of actually delivered daily physical activity using light-emitting diodes.** **3) At a personalised website, participant and coach could formulate a personal goal based on kilocalories; feedback of the monitor was directly related to this personal goal.** **4) Since data of the monitor were uploaded to this website, participant and coach could monitor the individual progress.** **Frequency: NR** **Duration: 24 weeks** **Setting: Community Hospital**			

FITT=Frequency, Intensity, Time , Type; H & Y=Hoehn and Yahr; M=Male; F=Female; RCT=Randomised control trial; PD=Parkinson's disease; IPD=Idiopathic Parkinson's disease; LLFDI=Late life function and Disability Instrument; mHealth=mobile health d/wk.=Days per week; ; 6MWT=6-minute walk test; PDQ-39=Parkinson's disease Questionnaire-39; Min=Minute; N/A=Not Applicable; TAE=Telecoach-assisted exercise; SRE=Self- regulated exercise; STS=sit to stand; PDQ-8=Parkinson's disease Questionnaire-8; TUG=Timed Up and Go; NR=Not reported; LAPAQ=LASA physical activity questionnaire.

Description of studies

4.4.2 Study characteristics

Study quality was mixed. Included were four randomised controlled trials (Tickle-Degnen *et al.*[91], n=107; van Nimwegen *et al.*[166], n=586; Ellis *et al.*[159], n=51; Peteet[165], n=19), two n-RCTs (Lee *et al.*[163], n=42; Lai *et al.*[161], n=20) and five single-arm feasibility studies (Landers and Ellis[162], n=28; Long[164], n=13; Hermanns *et al.*[160], n=5; Ellis *et al.*[52], n=20; Colon- Semenza *et al.*[158], n=10).

Control group interventions were described as no rehabilitation[91], standard exercise intervention[159,165,166] and usual pharmacological care only[163]. Most studies were conducted in the United States of America[52,91,158-162,164,165], one in South Korea[163] and one in the Netherlands[166].

4.4.3 Risk of bias within studies

The outcome of the risk of bias assessment of the RCTs was mixed. Only Ellis *et al.*[159] was considered to have a low risk, with the others considered moderate[91,166] or high[165], due to potential bias from deviations from the intended intervention[91,165], poor randomization[165], and lack of allocation concealment[165].

Most of the seven non-RCTS were deemed at a moderate risk of bias using the ROBINS-I tool. Potential sources included the selection criteria[160], lack of blinding[52,163,164], inability to adjust, or control for confounding variables[158,163,164] and failure to report participant withdrawal[163] (Figure 4.2 and Appendix A, Table A2 and A3).

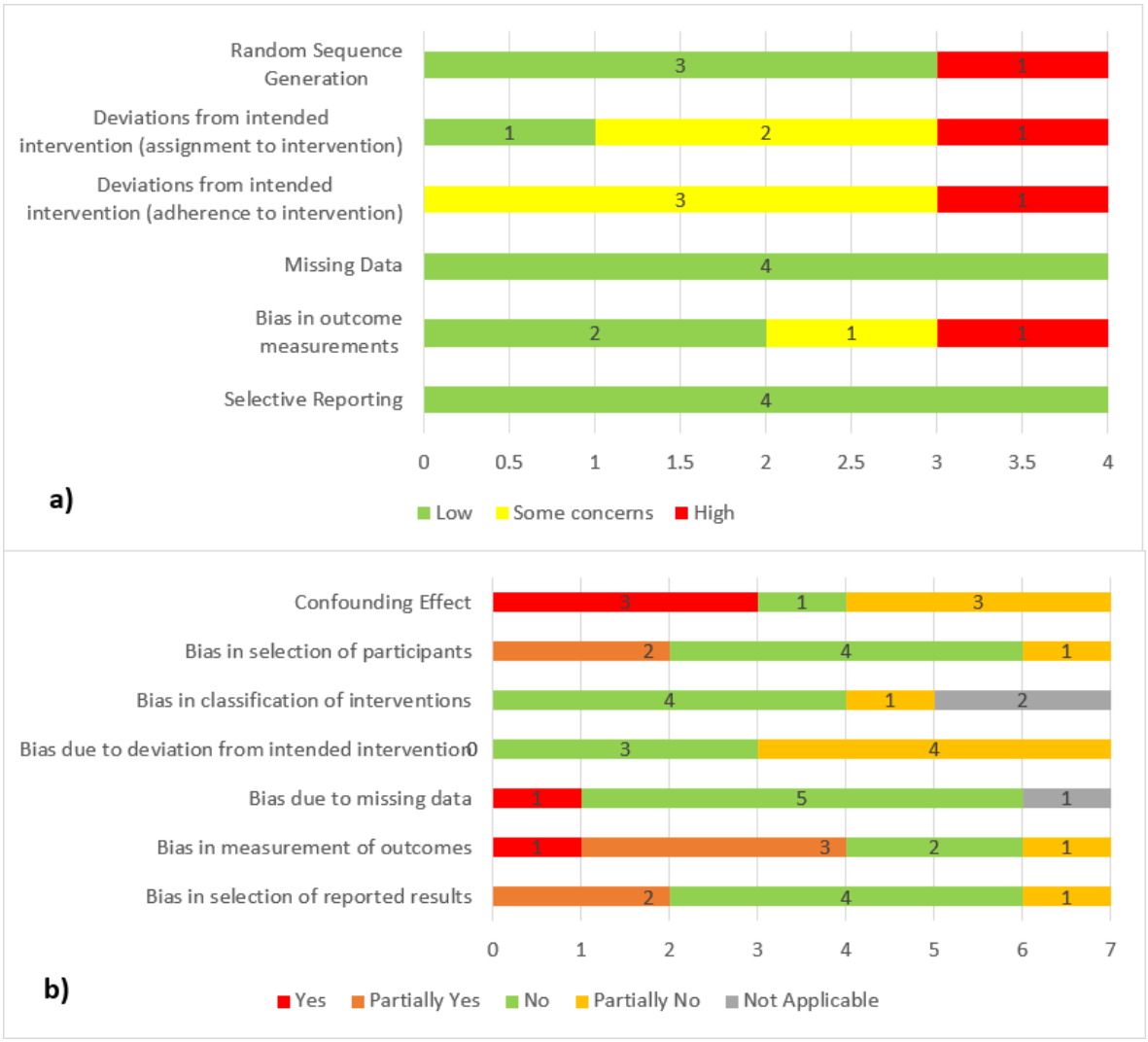


Figure 4.2: a) risk of bias across randomised controlled trials b) risk of bias across non-randomised studies.

4.4.4 Participants

In total, 901 participants were included (570 males, 331 females; mean weighted age 65.17 years). Sample sizes ranged from five[160] to 586 participants[166]. Nearly all used the original or modified Hoehn and Yahr (H&Y) scale to determine disease severity. Three studies[160-162] did not provide individual H&Y stages (n=179 participants). Most participants were Stage 2/2.5 (n=623) and only one study included participants at Stage 4[159].

4.4.5 Theory/Models underpinning BC interventions

Eight studies used a theory/model to underpin the BC intervention[91,158,160,161,163-166]; the Social Cognitive Theory[91,158,160,161,163,166], Transtheoretical Model of Behaviour Change[164-166], Self-determination Theory[158,164], and Self-Efficacy Theory[164].

4.4.6 The BC interventions mapped to the Theoretical Domains Framework (TDF)

The BC interventions consisted of education[91,164-166], behaviour techniques[164-166], technology[52,158-162,164,166] and peer/support groups.[52,158,160,163,164,166] Intervention duration varied greatly from 4 weeks to 12 months.

A total of 47 items from the interventions were extracted, coded, and mapped to the TDF (Table 4.4). Of interest, over half (57%) of the items aimed to improve intrinsic motivation (personal factors; barrier identification, goal setting, action planning), while fewer than 20% related to external motivators (social factors, activity monitors, incentives, support groups). (Appendix A, Table A4 and A5).

Education programmes consisted of either workbooks/brochures[164,166], or weekly lectures.[91,165] Topics included the condition and symptom management, importance of physical activity, suitable exercises including relaxation, overcoming barriers, and fall prevention[91,165] (Table 4.3). As anticipated, knowledge and skills domains of the TDF were addressed in all the studies utilizing education.

Behaviour techniques such as goal setting[164,166], barrier identification[165,166], cognitive restructuring[165], problem-solving[165], decision-making[165], action planning[164,165] and relaxation[165] were explored through informal groupwork or workbooks[165,166] (Table 4.3). Behaviour techniques mostly aimed to enhance knowledge, beliefs about capabilities, and

promote behaviour regulation, control environmental contexts and social influences (Table 4.4 and Appendix A, Table A4).

Technology included activity trackers[158,160,164,166], pedometers[52], virtual coaches[52,161] and online exercise apps[159,162] which provided prompts and feedback to participants regarding exercise (Table 4.3). Technology was mainly used as an extrinsic motivator (behaviour regulation), with some studies incorporating intrinsic motivation strategies (knowledge about their condition, action planning, decision making, and awareness of negative consequences). Of note, technology addressed the same issues as the other behaviour change interventions (education, behaviour techniques, and support groups), and while it may not provide more than other interventions, it may be efficient and can be tailored to the person's needs and intrinsic motivation. Of note, technology was always managed by a trained professional or trained peer (training prior to the intervention).

Support groups were delivered either individually, through telephone peer coaching[158] or motivational counselling[163], peer-group online sessions[160], or therapist-led support[164,166], and aimed to address most of the TDF domains (9/14 domains). Participants were encouraged to identify their progress, problems encountered, strategies to overcome barriers, and resources were made available (Table 4.3). Only Lee *et al.*[163] used it as a single intervention to support behaviour change (action planning, awareness of negative consequences, barrier identification and recruitment of social supports).

From the mapping exercise, we can see that each intervention provided elements to address most of the TDF domains. Education addressed knowledge and self-management skills. Behaviour techniques addressed the intentions of the individual, environment context and resources and decision-making processes. Technology addressed beliefs about capabilities, goal setting and social comparisons. Finally, support groups addressed action planning and

social influences through peer/group support and address individual's beliefs about consequences.

Table 4.4: Intervention type mapped across TDF domains

	Education	Technology			Support groups	Multi-component					
						Behaviour Techniques + Education	Technology + support groups			Technology + Behaviour Techniques + Support groups + Education	
TDF Domain	***Tickle -Degnen *et al.*[91]**	***Ellis *et al.*[159]**	**Lai *et al.*[161]**	**Landers and Ellis[162]**	***Lee *et al.*[163]**	**Peteet[165]**	**Colon -Semenza *et al.*[158]**	**Ellis *et al.*[52]**	**Hermanns *et al.*[160]**	**Long[164]**	***Van Nimwegen *et al.*[166]**
Knowledge	■					■		■	■	■	■
Skills	■		■	■		■		■	■	■	■
Memory, attention and decision processes					■	■		■			
Behaviour regulation	■	■	■	■	■	■	■	■	■	■	■
Beliefs about Capabilities	■	■	■	■	■	■	■	■	■	■	■
Beliefs about consequences	■				■	■	■	■		■	■
Social/ professional role and identity	■				■	■				■	■
Emotion	■				■	■					
Intentions	■		■			■		■		■	■
Reinforcement	■	■	■	■	■		■	■	■	■	■
Goals	■	■	■		■		■	■		■	■
Optimism											
Environmental context resources	■		■		■	■	■	■		■	■
Social Influences	■	■	■	■	■	■	■	■	■	■	■
Total	**12/14**	**5/14**	**8/14**	**5/14**	**10/14**	**11/14**	**7/14**	**11/14**	**6/14**	**11/14**	**11/14**
***=Significantly positive findings for what outcomes**											

Outcomes of the interventions

4.4.7 Summary of overall findings

Only four of the 11 studies detected significant changes in one or more outcomes (Ellis *et al.*[159], n=51; Lee *et al.*[163], n=42; Tickle-Degnen *et al.*[91], n=107; and van Nimwegen *et al.*[166], n=586). Improvements in QoL[91,159,163], physical function[166], and exercise adherence[166] were found. No improvements in exercise self-efficacy were detected, however only the smaller/feasibility studies measured self-efficacy, hence the effects remain unclear.[158,160,164,165] Finally, no negative effects were reported.

Interventions included education only (Tickle-Degnen *et al.*[91] (n=107)); technology only (Ellis *et al.*[159] (n=51)); multi-component intervention (van Nimwegen *et al.*[166] (n=586)) and support groups only (Lee *et al.*[163] (n- RCT, n=42)). Only Van Nimwegen *et al.*[166] detected improvements in more than one outcome (physical function and exercise adherence), suggesting that a multi-component intervention encompassing education, behaviour techniques, technology and support groups could be more effective (improved QoL, physical function, and exercise adherence).

4.4.8 Quality of life

Using various BC interventions, three RCTs[91,159,166], and one n-RCT[163] reported QoL changes, using the Parkinson's disease questionnaire (PDQ-39)[91,159,163,166] (Appendix A, Table A6).

With 18-hours/27-hours of interdisciplinary self-management education (n=107), Tickle-Degnen *et al.*[91] detected improved QoL (54%), with some benefits persisting six months after the programme. Similarly, using a health app, Ellis *et al.*[159] detected better mobility-related QoL in the less-active participants, (n=51, 12-month intervention). Finally, Lee *et al.*[163] found 12-week telephone counselling (support groups, n=42) improved QoL (+15%), which further

improved at 16 weeks (+21%) however this study was non-randomised. Conversely, van Nimwegen *et al.*[166] (RCT, n=586, 24-week multi-component intervention) reported no changes in QoL. This robust large study suggests no additional impact on QoL with a comprehensive BC intervention, however, more large-scale studies need to re-confirm this finding.

Mapping to the TDF revealed no clear pattern. Common domains included belief about capabilities, social influences, and behaviour regulation, while most of the other domains were addressed by two or less studies (Table 4.4).

4.4.9 Physical function

Only two RCTs (Ellis *et al.*[159], n=51; van Nimwegen *et al.*[166], n=586) measured physical function, both using the 6MWT (Appendix A, Table A6). Van Nimwegen *et al.*[166] (24-week multi-component) found improved physical function and Ellis *et al.*[159] (12-month mHealth intervention) detected only within-group improvements.

Again, mapping to the TDF revealed no clear pattern. Key common domains included belief about capabilities, goals, and social influences (Table 4.4).

4.4.10 Exercise activity/adherence

Of three RCTs[159,165,166] measuring exercise uptake/adherence using activity trackers or various questionnaires, only van Nimwegen *et al.*[166] detected more physical activity compared to conventional physiotherapy[166] (11/14 TDF domains, Table 4.4).

4.4.11 Which TDF domains are most effective?

The TDF domains addressed in the larger adequately powered studies were grouped to identify the most effective TDF domains. To recap, Tickle-Degnen *et al.*[91] implemented an education intervention (12/14 TDF domains), Ellis *et al.*[159] utilised technology (5/14 TDF domains), van Nimwegen *et al.*[166] used a multi-component intervention encompassing education, behaviour techniques, technology and support groups (11/14 TDF domains) and Lee *et al.*[163] conducted

support groups (9/14 TDF domains). Only five TDF domains were addressed by all four studies (behaviour regulation, belief about capabilities, goals, reinforcement, and social influences). Three further domains were addressed by only three studies[91,159,166] (belief about consequences, social and professional role and identity, and environmental context resources). From this, the TDF domains were categorised into three tiers (of effectiveness) based on the domains represented by these studies (Figure 4.3).

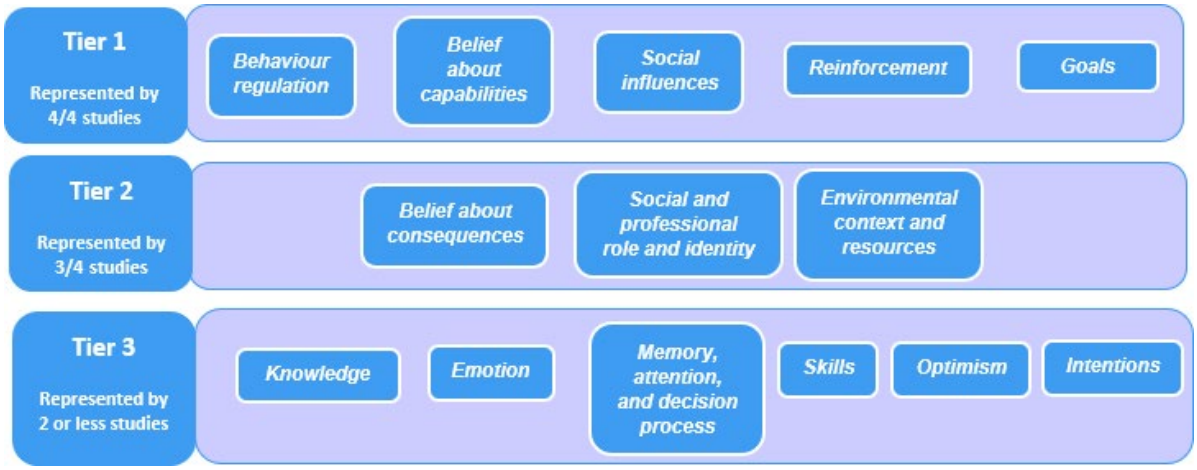


Figure 4.3: TDF domains used in studies detecting significant improvements.

Therefore, the findings would suggest that Tier 1 displays the more commonly addressed TDF domains, with Tier 3 displaying the domains addressed least. While there is no strong evidence for one approach over another, the most effective studies employed an intervention addressing many TDF domains.

4.5 Discussion

People with Parkinson's disease have trouble sustaining exercise and reaching the recommended physical activity guidelines, increasing their risk of frailty and falls. The aims of this review were to firstly, identify BC interventions aimed to improve exercise self-efficacy and adherence, secondly, to map them to the TDF, and finally, to examine their effect on health outcomes. We identified education, behaviour techniques, technology, and support groups,

either as a single or multi-component intervention, were used to address most domains of the TDF. However, the most effective interventions addressed behaviour regulation, belief about capabilities, goals, reinforcement, and social influences. The quality of the included studies was poor. Therefore, we can assume that the evidence of BC interventions to improve self-exercise adherence and self-efficacy is limited and of low quality, further demonstrating that the topic is relatively new and unknown.

We found the TDF gave us a good understanding of the BC interventions. The framework helped to tease apart the issues/barriers addressed by each intervention and structure our analysis accordingly. It helped to identify the importance of intrinsic factors, and which domains appeared most effective. Of note the TDF was originally aimed at healthcare providers, hence it was unclear whether PwPD were aware of their "intentions" and "social and professional role and identity" (domains listed in the TDF).[53]

From the literature, multi-component interventions appear to be used commonly, and our review suggested that the multi-component intervention (van Nimwegen *et al*.[166] (n=586)) appears to be the most effective. In a recent review (n=24 studies), Tennigkeit *et al*.[58] found that uni-dimensional BC interventions often failed to address the complex cognitive- behaviour challenges with Parkinson's disease, while multi-component self-management programmes improved health, mobility, QoL, as well as self-efficacy and depression, demonstrating effects on non-motor features. The authors did not examine exercise adherence or physical activity. It is difficult to draw conclusions from our review, we found some encouraging evidence of improved exercise adherence, but no definitive study measured exercise self-efficacy. Therefore, we conclude that effective interventions to enhance exercise self-efficacy remain unknown, a fundamental requirement for long term exercise adherence.

4.5.1 Behaviour change interventions targeting intrinsic motivation

Many intrinsic methods improved outcomes, including goal setting[91,159,163,166], social supports[159,163,166], coping strategies[91] and barrier identification[91,163,166] (Appendix A, Table A5 for further details). These findings concur with findings of Room *et al.*[167] (n=11 studies), who found that intrinsic behaviour techniques improved exercise adherence in older adults. Techniques were categorised as (1) comparison of behaviour, (2) social support, (3) identity of goals and planning, (4) natural consequences and (5) feedback and monitoring. While the evidence was insufficient to recommend intrinsic behaviour techniques, the results are similar to ours (goal setting, social support, feedback and monitoring, identification of barriers and action planning), further strengthening the concept that intrinsic motivation is an essential aim of BC interventions.

Recognising the importance of intrinsic motivation in physical activity maintenance, Krishnamurthi *et al.*[168] is currently examining the differences between the ReadySteady intervention (motivational sessions, mobile app, pole striding and education), versus a pole striding and education intervention, versus education alone.[168] Some evidence exists in the older adult population. In a non-randomised trial, Azizan *et al.*[169] found a twofold increase in exercise self-efficacy and threefold increase in physical activity with a BC intervention (based on the Transtheoretical model of behaviour change) with a 24-week exercise programme (n=63).

To the best of our knowledge, this is the only review exploring the effects of BC interventions on exercise self-efficacy and adherence to exercise and physical activity among PwPD.

4.5.2 Limitations

The synthesis combined both randomised and non-randomised evidence, which come from different levels of hierarchical evidence and must be interpreted with caution. Many studies

had inadequate sample sizes (n ≤ 20 were common), or poor study design (2 n-RCT, 4 feasibility studies). Most studies recruited only highly educated Caucasian individuals, and all failed to control (or failed to report control of) participants' additional exercise beyond of the intervention. Some studies identified selection bias in their recruitment process.[52,158-160,162] Finally, inadequate methodology reporting prevented a comprehensive assessment of the methodological quality, or when reported well, most were deemed to be a moderate risk of bias.

4.6 Conclusion

We conclude that there is insufficient high-quality evidence to recommend the most effective BC intervention to promote exercise adherence among PwPD. Our analysis using the TDF has helped highlight the most effective domains to bring about change.

Future research should explore multi-component BC interventions encompassing the five most effective TDF domains (behaviour regulation, belief about capabilities, social influences, reinforcement and goals). Future trials should be sufficiently powered, with diverse populations recruited, and sufficient follow-up periods to indicate sustained exercise adherence.

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4.8 Authors' Contributions

LA: Conceptualization, Formal Analysis, Methodology, Writing – Original Draft Preparation. ST: Conceptualization, Supervision, Writing – Review & Editing. SL: Supervision, Writing – Review & Editing. RMcC: Conceptualization, Methodology, Supervision, Writing – Review & Editing. All authors read and approved the final version of the manuscript.

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Chapter 5

Conclusions from Phase 1 and Introductions to Phase 2

5.1 Conclusions from Phase 1

Phase 1 aimed to describe the most common and determine the most effective behaviour change interventions to improve exercise adherence and map the identified intervention components to the Theoretical Domains Framework (Chapter 4).

A comprehensive review of the literature identified eleven studies for inclusion. Quality was mixed, with many studies small, aiming to feasibility test or explore proof of concept. Heterogeneity in both study design and application of BC techniques was considerable. Most interventions were multi-component, including education, behaviour techniques, and support groups. Analysis showed no clear effective technique of applying behaviour change, with no effect on exercise self-efficacy or adherence detected, but some small effects on QoL and physical function were detected.[59] Using the TDF to structure the analysis, the most promising domains were identifiable, regardless of the mode of delivery; namely *behaviour regulation*, *belief about capabilities*, *social influences*, *reinforcement* and *goals.*[59] Heterogeneity between studies prevented a meta-analysis. The findings of this review provided some preliminary knowledge about effective behaviour change techniques to guide PwPD towards a more active lifestyle but ultimately, this is an emerging field of research, with more exploratory and feasibility work to be completed to provide a clear understanding of its effectiveness[59] (Chapter 4).

5.2 Introductions to Phase 2

5.2.1 Rationale for objectives for Phase 2

Research to date, as identified in the systematic review, has not conclusively identified which behaviour change technique(s) and domains can promote change. However, the five TDF domains identified in the systematic review; *behaviour regulation*, *belief about capabilities*, *social influences, reinforcement* and *goals*, showed most promise and were therefore further explored through qualitative research.

Qualitative research was chosen as it is recommended by the MRC framework[56], but also to further understand lived experiences. Firstly, as this research aims to improve exercise adherence, it gave the opportunity to explore motivations, barriers, and facilitators of exercise behaviour in PwPD, potentially helping healthcare providers to develop more personalised, person-centred strategies, aligning with their needs and preferences. Secondly, by gathering insights into the personal experiences of living with Parkinson's disease, an understanding of their challenges, emotions, and day-to-day struggles and unmet needs could be gained. With the objective to reveal the underlying reasons (belief and capabilities, belief about consequences, optimism, social influences, environmental resources, etc.) why certain strategies work or don't work, such personal insights are crucial for effective intervention design.

5.2.2 Rationale for methodology

A framework analysis using the Theoretical Domains Framework was initially planned. However, upon analysing the initial data, it became evident that this method was not appropriate, as the data did not align with the framework. Therefore, Grounded theory was chosen as the underpinning methodology because grounded theory emphasises the importance of the participants' voices, ensuring that the resulting theory is deeply rooted in their lived

experiences.[170] The iterative nature of grounded theory, i.e., where data collection and analysis occurred simultaneously, allowed me to refine the focus and deepen my understanding as the study progressed.[170] This ensured that the emerging themes closely aligned with the reality of participants' experiences.[170]

For this qualitative study, a sequential interview process was conducted with the first stage informing the subsequent stages. Interviews were conducted with PwPD first, and then with their family members and experienced physiotherapists who work with PwPD, to gain more insights into the lived experiences by exploring motivation, support and self-management to exercise (Chapter 6). By interviewing these stakeholders, this research obtained unique perspectives from three different viewpoints, to allow me to broaden my knowledge and understanding of the challenges that are faced with regards to accessing, engaging in, supporting and maintaining physical activity and exercise (Chapter 6).

Individual, semi-structured interviews (SSIs) were chosen for PwPD to allow for deeper exploration of individual perspectives, allowing the opportunity to probe personal experiences, feelings, and insights, which may not have been fully shared in a group setting.[171] Further to this, SSIs allowed the interviewer to tailor questions to each participant's unique experiences, allowing for follow-up questions that dig deeper into a participant's specific context, which would have been more difficult in a group.[171] The SSIs may have allowed the participants to feel more comfortable discussing sensitive topics one-on-one, whereas in group settings, some may hesitate to share openly due to fear of judgment or social desirability bias.[171] Lastly, some PwPD may experience articulation difficulties (e.g., dysarthria – slurred speech) which may have deterred them from speaking up in a group interview which may have focused the discussion towards other participants, while personal interviews allowed every participant to have their voice heard equally.[171]

In contrast, group interviews were chosen for the family members (n=4), and also for the physiotherapists (n=5), because in a group setting, participants would stimulate and build upon each other's ideas.[171] This interaction generated richer data, as group discussions can lead participants to express thoughts they might not have considered in isolation, or give insight into how the participants collectively respond to particular challenges.[171] Therefore, I felt that the collective understanding would be more meaningful than individual perspectives alone.

The data identified an unexpected theme – the impact of the diagnosis and the lack of signposting to services on self-management, exercise and care. The analysis revealed this as an important unique topic; hence it has been written up in a second paper (Chapter 7).

The project progress is shown in figure 5.1 (phase 2 is highlighted in orange).

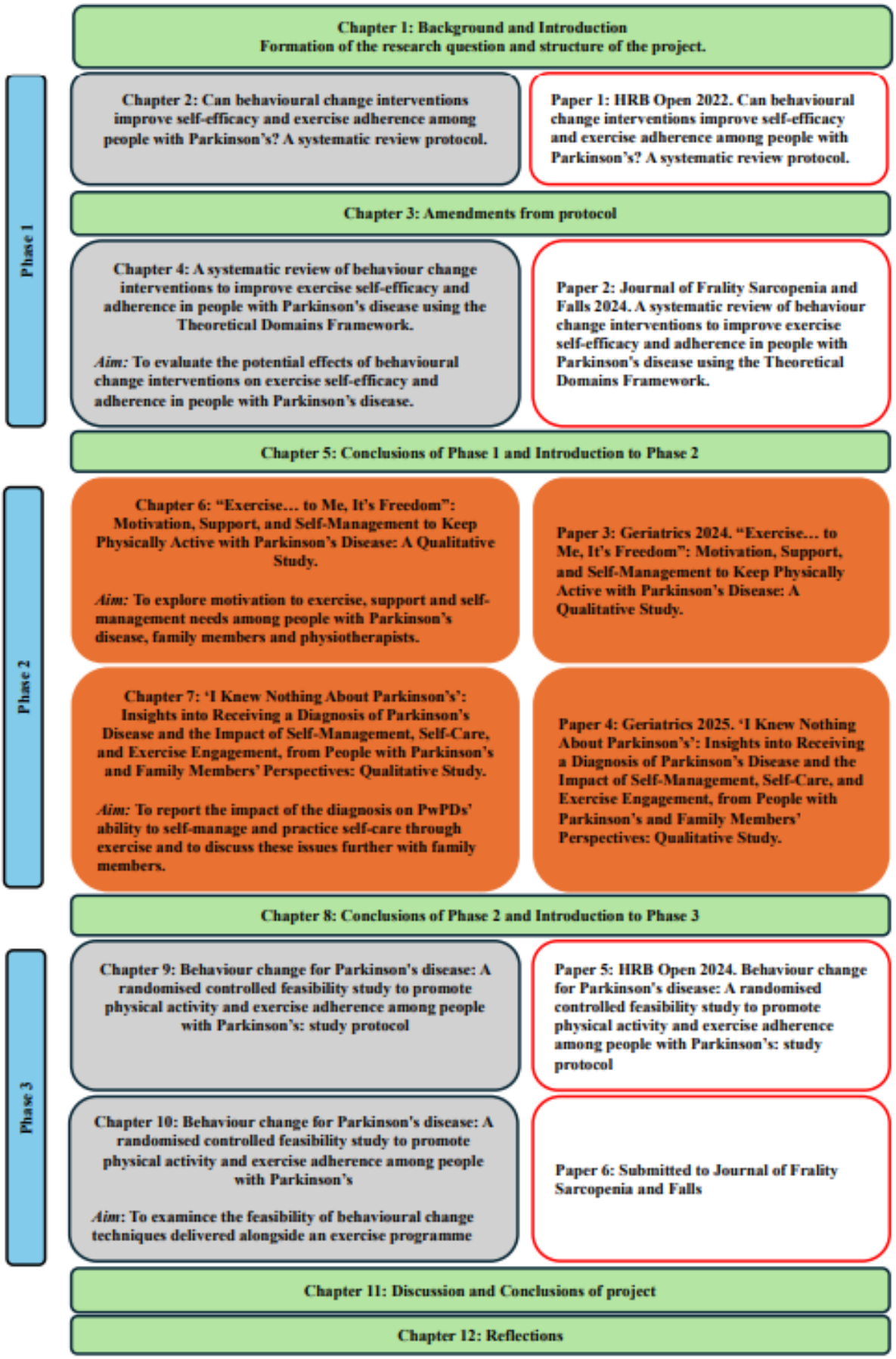


Figure 5.1: Project Structure (Phase 2)

Chapter 6

"Exercise….to me, it's freedom": Motivation, support, and self-management to keep physically active with Parkinson's disease: A Qualitative Study.

Abstract

Background: The benefits of exercise have been widely explored among people with Parkinson's disease (PwPD). Exercise can improve non-motor (fatigue, pain, sleep, etc.) and motor features (balance, muscle strength, gait speed, etc.), maintain function as well as prevent disease progression. Although the benefits are well known, PwPD continue to show difficulty adhering to physical activity and exercise. ***Objective:*** This study aims to explore motivation to exercise, support, and self-management needs among people with Parkinson's disease, their family members and physiotherapists. ***Methods:*** Purposeful and maximum variation sampling methods (age, sex, geographical setting, and disease severity) were employed. PwPD and family members were recruited through physiotherapy services and local support groups. Twelve semi-structured interviews with PwPD, and two group interviews, one with family members (n=4), and one with physiotherapists (n=5) were conducted. Interview guides were informed by patient and public input, and a recent systematic review. Interviews were recorded, transcribed, and analysed using thematic analysis informed by the Grounded theory methodology. ***Results:*** Four common themes emerged: 1) The value of an intrinsic connection with exercise: but there are challenges. A greater connection to exercise led to long term adherence. 2) Adapting exercise to the needs and preferences of a person is essential. Preferred exercises and environments were mixed, with differences emerging between sexes. 3) Physiotherapists' aim to only maintain physical function led to frustration.

Limited self-management opportunities, stigma and dehumanisation were discussed. 4) Non-motor symptoms, stigma, fear, determination, apathy, pain, and low mood were discussed. ***Conclusion:*** Exercise provided physical, emotional, and social rewards. Supports are necessary; however, challenges arise when PwPD's motivation are mismatched to family members' and physiotherapists' goals. Co-created goals, tailored to their preferences, and exercise plans with supported self-management are recommended.

Keywords: Parkinson's disease; Exercise; Physiotherapists; Social Stigma; Qualitative Research.

6.1 Impact statement

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

6.2 Clinical implications

- Differences in exercise patterns and preferences between sexes should be considered when designing exercise programmes (targeting individual's intrinsic motivators and perceived needs).
- Family members are crucial to support exercise, and physiotherapists rely on them especially in cognitive decline. However, frustration can arise when they are "pushing" exercise, rather than supporting exercise.
- Explaining the rationale for tailored exercises is important, but people value having ownership and independent self-management of their exercise programmes.

- Exercise intensity is often under prescribed, missing the opportunity to guide people to high intensity exercise, which may have a neuroprotective effect, slowing disease progression.
- Highly functioning, motivated people feel excluded from challenging exercise. They are signposted to community-based classes or neurological gyms, where they feel underchallenged.

6.3 Introduction

Alongside pharmacological management, exercise is important in the management of Parkinson's disease. Exercise has been shown to attenuate motor and non-motor symptoms[11], improve sleep[172], mood[173], and memory.[173] There are some indications that exercise can subsequently slow disease progression, especially in the early stages.[12,13] The positive effects are detected across a wide spectrum of exercise types and intensities, high-intensity aerobic exercise, high-intensity balance training and unstructured physical activity have all shown attenuated motor symptoms and improved function[174], irrespective of nigrostriatal degeneration.[175]

However, adherence to exercise is challenging. Despite growing evidence of its value, as few as 30% of people with Parkinson's disease (PwPD) with mild disability achieve the World Health Organisation recommended activity levels[15,176]; with some inactive for 70% of the day; considerably less active than age-matched peers.[16] Ellis *et al*.[107] has identified self-efficacy and outcome expectations as strong predictors of exercise adherence in PwPD. Similarly, Dobkin [177]recommends self-management strategies in all neurological rehabilitation, to improve exercise adherence, optimise motor learning, and improve long term outcomes. A recent systematic review examined the effects of behaviour change (BC) interventions to improve exercise self-efficacy and adherence in PwPD.[59] The BC interventions were mapped to the

Theoretical Domains Framework[53], which helped identify effective core components across the interventions.[53] Most were small exploratory studies[52,158,160-162,164,165], and interventions were multicomponent[52,158,160,164-166], including education, behaviour techniques, and support groups. While exercise self-efficacy remained unchanged, it appears that exercise adherence, QoL and physical function improved.[59] The most effective TDF domains were behaviour regulation, belief about capabilities, social influences, reinforcement, and goals.[59] Heterogeneity between studies prevented a meta-analysis, highlighting the novelty of the topic and need for further exploration.[59]

While self-efficacy and exercise adherence seem to be difficult to change, qualitative evidence suggests that social and physical environment[60,61], and family support[60-62] are important in sustaining physical activity. In light of this, we need to explore family support and physiotherapy support in sustaining physical activity. Early physiotherapy involvement, daily exercise, and support from both clinicians and family empower PwPD to stay motivated and involved in activities.[178] Many PwPD look forward to engaging with their therapists, exercise instructors and fellow classes members.[179] While many studies have explored barriers and enablers of PwPD, they have not provided insight into their support systems; their physiotherapists' and family members' experience of supporting exercise and activity to PwPD.

Therefore, this study aims to explore motivation, support, and self-management to keep physically active among PwPD, and to discuss these further with family members and physiotherapists. Interviewing PwPD, family members and physiotherapists will provide us with an understanding of PwPD's motivation to exercise, and the challenges to supporting meaningful, enjoyable exercise for all involved. To gain insight into the relationship between their experiences, this is a sequential qualitative interview study with the first stage informing the subsequent stages. In Stage 1, through semi-structured one-to-one interviews with PwPD, the main supports and motivation needs of the PwPD were identified. These topics were

brought to the subsequent Stage 2 group interview with their family members, and Stage 3 group interview with their physiotherapists.

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

6.4 Methods

6.4.1 Design and ethical considerations

The study was conducted between November 2022 and January 2023 and is reported following the consolidated criteria for reporting qualitative research (COREQ).[180] Local ethical approval was received [ECM 4 (d) 11/1/2022].

6.4.2 Recruitment and study sample

Purposeful and maximum variation sampling methods were employed to recruit PwPD, of varying age, sex, geographical setting, and disease severity. Posters were used in urban primary care centres and local support groups to recruit participants and their family members. Interviews were offered in person, by phone and online. People with cognitive and mood disorders were not excluded from the study, it was suggested that a family member attended (dyad interview) to validate the data. A convenience sample of local community/hospital (public healthcare) physiotherapists with a minimum of three years' experience of working with PwPD were recruited by email.

6.4.3 Data collection

The topic guides were informed by a recent systematic review[59], clinical experience, and patient and public involvement group (PPI)[*see Appendix B7, B8 and B9*]. In line with this systematic review, the Theoretical Domains Framework was used to structure the topic guide, to explore barriers to exercise[53], focusing on the five key domains of behaviour regulation, beliefs about capabilities, social influences, reinforcement and goals.[59]

The interviews were conducted by a registered physiotherapist (LA) with qualitative research training. All interviews lasted up to one hour and were conducted in a quiet, private room at the physiotherapy department. At the end of the interviews, all participants briefly reviewed the interview for verification. Between interviews, the data was checked for emerging themes and to allow self-reflection. Stage 1 was terminated when data saturation based on *code meaning*[181] (no new themes emerging and the data was beginning to repeat), was reached. All interviews were video recorded, transcribed, and checked for verification. The transcripts were used for analysis.

6.4.4 Data analysis

The data were analysed using a Grounded theory approach, using Braun and Clarke's reflexive thematic analysis.[182] (1) The data were reviewed with reflexivity, highlighting the key notes (LA). (2) Text was coded and highlighted data was extracted (LA). Codes were reviewed by a second experienced qualitative researcher (CC). An integrated code and corresponding list of quotations was completed. (3) Subthemes and themes were developed (LA). (4) The themes were independently reviewed for overlap and sense-making (RMC, ST). (5) Refinements were made (LA), similar topics were merged, and large topics were split repeatedly until all authors reached a consensus, with no new themes. (6) Finally, all authors examined the relationship between the themes and finalised the report with supporting illustrations.

6.5 Results

6.5.1 Participants

Forty-two people were contacted (n=20 PwPD, n=12 family members, n=10 physiotherapists); twenty-one were interviewed, (n=12 PwPDs (6 women), n=4 family members (1 woman) and n=5 physiotherapists (5 women)) (see Table 6.1). Two PwPD completed a dyad interview, (one online) and one interview was completed by telephone. Neither dyad-interviewed family

member participated in the family member group interview. All physiotherapists were at senior grade (Table 6.1). One person with Parkinson's disease engaged in advanced therapies (deep brain stimulation). Eleven PwPD self-reported that they engage in regular physical activity; the twelfth self-reported that they exercise infrequently. Eight were urban dwellers, while four were rural dwellers.

Table 6.1: Clinical characteristics of participants.

Stage 1 participants: People with Parkinson's disease

Code	*Interview performance method*	*Age (years)*	*Sex (M/F)*	*Hoehn & Yahr Stage*	*Years Since Diagnosis*	*Geographical setting*	*Mobility*	*Activities of Daily Living*	*Main Caregiver*
P1	In person	57	F	1	4	Rural	Independent (no aid)	Independent	Oneself
P2	Phone interview	-	F	3	12	Urban	Independent (no aid)	Minimum Assistance	Oneself
P3	In person	57	M	1	17	Urban	Independent (no aid)	Independent	Oneself
P4	In person	62	F	1	2	Urban	Independent (no aid)	Independent	Oneself
P5	Online dyad interview (spouse present)	68	M	2	6	Rural	Independent (with walking aid)	Moderate Assistance	Spouse
P6	In person	52	F	1	2	Urban	Independent (no aid)	Independent	Oneself
P7	In person	84	M	2	8	Urban	Independent (no aid)	Independent	Daughter
P8	In person	82	M	2	11	Urban	Independent (with walking aid)	Minimum Assistance	Spouse
P9	In person	76	F	3	6	Rural	Independent (no aid)	Moderate Assistance	Spouse
P10	In person	73	F	2	8	Urban	Independent (no aid)	Minimum Assistance	Oneself
P11	In person	73	M	1	1	Rural	Independent (no aid)	Independent	Spouse
P12	In person dyad interview (spouse present)	76	M	3	6	Urban	Independent (no aid)	Independent	Spouse

Stage 2 participants: Group interview with family members (of participants from phase 1)

Code	*Sex*	*Relationship with phase 1 participant*	*Phase1 participant code*
FM1	F	Spouse	P8 (11 years diagnosed)
FM2	M	Spouse	P4 (2 years diagnosed)
FM3	M	Spouse	P10 (8 years diagnosed)

FM4	M	Spouse	P9 (6 years diagnosed)

Stage 3 participants: Group interview with physiotherapists

Code	*Sex*	*Years working years with PwPD*	*Work Location*
PT1	F	14	Residential care
PT2	F	7	Urban Primary Care
PT3	F	5	Urban Primary care
PT4	F	15	Outpatient department
PT5	F	12	Rural Primary care

The analysis of the transcripts was underpinned by Grounded theory methodology, to better understand the meanings of participants' subjective experiences with engaging with exercise and physical activity, their supports and social actions. Data analysis led to four themes across PwPDs, family members and physiotherapists. Each theme is presented as PwPDs' perspectives, then family members' perspectives and finally physiotherapists' insights. Figure 6.1 presents the themes and subthemes which emerged from the data. While the representing quotes (within the subthemes), are displayed in Table 6.2.

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

A common consensus among **people with Parkinson's disease** was that exercise was wider than just planned or structured activity. An intrinsic connection with exercise (an extremely important and basic characteristic of a person, being closely connected with [exercise]) was linked with long term exercise adherence. Those with a deeper connection viewed it as a relationship rather than a task ('*it's freedom')*, and while personal, it was portrayed as a pleasant experience providing physical and mental benefits (*P1: 'it invigorates me, it makes me feel brave, it* ***lifts*** *me'; 'It's just* ***my time*** *and my space').* Overall, it appeared that those intrinsically motivated to be active prior to diagnosis, displayed stronger exercise self-efficacy and self-motivation, important predictors of long-term adherence. Importantly, exercise seemed to

provide a sense of control and empowerment, bringing greater beliefs about their capabilities, especially that exercise was essential for "*fighting*" Parkinson's disease.

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

Theme 2: Adapting exercise to the needs and preferences of a person is essential.

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

All the **family members** understood that exercise was important (*FM3: '...last year...[I] bought the bike…. The greatest thing I ever bought for exercise, and she uses it. That's if she can't get out on a day like today… So, I think exercise is paramount'). (FM1: 'if I can get my husband just even walking. So, he's not sitting in his chair all day').* **Physiotherapists** agreed,

stressing the importance of accessible exercises, easily embedded into daily lives (*PT2: 'To try and make this a more normal part of their lives'),* and adapting the exercises to the patient's ability and environment.

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

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

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

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

Conversations revealed frustration and dissatisfaction amongst **people with Parkinson's disease** when the support they receive does not match their needs. While people were motivated to *improve* function through exercise, they were frustrated with the physiotherapists' primary

goal to *maintain* function. Many PwPD felt that physiotherapists were overly authoritative rather than supportive.

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

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

Physiotherapists too expressed frustration. They believed they need to educate people how to exercise *safely* and correctly in the early stages, and motivate people to exercise. Equally, the physiotherapists described that some **PwPDs** need a lot of education to even begin exercising. Physiotherapists's discussions showed that their focus is to *maintain* function as the disease progresses, conflicting with the PwPD's motivation to *improve* rather than maintain function. Resources issues frustrated the physiotherapists: lack of accessibility, staffing and expert knowledge among available staff. One physiotherapist recognised these high-functioning

individuals were not being referred to physiotherapy and resource issues. Family members did not voice any concerns about physiotherapy services – response bias may have influenced these findings.

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

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

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

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

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

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

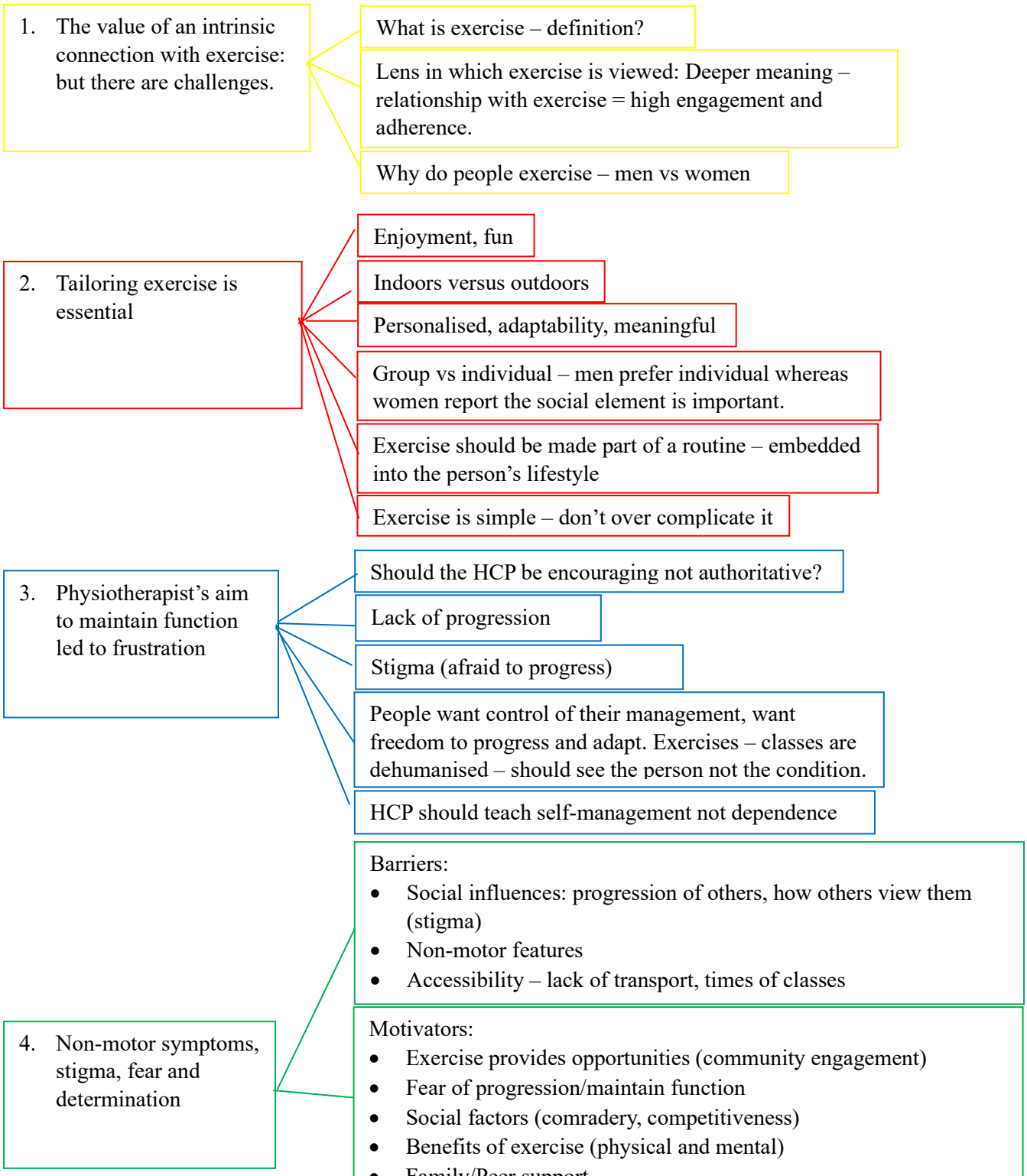


Figure 6.1: Themes and Subthemes

Table 6.2: Themes, Sub-themes, and Quotations

Theme 1: The value of an intrinsic connection with exercise: but there are challenges	
People with Parkinson's disease	
Subtheme	Quotation
Meaning of Exercise	*P3: exercise is **anything and everything** you know, it can literally be a walk to the shops, getting up and walking up and down the stairs.*
	P9: ……as long as you are moving its exercise.
Physical and Mental Benefits of exercise	*P11: I believe a good workout sorts a **lot of other problems**. It flushes out the system, it rejuvenates it. If I don't get out for three or four days with three or four weeks, my **mental health** and everything starts and **slide**.*
Exercise was essential to 'fighting' Parkinson's disease.	*P3: I would try to **combat** it [Parkinson's disease] through exercise. Doing the exercises isn't necessarily for fitness, it's about **not letting it take control** over you. You're both there under sparing of each other, who's **going to win**? Who's gonna last the longest?*
	*P2: I'm **still able** to do the things I want to do, and I believe it's just because I exercise regularly.*
Intrinsic motivation leads to long term adherence	*P11 (male): …. I **always like** to exercise; I think it is just a gene you are born with.*
	*P4 (female): I **always prided** myself on having the insight to know that we need to keep fit.*
Family Members	
Subtheme	Quotation
Reluctance to suggest exercise	*FM3: It depends. She's always saying, **I'm tired** and I have something else to do. And she'll always **find an excuse**.*
	*FM4: I **had it out with Julie** three weeks ago, four weeks ago. ….. Because I felt that, I was taking over all that and I suppose, you see, if [she is] the recipient of that, [she] can say "I'll **sit back for a session**, he is going to remind me to do those things.*
	*FM1: Tom gets irritated with me; he gets mad says **I'm nagging him**.*
Physiotherapists	
Subtheme	Quotation
Emotional burden on family members	*PT1: Yeah, I I agree. I guess over the years I felt sometimes not like a **referee**…and then the wife's like 'I'm always telling him that.'. And they like 'he gets cross when I remind him' you know.*
Theme 2: Tailoring exercise is essential.	
People with Parkinson's disease	
Subtheme	Quotation
Exercise should be personalised and adapted to each individual	*P11: Well, what works for me doesn't work for a lot of people. But there is a lot more to it than that you have to check the **individual** and design a programme **that suits him**.*
Exercise preferences varied per individual	*P4: I would have always been a very **outdoorsy person**…..So, like, if the sun is shining …. natural vitamins that are out there.*
	*P1: People with Parkinson's should be **outside**; they should be outside and getting the natural vitamins from the sunlight rather than kept indoors and dark places.*
Group exercise created a sense of belonging	*P11: **camaraderie** is a great thing if, if you can inject, you can inject that into your group. They, they help each other then and it's, it's **comforting**.*
Exercise preferences varied among sex	*P2 (female): Even though the exercise may not be enjoyable, that **social** event is very important to keeping people going. … These social events should allow for a social discussion. **Don't make it medical**.*
	*P4 (female): I find I like to exercise in the **group** setting like a, so I don't really fancy the walking. I walk with anybody. But I don't like doing it on my own. And it just being part of a group.*
	*P10 (female): The. There's good **camaraderie**… In the group. That are in there with me and…. The **craic**, as they say (giggles). It's the social aspect of it that's it.*
	*P3 (male): It's not the kind of thing that I would enjoy (group classes), and I think there's a degree that you can put yourself under too much pressure to participate you know? **I prefer to do it myself**.*
	*P12 (male): [For] someone who needs it to be fun, I think group exercise would work. **But I am happy exercising just me**.*

Mindfulness	*P6: My joints were sore. Every part of me. Do you know? **I know my body** and I just knew, like, this is my Parkinson's. So just take a break this week.*
	*P4: And, I started looking into **mindfulness**, and I then realised it's so important to have a plan, to be able to know, I **didn't even know my body**.*
Family Members	
Subtheme	Quotation
Benefit of social element	*FM4: She is very happy about that, and I think it's as well the **meeting other people**.*
	*FM4: She **needs to be mixing**. She used to get into the car and visit her sister's every Thursday night and a couple of jazz get a taxi home and that kind of thing, so I think when she is **exercising the socialising** in a group is **good** for her.*
Physiotherapists	
Subtheme	Quotation
Adapting exercise to the person	*PT3: we have to look at what we're actually giving the patient, **taking time** to go through that with them and I suppose finding out **what works for them** what doesn't work for them.*
	*PT2: The other thing then would be, I, when they can't access it, 'well then what **exercise can you access**?' And saying that **anything** is better than **nothing**.*
Theme 3: Physiotherapists' aim to only maintain physical function led to frustration.	
People with Parkinson's disease	
Subtheme	Quotation
Physiotherapists should be encouraging not authoritative	*P1: Just say "you know what you're **doing brilliant** now, come back in a month time I know better you'll be after improving, we'll see now, I bet **you will be better**", **not** "you **must** do this, and you **must** do that."*
Under prescribing – intensity too low, lack of exercise progression	*P3: being told what you can do and can't do. People telling me that I **shouldn't** do this then I shouldn't do that or I **need** to slow down or I need to stop……..if I can cycle nine kilometers there and I'm going to cycle nine kilometers back, but my chart says I'm only supposed to do so many minutes so I **can't do any more than that**…..like I find it **frustrating**.*
	*P1: I have asked and asked and asked and **I'm not being assessed**. I shouldn't have to ask to be assessed I should be assessed naturally; **my exercises should be progressed as I get better.***
	*P12: the classes **aren't hard enough** for me. I'm not saying it is beneath me, don't get me wrong, **but I just need harder to be beneficial***
PwPD want more responsibility, independence to progress	*P3: being told what you can do and **what you can't do**. And I'm constantly trying to break the system you know. People telling me that I **shouldn't** do this then I **shouldn't** do that, or I* **need** *to slow down, or I need to **stop**.*
	*P3: but I jump on it, and I hop straight up to level 18 **because I'm capable of this**, and then he (physiotherapist) has a hernia.*
Family Members	
Subtheme	Quotation
Mismatch between need and the service provided	*FM4: She has [Parkinson's disease] for about 7 **years**, and slowly but surely the deterioration, even though [the doctor] don't notice it (speaking to interviewer), because [they are] not living with the person. Her **strength** is quite **good**, but a **dexterity is awful**, she can't open the tops of bottles. She can't put on her bra. Like you said (speaks to FM1) **[I'm] actually caring for the person**…. if I leave the house, I have to leave something for her to eat. And I wouldn't want to be going out too much like (laughs), because again it's the dexterity issue**….but everytime I mention it to a doctor, I'm told she is doing well**….all because she can walk perfectly.*
Physiotherapists	
Subtheme	Quotation
Education is the first step	*PT1: but I think it's taken the time to actually **teach** them the **right way to exercise**, teach them **what this is and like, try and get them started** on that and look into the **barriers** that might be there.*
	*PT2: It's a **cultural** thing. And a **health literacy** thing as well. They might **have never exercised a day** in their lives. Now they are being told they have a engage in regular exercise – that's **difficult** for anyone.*
	*PT4: If the GP hasn't accessed the service, people could have never accessed the services nor seen a neurologist, and **they haven't been educated** so they **don't actually know that exercise is good**.*

Focus is to maintain function	*PT2: **introducing** them to exercise and showing them and how they're going to **maintain** themselves.*
	*PT4: I suppose we see a lot of them when in with early (stages). You know, they've just been diagnosed with Parkinson's. And I suppose the, your **education** component would be **huge** in that. They might be functioning at a very high level but just to **educate on the progression of Parkinson's** and the **importance of exercising** at every stage and you know, the **problems associated with progression**.*
Lack of resources and expertise, poor awareness	*PT5: **it's really hard** to give patients the amount of **time** they need and maybe the number of **sessions** they need to set them up.*
	PT1: Not every therapist will have expertise in the area.
	*PT2: GPs not thinking I should get them into physio now, because they're not bad, they are relatively high functioning…And I think it **often boils down to resources** as well because … if somebody's **functioning** well, there's no resource there to look at **that prevention piece**.*
Theme 4: Non-motor symptoms, stigma, fear, and determination	
People with Parkinson's disease	
Subtheme	Quotation
Non-motor barriers	*P11: unfortunately, I **had to stop** because when you're racing you to make some very **quick decisions** and I that side [thinking and concentration] just **doesn't work right**.*
	*P5: Well, I think it's it's important not to try and do your exercises **when you're tired**. Because if you do, **you're more inclined to make mistakes** or twisting the knee or, you know, like.*
	*P4: Anxiety, **anxiety is a big one**.*
Stigma	*P6: Well for me. People have said to me, God, you don't **look like** a person to have Parkinson's. And my answer is, what does a person look like that has Parkinson's. Maybe in the elderly 70, 80 he would walk in frame and bent over their limbs and stuff, you know and. But for a young person, what? **What's a young person supposed to look like with Parkinson's**?*
	*P4: It's just the fact that when I say (about diagnosis) **they're probably expecting me to be doddering over** or whatever.*
"Being a burden"	*P2: but maybe people have had to stop driving for one reason or another. **Asking for lifts can prevent people from going to classe**s. feels that they are in the way. Not only are people asking for lifts but during the class **the driver must wait for an hour** outside.*
Exercise to fight against Parkinson's disease	*P4: OK, I have to give up my body to this disease at some stage and give more than I ever want, but it would take me **kicking and screaming**.*
Exercise to maintain	*P12: I would seize up. You know now when I say seize up, **I would be stiff and slow**.*
Family Members	
Subtheme	Quotation
Non-motor barriers	*FM1: He can do it (exercise). He can do it. But he's suffering very badly **from mood swings,** and he did before and then it got a bit better, and he exercised a little bit more. Mood swings and **mood swings are a terrible thing** because you don't know when you have them.*
	*FM4: She knows what to do but she finds it **very frustrating** that she can't do those things.*

6.6 Discussion

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

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

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

This research identified three key considerations for exercise services for PwPD. These include careful tailoring in exercise prescription, including sex considerations, the importance of creating shared responsibility for exercise progression, and preventing the exclusion of higher-functioning PwPD in exercise classes. Although data saturation was achieved in this high-functioning cohort there is a need to explore whether these findings/issues are similar in people with limited function.

6.6.1 Considering sex in tailoring exercise prescription

Sex specific exercise preferences in this study included types of motivation, the ideal exercise environment, and mindfulness. Women with Parkinson's disease appeared to be motivated to exercise with peer support and company, while men with Parkinson's disease engaged in exercise for the physical and/or mental benefits. Family members also valued the social aspect of exercise for the PwPD. van Uffelen *et al*.[183] similarly found that older women were more motivated by spending time with others, meeting friends or improving appearance, while older men were motivated by managing stress, preventing health problems and the "feel good" factor associated with exercise.[183]

Women consistently reported enjoying exercising outdoors, while men did not express a preference. However, this does not seem to be universal. Older men were found to have a stronger preference for outdoor activities than older women[183,184], and described it as a "spirit lifter"[185] (p. 9). Generally outdoor activity was preferred among both men and women Swedish and Irish seniors.[186,187] The importance of being outdoors with nature was highlighted in this study.

Other "spirit lifters" mentioned were music, enjoyment, fun and mindfulness. Mindfulness motivated some women to self-manage and adhere to exercise; this was not the case among men. Blair Kennedy *et al.*[188] have reported improved exercise adherence and self-efficacy when mindfulness is integrated with exercise.[188] An emerging area of research, Nymberg *et al*.[189] in Sweden, are currently examining the impact of mindfulness on motivation and adherence to physical activity in middle-aged to older adults.[189]

6.6.2 Shared responsibility to tailor exercise type, dosage, and intensity

Importantly, PwPD want to share responsibility for their exercise progression. Person centred care is at the forefront of our practice[190], however, when prescribing exercises, this principle

can be inadvertently de-prioritised. PwPD felt unheard and frustrated with little shared ownership of their exercise programmes.

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

Exercise can improve balance, strength, gait, and physical function[10], and non-motor features including quality of life and depression.[191] Emerging evidence suggests that high-intensity exercise (65-85% max heartrate) is associated with neuroprotective effects, slowing disease progression and appears to be feasible and safe[174], but more research is required. Thus, healthcare professionals should consider higher intensity exercise initially for PwPD and keep informed of emerging evidence.

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

6.6.3 Strengths and limitations

A few factors hinder transferability of the findings. Firstly, the study mostly represents high-functioning PwPD. Although the recommendations provided by Mutrie *et al.*[192] were followed and every attempt was made to recruit people with varying exercise adherence and by, the sample included participants who were more interested/already engaged in exercising only. Secondly, the sample size of PwPD is small[193], however guided by information power versus data saturation[194], rich data from twelve high functioning PwPD with varying sex, years since diagnosis, and living circumstances was gathered. Data saturation was achieved with no new emerging themes in the final interviews. Furthermore, the small sample size of both interview groups limits the transferability of this study. For future studies, we would like to include a larger sample of family members and physiotherapists. Finally, the findings only represent physiotherapists worked in the Irish National Public Health system. All were women; recruiting male physiotherapists was challenging as 74% of physiotherapists in Ireland are women.[195]

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

6.6.4 Summary and key Messages for PwPD, clinicians and family members

The interviews highlighted an interest from all parties to willingly partake in health and activity. However, a discordance emerged at times between the person with Parkinson's and their supportive network, leading to frustration and challenges. It was evident that family members

were frustrated if PwPD were not active "enough". Physiotherapists were frustrated with resource issues, and PwPD were frustrated with the lack of support and focus on maintaining function from physiotherapy services. Ultimately, the interviews have highlighted the need for a patient centred, patient led approach to support, beginning at a level they feel comfortable with.

The data has shown the importance for PwPD to express their motivation and preferences for exercise. Factors such as social engagement and mindfulness were important, especially among the women interviewed, while men expressed frustration with exercise prescription being "*a flat liner*". Rather than encouraging more exercise, family members could explore motivation and personal preferences to identify meaningful ways to exercise or stay active, such as the stationary bike being "*the greatest thing [they] ever bought*", or "*being out with other people*". Importantly, physiotherapists need to hear the PwPDs' preferences and their challenges, and guide family members to be supportive in the home, rather than be "*coaches*". Through hearing the PwPD's motivation and preferences, a meaningful and engaging programme can be co-created. Opportunities to exercise beyond physiotherapy can be explored. It is important for the individual to be safe and enjoying the activity.

Opportunities to self-manage was often overlooked. It was evident that PwPD were well informed, however the service demanded a crutch-like dependency on physiotherapy guidance, with limited resources. Parkinson's disease is a lifelong condition and providing all PwPD with the skills and knowledge to self-manage their condition is important, empowering, and respectful. Education, signposting to services, safe exercise guidance, highlighting issues that may need medical attention, and ease of access to services when required will facilitate self-management.

It is important to change and adapt exercise routines. As guided by the evidence, including strength, balance, aerobic and stretching in all exercise routines is recommended. The intensity must be adequate to ensure effectiveness. Consider including more specific exercises to target individual challenges i.e. hip or knee strengthening for pain. As noted, exercise intensity is often under prescribed. To prevent this, exercise intensity should be monitored, for example by the Rate of Perceived Exertion Scale.[196]

Suitable outcome measures can include validated physical or functional performance measures in Parkinson's disease (Six Minute Walk Test, 30-second sit to stand) and a self-reported QoL measure (PDQ-39). Qualitative indicators of effectiveness can include self-reported motivation and adherence, and family members perceptions.

6.7 Conclusion

While studies have explored perceptions and experience of exercise, the focus was on settings[62], barriers and facilitators[45,62,197] and experience of specific exercise programmes.[45,197-201] To our knowledge, this is the first study to specifically explore motivation, support and exercise self-management needs in Parkinson's disease through multiple viewpoints. An important finding is the mismatch between physiotherapist and PwPD's goals with exercise. Physiotherapists were perceived to focus on the condition rather than the physical, social, and mental wellbeing of the individual. Higher-intensity exercises were sought by PwPD, and early evidence suggests that it can be neuroprotective and safe. Exercise preferences appeared different between sexes and could be considered to make exercise more enjoyable. Women were more motivated by external factors such as social interaction, while men had higher intrinsic motivation to exercise. Most importantly, this study highlights the welcome of a shared responsibility between therapist and patient, as part of overall disease self-management. Family members play an important role in supporting exercise, but an expectation to drive or coach exercise can be detrimental. Although this study included a small sample size and has a low

representativeness of the people enrolled across the disease spectrum, the findings of the study provide insights for improving clinical practice and future investigations on the topic.

Chapter 7

'I knew nothing about Parkinson's': Insights into receiving a diagnosis of Parkinson's disease and the impact of self-management, self-care and exercise engagement from patients' and family-members perspectives.

Abstract

This paper draws on stories of diagnosis that emerged from a broader narrative study exploring beliefs about exercise, and challenges facing people with Parkinson's disease.

Objective: By interviewing people with Parkinson's disease (PwPD) and their family members, this study gains insights into patients' experiences with diagnosis and how it influenced their exercise engagement, and their access to services and care pathways in Ireland. ***Methods:*** Purposeful and maximum difference sampling methods were employed. PwPD (of varying age, sex, geographical setting, and disease severity) were recruited from physiotherapy services in urban areas (using recruitment posters). Semi-structured interviews with 12 PwPD and a group interview with 4 family members were conducted. Interview guides were informed by patient-public input, and a recent systematic review. Interviews were recorded, transcribed, and analysed using thematic analysis. ***Results:*** Four themes emerged: 1) *Experiences with diagnosis*: PwPD expressed a frustration due to a delay in diagnosis and emphasised the importance of language and empathy during the diagnosis experience. 2) *Lack of signposting and available services*: there is a strong need for signposting and providing information regarding available services and resources. Lack of signposting could lead to social disengagement. 3) *Education on exercise management*: PwPD reported receiving little education regarding exercise, resorting to self-education; many would have appreciated

education at time of diagnosis. 4) *Impact on the family member*: similarly, family members not only carry the logistical burden of managing their spouses care, but they also face the emotional burden, one which they try to conceal. ***Conclusion:*** The delivery of a Parkinson's disease diagnosis could be improved by acknowledging the psychosocial implication of the diagnosis on the patient and family. Conversations showed the value of providing adequate information about their diagnosis, and the available services and supports within a few weeks of diagnosis. Lack of exercise education influenced people with Parkinson's ability to self-manage with exercise engagement. Early access to physiotherapy services is strongly recommended, as this may delay a decline in function and encourage an active lifestyle.

Keywords: Parkinson disease, Diagnosis, Health Services, Caregiver burden, Qualitative Research, Motivation to exercise

7.1 Clinical implications

- Empathy, importance of language during delivery of diagnosis: acknowledging the emotional impact of receiving a diagnosis and allow adequate time and support to process the information is recommended.
- Information sharing and signposting: prompt provision of information about the condition and available services would be welcomed in a follow-up appointment.
- Early referral/access to physiotherapy services: patients could be referred to physiotherapy services at the time of diagnosis and not after a functional deterioration, to promote self-management through exercise.
- Burden on the family-caregiver: healthcare professionals can build rapport with family-caregivers to provide maximal support and refer to the necessary services if required.

7.2 Introduction

For patients and their families, the moment of receiving a diagnosis of Parkinson's disease (PD) is the beginning of a life-altering journey. It's an emotional event which may evoke an array of emotions, extending from fear and uncertainty to relief or even a sense of validation for symptoms long endured. The experience of receiving a Parkinson's disease diagnosis can have a substantial impact on patients' quality of life for many years following the diagnosis[202], which may influence their ability to self-management through exercise engagement. Therefore, understanding the subtleties of this critical moment and its emotional impact is vital not only for healthcare professionals tasked with delivering these diagnoses but also for shaping interventions and support systems that are tailored to the unique needs of these individuals' navigating life with Parkinson's disease.

Parkinson's disease, a progressive neurodegenerative disorder, affecting millions of individuals worldwide.[203] Advances in medicine have made it possible to manage symptoms and enhance quality of life, but the psychosocial impact of receiving a Parkinson's disease diagnosis remains profound and at times overlooked. The time it takes to diagnose a condition: the referral procedure, how the decision was reached, how it is communicated, the information given and explained, the planned follow-up actions, and the initiation of treatment are all likely to be factors that impact a person's experience of diagnosis.[204] Each person's journey is immensely unique and multifaceted, including adjusting to physical and mental challenges to overcoming the shock of a diagnosis which may impact every aspect of their lives.

Person-centred care has been increasingly important in the treatment of chronic illnesses like Parkinson's disease in recent years.[205] Understanding patients' needs, preferences, and personal experiences is fundamental to this approach which serve as the foundation for personalised treatments and support services.[205] By giving voice to the lived experiences of individuals

diagnosed with Parkinson's disease, we can gain invaluable insights into the diverse ways in which the diagnosis shapes their perceptions, priorities, coping mechanisms and in particular, their engagement with self-management, including exercise.

The authors are aware of only four studies that have explored patient's experiences with receiving a Parkinson's disease diagnosis.[206-209] Schrag *et al.*[206] in 2016 surveyed patients' experiences through the European Parkinson's disease Association in eleven European countries (n= 1775 patients). Peek[207] (2017, n=37) and Warren *et al.*[208] (2016, n=6) conducted qualitative interviews with PwPD living in the UK. Although dated, their findings clearly highlight the shortcomings of the diagnosis experience that need to be addressed and highlight the importance of support systems. More recently, Krieger *et al.*[209] conducted focus groups and semi-structured interviews with PwPD and family members in Germany (n= 52 PwPD and 29 family members). They identified the persistent lack of support for PwPD when obtaining self-management strategies, the lack of structured and adequate provision of information, system orientation and social awareness.[209] These studies show that regardless of time or national health provision, people are still finding self-management challenging and need more support.

The initial aim of our qualitative study was to explore PwPD's relationship with exercise, their motivations, needs and supports. However, the impact of receiving the diagnosis on people's ability and motivation to manage their Parkinson's disease emerged through the initial interviews. This led to an iterative expansion of the topic in the interviews.

This paper seeks to describe the multifaceted experiences of individuals receiving a diagnosis of Parkinson's disease, its impact on the emotional, social, and practical dimensions of their journey but also their early management of their condition through exercise. Through qualitative analysis of patient narratives and experiences, we aim to uncover common themes, challenges, and resilience factors encountered throughout and after the diagnosis process. This

knowledge will inform a more compassionate and holistic approach that respects the lived experiences of patients and their families.

By conducting this research, we intend to increase compassion, empathy, awareness and support both within and outside of the healthcare sector, ultimately enabling people to face Parkinson's disease with dignity, resilience, and empower them to self-manage their condition. Therefore, this paper explores the impact of the diagnosis on patients' ability to self-management, and self-care through exercise.

7.3 Methods

The methodology for this study is described in detail in our previous publication, Ahern *et al.*[210] (Chapter 6). A brief description is as follows.

7.3.1 Design

The study is reported following the consolidated criteria for reporting qualitative research (COREQ).[180] This research was conducted between November 2022 and January 2023. Ethical approval was given by the local research ethics committee ((ECM 5 (4) 06/07/2023).

To gain insight into key stakeholders' experiences, we conducted a sequential qualitative interview study over two phases, with the first phase informing the enquiry of the subsequent phase. Phase 1: Semi-structured one-to-one interviews with PwPD and Phase 2: An interview group with family members/caregivers of a person with PwPD in the study.

7.3.2 Recruitment and study sample

Purposeful sampling and maximum difference sampling methods were employed to recruit PwPD (inclusion criteria: Hoehn and Yahr disease stage 1-4, communicate in English), of varying age, sex, geographical setting, and disease severity. Their family members/caregivers were also invited to participate. Participants were recruited through primary care services in urban areas, where they volunteered to take part in the study by responding to recruitment

posters. To accommodate participants and their ability to attend in person, interviews were offered in person, by phone and online. All participants gave written informed consent before the interviews.

7.3.3 Data collection

Based on the findings of our systematic review[59], the author's clinical experience, and feedback from our patient-public involvement (PPI) group, we developed a topic guide each for the semi-structured interviews and for the group interview *[see Appendix B7 and B8]*.

The interviews were conducted by a registered physiotherapist (LA) who received qualitative research skills training. The interviews were conducted in a private room. Interviews lasted a maximum of 60 minutes (including group interview). People with Parkinson's were offered the option of dyadic interviews for support and prompting if required. All interviews were video recorded and then transcribed. At the end of the interview, the interviewer completed member checking by reviewing the topics discussed and ensured that the information was interpreted correctly.

The data was analysed on a rolling basis, including self-reflection by the interviewer between interviews. We terminated the recruitment of each phase when data saturation was reached (based on criteria *code meaning*[181] (no new themes were emerging and the data was beginning to repeat)), and progressed onto the next phase, using the data obtained to inform the next phase's interview topic guide.

7.3.4 Ethical considerations

The study received ethical approval from the local research ethics committee [ECM 3 (gg) 22/02/2022). All participants provided written informed consent. Quotes used to illustrate findings were carefully chosen to reflect the participants viewpoints, and identifiable information removed or adapted.

7.3.5 Data analysis

To allow for emerging themes, the data were analysed *inductively* using Braun and Clarke's thematic analysis framework.[182] (1) LA transcribed each interview, highlighting the key notes in the text, and reviewed the data with reflexivity. (2) LA coded the transcripts line by line and highlighted text to extract data. Codes were reviewed by a second experienced qualitative researcher (CC) and relevant adjustments were made. Finally, an integrated code and corresponding list of quotations was completed. (3) LA developed subthemes and themes from the code list. (4) RMcC and ST independently reviewed the extracted themes for overlap, and sense-making. (5) LA made any required changes, merging similar topics and splitting large topics where required. This method was repeated until all authors reached a consensus and no new themes appeared. (6) Finally, LA, RMcC and ST examined the relationship between the themes and finalised the report of the findings with supporting illustrations.

7.4 Results

7.4.1 Participants

We contacted thirty-two people (n=20 PwPD, n=12 family members). Sixteen were interviewed, n=12 PwPDs (6 females and 6 males, aged 52-84 years), and n=4 family members/caregivers (3 males and 1 female, all were unrelated) (see Table 6.1, Chapter 6). The group interview with the family members was held face-to-face (online option was offered). One person with Parkinson's disease requested a telephone interview, while two PwPD requested a dyad interview, (one online and one face-to-face). For the dyad interviews, the family members declined to partake in the subsequent group interview with other family members. Of the 12 PwPD, 11 self-reported as being keen exercisers, engaging in regular physical activity (self-reported achieving the World Health Organisation physical activity guidelines weekly) and one self-reported as an infrequent exerciser (P8). Eight were living in urban settings while four were from rural areas.

The analysis of the data led to four overarching, common themes which demonstrated the views of PwPDs and family members' experiences with receiving diagnosis, education regarding their condition, knowledge of available services and the impact of the family members. Each theme is presented as PwPDs' perspectives, then family member/carers' perspectives. Figure 7.1 presents the themes and subthemes which emerged from the data.

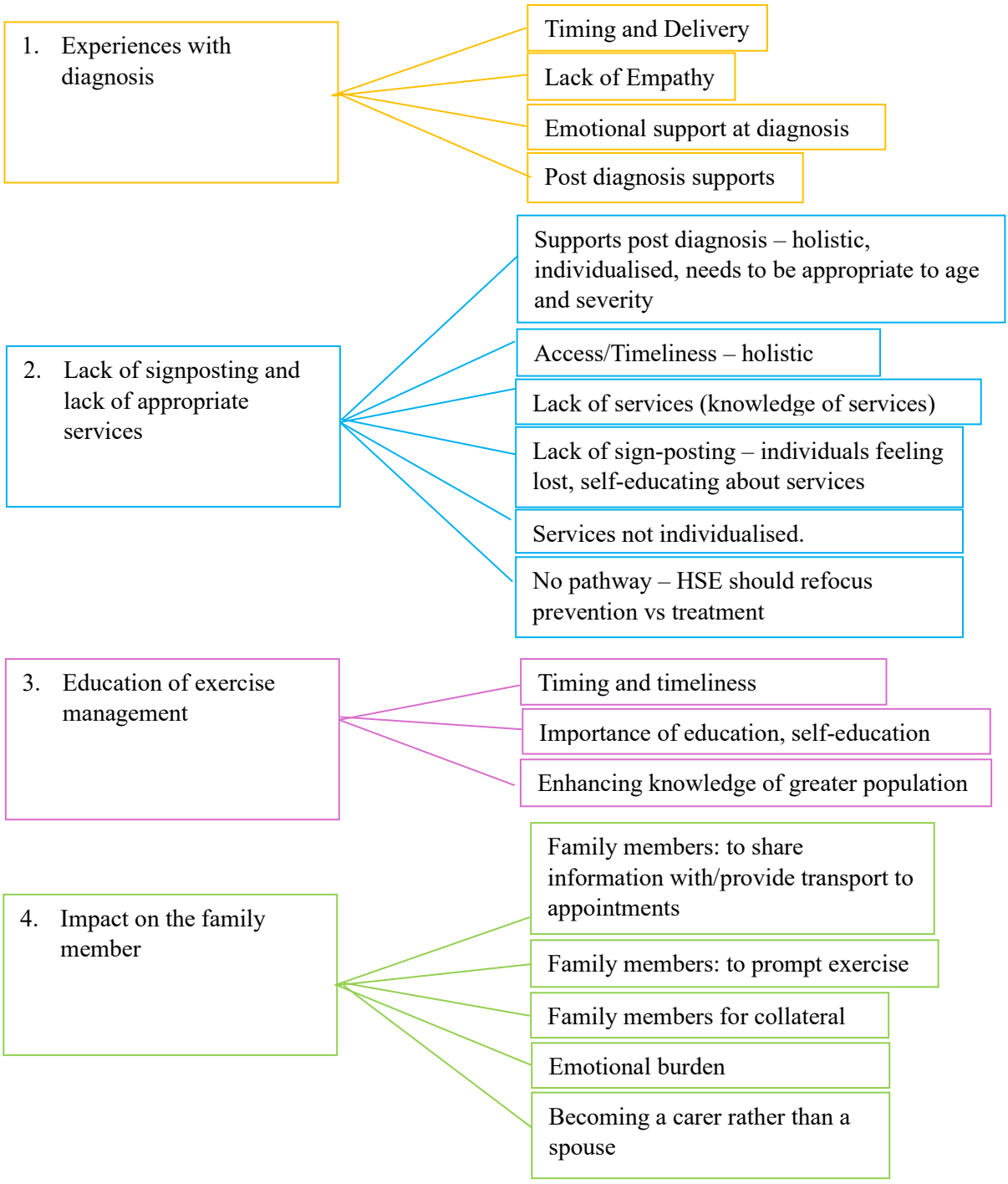


Figure 7.1: Themes and subthemes

Theme 1: The diagnosis came as a shock, offering little support or hope

People with Parkinson's disease felt frustrated due to a delay in their diagnosis and felt that healthcare professionals were not taking their concerns seriously at time of diagnosis (P1: *"I went to see three consultants, and I told my GP, and none of them* ***listened****....and that was infuriating").* **PwPD** also expressed disappointment at the lack of empathy portrayed by healthcare professionals during the delivery of their diagnosis (P4: *"[The consultant] is probably so used to it, [the consultant] just didn't realise that they had just taking my world* ***and pulled the rug from under me*** *(emotional, tears up). (Shakes head) Completely, I couldn't speak,.. Because I had aged, I went in with, a frozen shoulder and came out with Parkinson's."*, further emphasizing the importance of language and phrasing (P6: *"it was very much like…."Well, this is where we are now. And you have Parkinson's. And you got a good ten years before you really have to worry")* often time resulting in the **PwPD** feeling dehumanised and lacking hope (P12: *"[The consultant] didn't give me much hope you know. And [the consultant] is finished with me, [the consultant] said "there* ***isn't much more I can do for you****").* With others echoing the need for empathy and understanding during diagnosis (P10: *"[The consultant] didn't have the words to console me, because they are a step above (gestures hand over head to show above) the personal side of it. Like, I just wanted someone to (gestures putting a hand around someone) an arm around me and let me ball. Because nobody dealt* ***with the shock. It's a frightening place to be****")* emphasizing the importance of the personalised rapport (P4: *"when you get those words, and the doctor is a highly professional person. But* they *[the consultant] understands practices,* ***but they don't understand me****").*

An important consideration of the diagnosis that was mentioned was the need for support at the time of diagnosis. **PwPD** reported that having a family member or friend with them when receiving the diagnosis was important, with one participant comparing the experience to

*"**quicksand**"* reporting that once *"you hear whether it's good news or bad news…... **you switch off**... that's the advantage of having somebody with you ... they're listening and taking in".*

One **family member** echoed the experiences of the PwPD with regards to the lack of empathy during the diagnosis (FM2: *"When delivering news like that, you need empathy, and you need to give them time, because when it hits them, they are sitting there on their own. I can own imagine what goes through their head because (shrugs shoulders)")* and reported often time feeling dismissed by healthcare professionals (FM1: *"And I asked the question, you know, why wasn't it picked up and the and they [the consultant] said probably better machine [MRI scanner]. I felt totally dismissed. Totally dismissed coming out").* One **family member** reported visits with the consultant are *"just business"*, explaining that the visits do not feel like a personalised experience *"they're [consultant] writing (demonstrates writing), writing, writing, writing, answering questions, but they are never looking at the person who's asking those questions".* **Family members** expressed the importance of including them in the care plan (FM1: *"I think as a carer, you can't, you know, you need to be sat down and you need to have a discussion, you need to be included in the plan as we are the person looking after them")* and for healthcare professionals not to assume the family member's knowledge (FM2: "*And I think it's it's probably important that they don't assume that you know and like as the years go on and say, things change and that you kept up to date [with research] with everything that's changing. You know and different exercises and, don't assume that we already know something"*).

Theme 2: Lack of signposting and lack of available services

People with Parkinson's disease reported that following diagnosis there is a lack of signposting towards available services (P1: *"no, nobody told me about anything, nobody has ever told me about anything",* P8: *"in my own opinion, I think there is a lack of communication")* leading to a lack of knowledge regarding their condition and the services

(P5: *"I can see why people would be freaked out, you know?* ***People are afraid*** *of it [Parkinson's]. Because they don't know"*). This led to some **PwPD** independently educating themselves about their condition and the available services resulting in them feeling unsupported by the health service as they felt "*it shouldn't be the individual's responsibility to go and see what's out there"*.

Of the available services, **PwPD** feel they are not tailored and personalised (P3:*" they're* ***not always tailored*** *for the individual"*), are not suitable for young people and lack peer support (*"There needs to be a step in between, everyone should be able to* ***find their village you have to find a tribe****, to be part of something, that's where it's lacking, you either go straight to the Parkinson's society or you're staying here on your own"*).

As a result, **PwPD** are frustrated with the lack of care pathway (P6: *"I think if you're in the [Health] system, you can get through it [services] very, very quick, but if you're not or your GP is not good, or your consultant is not on the ball with you. Yeah,* ***you're forgotten about (whispers)****"*) and services, reporting that *"The* ***biggest hurdle*** *is getting the GP's and consultants* ***to recommend services****. The* ***challenge*** *is how to* ***get referred*** *to anything."* and believe the health system should redirect its focus from treatment to prevention (P3: *"Throughout the* ***early stages*** *when someone is diagnosed* ***why aren't they redirected towards exercising, towards classes****? The HSE is going to capture them at some point but when they do it will be* ***too late, they need to start exercising early****"* P7: *"Straight away I would say,* ***go on an exercise program, now****! Don't wait for 12 months".* **Family members** also expressed a lack of knowledge and signposting regarding the available services.

Theme 3: Education of exercise management

People with Parkinson's disease highlighted the importance of education regarding the management of their condition, emphasizing the need to educate them on the importance of

exercise (P7: *"At the start I was afraid of moving my body, but **I'm not afraid of moving my body now** because I know better now"*). All the **PwPD** reported awareness of the importance of exercise in the management of Parkinson's disease but reported at the time of diagnosis, they didn't focus on its importance. With encouragement and support from healthcare workers, they got back into exercise. The timing of this support and prompting is crucial. Two **PwPD** reported receiving this information from their consultant early after receiving their diagnosis (P6: *"When I got the diagnosis, [exercise] kind of took a back burner….then, the **neurologist** said to me "**Tina** [pseudo name] **get back to your life**"…. So, I started fast walking again. Started going hiking, which I love"*, P5: *"The consultant was adamant about that the first day, exercise"*).

While others reported not receiving this information until years into their diagnosis (P7: *"the only [exercise-related] knowledge of Parkinson's that I got was from a physio and that was about 5 or 6 years after I was diagnosed"*, P9: *"They did [receive education], but not straight away"*), and as a result increased the risk of social isolation (P4: *"I had **worked myself into such a state**. **I didn't want to go out**"*) While three reported receiving no education (P1: *"nothing, I was left off."*, P2: *"Exercise was never encouraged"*, P3: *"at the time I was told to take it easy. Don't get wound up and relax for myself and not to get exercise or not to be overly strenuous"*) and as a result many resorted to self-education to improve their knowledge. All PwPD reported that they would prefer the education to be provided to them within a few months of diagnosis, it was not specified which healthcare professional should provide the information, but the PwPD strongly highlighted that the information should be provided rather than them resorting to self-education.

Family members also expressed a lack of education regarding the progression and management of the condition, again relying on self-education (FM2: *"and I don't think I really seen this serious side of it [the condition] yet, but I have a good idea what's coming down the*

line…. I have researched it online, no one sat me down and told me what to expect") and echoed the need for education to be provided for family members.

Theme 4: Family members tried to hide their shock and fear for the future, while supporting their spouse

People with Parkinson's acknowledged the emotional burden that is often time placed on their family members, reporting that it is not just the person with Parkinson's disease whose life is affected but also their families. All **family members** expressed fear for the future (FM2: *"She has always cared for everyone, and in my head, I'm looking down the line and saying the road is going to reverse"*, FM3: *" I worry what's down the road, you know? She's only 72 and I'm 83, who will care for her when I'm gone"* but also a sense grief for the past (FM1: *"I find it incredibly (shakes head), some days I find it incredibly hard. I mean, I want to scream. Because I still want to be doing things with him and he stopped talking, little things like that"*) while feeling they have to hide their emotions (FM1: *" I'm losing the man I'm married to, I'm married 53 years. So, I I don't have the man that I married. I I I, like you could get sad about it, but, and you get sad sometimes, but you can't give up, for them, they need us to the strong")*. Two **family members** recognised that often time they are viewed as the "carer" rather than the spouse (FM1: *"I'm very much a carer now, where I wasn't a carer. I was there, but I wasn't carer"*, FM4: *"Her strength is quite good, but a dexterity is awful, she can't open the tops of bottles. She can't put on her bra. She can't. Like you said (speaks to FM1) you actually caring for the person"*). All **family members** agreed there is a need for social supports for family members.

7.5 Discussion

This paper emerged as an important theme in initial interviews, where our objective was to explore motivation, needs and self-management of exercise.[210] We thus iteratively adapted the

topic guide to explore the impact of receiving their diagnosis and early information and signposting on self-management and exercise engagement. Four themes emerged:

7.5.1 Early referral/access to physiotherapy services

The PwPD reported that education about the importance of exercise from physiotherapists was very important. But a delayed referral/early access to physiotherapy, can result in a delay in receiving this information. It is well recognised that all healthcare professionals promote exercise. However, additional information and support may be needed in the early stages. By surveying healthcare professionals working with PwPD in the UK (n= 29 doctors, 17 nurses and 106 physiotherapists), Agley *et al*.[211] identified the main educators of physical activity in Parkinson's disease were the physiotherapists. This included providing evidence on the role of exercise and signposting to support groups; providing early supports needed to promote exercise self-management.

The Irish National Clinic Programme for Neurology[212] model of care has an appendix on Parkinson's disease, which calls for a timely and appropriate referrals to services i.e. it is recommended that PwPD are assessed by the relevant specialised clinicians, with access to the required investigations, and has easy access to all the relevant professions, information, and services that enhance the short and long term management of their condition.[212]

Similarly, the NICE guideline on Parkinson's disease advocates individuals are seen within six weeks of the referral.[213] However, referrals to physiotherapy services usually only occur when function deteriorates, not around the time of diagnosis.[211] A delayed referral, leading to delayed self-management and exercise guidance, can prevent the opportunity to develop beneficial habitual exercise patterns, optimising both physical and psychological health. This further highlights the need for early referral to physiotherapy services at the point of diagnosis.

7.5.2 Information sharing and signposting

All individuals reported receiving little or no information at the time of diagnosis, many resorted to self-education, but others were at the risk of becoming social disengaged, in particular the younger individuals (aged <65 years) as they felt there was no supports that suited their age profile.

O' Shea *et al.*[214] conducted a survey of PwPD's experiences with accessing the health service in Ireland, which supports our findings. Experiences included not being advised to bring a family member at the time of diagnosis, with the emphasis on issues that were non-modifiable, including too much emphasis on loss and degeneration, inadequate signposting and time to discuss available needs/services and self-management strategies, limited written information to take home, and a lack of empathy and privacy (especially for hospital in-patients).[214] Furthermore, over 75% were not contacted by a healthcare professional in the weeks following diagnosis.[214]

Agley *et al.*[215] further explored physical activity and exercise experiences, preferences and priorities of PwPD living in the UK through an online survey (n=405). They reported that the majority of participants did not received education (68%; n = 276) or exercise intervention (54%; n = 217) as part of their routine management by the national public health system since diagnosis and resulted in seeking services privately.[215] The authors noted that the knowledge of the overall benefits of exercise was good, however participants lacked specific knowledge on the impact of Parkinson's disease on posture, falls and muscle strength.[215] Agley's *et al.*[215] conclusions echoes the findings of this study. PwPD want physical activity and exercise education interventions that provide knowledge, skills and access to activities.[215] For the most part, these interventions have not been provided as part of their routine care pathway.[215] Physiotherapists reported that the education should be provided early; as soon as the patient is open to it (during diagnosis may not be appropriate).[210] To align with the priorities and

preferences of PwPD, physical activity and exercise interventions should be offered around the time of diagnosis, including relevant, individualised information, highlighting its value in mitigating symptoms of Parkinson's disease.[215]

Guidelines place a strong focus on evaluating the patient's knowledge and emotional wellbeing, providing information and treatment alternatives, and a contact soon after their receipt of the diagnosis.[216] Most of these guidelines are centred around terminal illnesses, but more emphasis is being placed on the delivery of bad news in neurology.[217-219] How a Parkinson's disease diagnosis is explained to patients still needs to be improved, particularly remaining sensitive and aware of patient's understanding, feelings, and expectations. Giving time to ask questions at the time of the diagnosis, providing information that is relevant to each individual (e.g. signposting to physiotherapy and/or exercise services) increases patient satisfaction with the diagnostic process.[206]

7.5.3 Diagnosis: empathy, importance of language during delivery of diagnosis

Experience of receiving their diagnosis was mixed. Most PwPD reporting a negative experience, with many being able to directly recall the consultant's diagnosing words, highlighting the emotional impact of their experience. This experience impacts their ability to self-manage and may delay their motivation to engage in exercise services.

Peek[207] highlighted the importance of creating open dialogue and the need for consultants to modify their consultation style in response to individuals.[207] Even though Parkinson's disease is often not regarded as the "worst" neurological condition[220], receiving a Parkinson's disease diagnosis should not be treated as a routine that ignores the psychosocial implications of this diagnosis. People respond differently to the same news, but regardless of these differences, everyone requires time to process the diagnosis, process their reactions, and express their worries and fears.[207] The participants' narratives revealed a desire to feel secure at this uncertain

time, empowered again during a period of disempowerment, and comforted knowing that a plan was in place for the future when they left the diagnostic appointment. At the time of diagnosis, they required guided and staged information instead than depending on themselves to learn about their condition. Individuals would welcome early information and signposting to community services for self-management and exercise engagement.

7.5.4 Burden on the family member/caregiver

All family members expressed fear for the future and identified the need for supports for family members. Family members often assume the role of caregivers and respond to changes in patient symptoms. These circumstances can impact family members' mental health, more than their physical health quality.[221] Mc Ardle *et al.*[222] conducted a pilot study aimed to identify psychosocial factors (of PwPD (n=64) and carers (n=40)) associated with habitual physical activity. They found that higher levels of carer anxiety and depression were linked to an increase in habitual physical activity volume, whereas poorer self-care among carers was associated with a decrease in activity volume over 18 months.[222] Greater carer strain was associated with taking longer walking sessions after 18 months while increased carer depression was correlated with reduced variability of habitual physical activity.[222] Therefore, emphasizing, that if family caregivers do not have a coping mechanism and adequate support from other family members and society, the condition may cause a decline in their health and quality of life.[223] Healthcare professional should discuss with family caregivers the need for support and refer them to the available services if required to help empower them to support PwPD.

7.5.6 Strengths and limitations

There is limited research that has investigated people with Parkinson's disease experiences' with diagnosis and how it impacts self-management using qualitative interviews. Current research mainly focuses on the diagnosis experience[207,208] or experiences with self-

management practices[209,224] in isolation, leaving a gap in understanding how the experience of diagnosis impacts a person's ability to self-management the condition. Alternatively, studies that have explored this relationship have often relied on surveys[206], which may lack the depth and richness of insight that qualitative interviews could provide. We believe this method allowed our participants to be completely open and honest about their experiences and provided us with rich data which may not have been acquired through surveys. The interviewer (LA) is a registered physiotherapist, whose special interest and clinical expertise in Parkinson's disease may have led to informed iterative questioning and credibility. Data analysis was completed by three members of the research team, improving credibility.

A number of factors hinder transferability of the findings. Firstly, the sample size of PwPD included is small[193], however guided by information power versus data saturation[194], we gathered rich data from 12 PwPD with varying gender, years since diagnosis, and living circumstances. We believe that data saturation was achieved with no new emerging themes in the final interviews. Secondly, the study mostly represents high-functioning PwPD. Although the recommendations provided by Mutrie *et al.*[192] were followed and every attempt was made to recruit people with varying exercise adherence and by, the sample included participants who were more interested/already engaged in exercising only. Thirdly, the participants were recruited from Cork city and surrounding areas, meaning that reproducing these results in a larger sample across multiple neurology services would be important in validating the results of this current study. Lastly, the sample size for the group of family members was very small impacting the transferability of these findings.

7.6 Conclusion

People with Parkinson's disease continue to face similar challenges during their diagnosis experience that were reported nearly ten years ago.[206,207] When delivering a diagnosis, healthcare professionals should take into account the psychosocial and emotion impact of the

words the person receives and their impact on their ability to engage in self-management exercise and physical activity. The patient should be provided with adequate time to ask questions and then receive a follow-up appointment with a healthcare professional within a few weeks of diagnosis to allow for further questioning and information sharing of available services and supports. The participants reported that while a few consultants recommended exercise, physiotherapists provided tailored information, which empowered them to self-manage through exercise engagement. Therefore, there is a strong need for early physiotherapy referrals at the point of diagnosis rather than when the patient deteriorates.

7.8 Acknowledgements

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7.9 Declaration of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

7.10 Data availability statement

The datasets presented in this article are not readily available to protect participant confidentiality. Requests to access anonymised partial datasets should be directed to r.mccullagh@ucc.ie.

Chapter 8

Conclusions from Phase 2 and Introduction to Phase 3

8.1 Conclusions from Phase 2

Phase 2 aimed to explore motivation to exercise, and support and self-management needs of people with Parkinson's disease (PwPD), as perceived by PwPDs, family members and physiotherapists (Chapter 6).

Within the theme of exercise, four main subthemes emerged from the Phase 2. Either an intrinsic connection, or motivation, to exercise provides physical and mental benefits, which family and physiotherapists were keen to support. However, challenges arose when expectations were mismatched, e.g., when the physiotherapist aimed to maintain function (e.g. with limited exercise progression) while the individuals aimed to improve function. Furthermore, physiotherapists were frustrated with limited resources and staffing issues, which led to the exclusion of highly functioning, motivated people, who were instead signposted to community-based classes or neurological gyms. There they reported feeling underchallenged and abandoned by the healthcare system (Chapter 6).

Considerable differences in exercise patterns and preferences between sexes were seen. Tailoring exercise programmes to individual's intrinsic motivation and perceived needs was clearly essential. Explaining the rationale for tailored exercises is important, while giving people ownership and independent self-management of their exercise programmes. Exercise intensity was often perceived to be under prescribed, missing the opportunity to guide people to high intensity exercise, which may have a neuroprotective effect, slowing disease progression (Chapter 6).

Family members are crucial to support exercise, and physiotherapists rely on them especially in cognitive decline. However, frustration can arise when they are "pushing" exercise, rather than supporting exercise. Non-motor symptoms and social stigma are considerable barriers, while fear and determination are motivators to exercise (Chapter 6).

While themes relating to motivation and readiness to exercise were expected, data analysis revealed an unexpected theme: how the experience of receiving a diagnosis (such as timing of diagnosis, signposting of services following diagnosis, and education regarding management following diagnosis) impacted their readiness to self-manage their condition, including their readiness for exercise. Four subthemes emerged under the theme of receiving a diagnosis. At the time of diagnosis, many PwPD were not told about the importance of exercise. This led to some learning through available supports and resources, leaving the others unaware, and not engaging in exercise activities until many years after diagnosis. It is well known that early development of exercise routine is important[225], suggesting that by improving the experience of receiving the diagnosis will also have an impact on their long-term well-being and health. Most PwPD suggested education and signposting to available services and resources could be provided at time of diagnosis. Participants described how this lack of signposting led to individual's feeling lost, and social disengaged. Early access to physiotherapy or exercise services were seen as important. Other individuals experienced a lengthy delay in diagnosis and emphasised the importance of language and empathy during the diagnosis experience. Family members not only carry the logistical burden of managing their family member's care, but they often are also faced with the emotional burden, one which they try to conceal (Chapter 7).

8.1.1 Limitations of study

Overall, this methodology worked well and aligned well with the aim of the research, particularly the sequential interviewing, which helped to identify the mismatch between the

aims of physiotherapy, between the PwPD (to improve physical health) and the physiotherapist (to maintain physical health). However, one of the main limitations of this study was the small sample size and lack of diversity in both group interview cohorts (group 1: n=4 family members; group 2: n=5 physiotherapists). A larger sample of physiotherapists may have been obtained if recruitment was widened to physiotherapists working in the private sector and the recruitment time period was lengthened. A second limitation was the limited variety of PwPD, especially in terms of their routine physical activity. It would be interesting to compare the views of PwPD who are less active. While attempts were made to recruit less-active people, recruiting through physiotherapy led to more active people being approached. Furthermore, all interviewed PwPD have been cared for by a neurological physiotherapist; recruiting individuals who have not met a neurological physiotherapist may have had difference perceptions about exercise. On reflection, a stronger link to Parkinson's Ireland (support and advocacy group), our PPI group, and other support groups, may have led to a greater diversity of people being interviewed.

A search of the literature revealed no other research exploring motivation, support and exercise self-management needs in Parkinson's disease through multiple viewpoints. Previous qualitative research on the role of exercise in Parkinson's disease has mainly focused on the extrinsic barriers and motivators to exercise[45,62,197], specifically focusing on the location of the exercise (at home or in a community centre)[62] or a specific exercise program.[45,197] Other studies have explored patients' experiences of exercise programmes[45,198-201] specifically around digital health[200], or a specific type of exercise program.[45,198,199,201] Hulbert *et al.*[226] explored therapists' experiences of delivering an exercise programme to PwPD. However, this study focused on a specific falls rehabilitation program[226] rather than general exercise and physical activity. We chose to interview PwPD specifically about behaviour change in exercise or activity, knowing they have trouble staying active, and report the value of social and family support. The findings

further validated the need to involve the individual in the exercise plan, to be led by *their* goals, reducing the risk of a mismatch and also the need to include their support network to empower them through social encouragement. It helped highlight the value of intrinsic motivation to exercise. And finally, it highlighted the value of family members as fellow exercisers, companions in exercise but not as coaches at home.

8.2 Introduction to Phase 3

8.2.1 Rationale for aims

An evidence-based Parkinson's disease Exercise and Education Programme (PEEP) was previously established by the PhD scholar in 2021 and delivered in a primary care centre in Cork. The programme began with a 6-week duration (2021) and has progressed to 12 weeks over the years in line with the evidence.[227] The programme included weekly exercise classes (45 mins) focusing on balance, strength and functional movements, progressing in intensity and difficulty each week (with the introduction of dual tasking at week 6), and weekly education (1 hour) classes delivered by a different healthcare professional each week. However, it was clear that the participants were having trouble completing their home exercise programme and continuing exercise after the program. Therefore, the question was, would the addition of behaviour change (BC) techniques improve exercise adherence and exercise self-efficacy?

The systematic review showed the effective behaviour change domains were *behaviour regulation, belief about capabilities, social influences*, *reinforcement* and *goals*. The qualitative interviews highlighted that differences existed in exercise preferences between men and women, and individuals expressed a strong desire to be more involved in planning their own exercise program. The findings from the systematic review and the qualitative research together helped to select the BC techniques for the intervention. Therefore, the intervention included

the addition of four behaviour change techniques (activity diary, peer support, exercise specific education, goals setting and barrier identification) to the existing Parkinson's exercise and education program. The resulting feasibility study aimed to examine the feasibility of implementing additional BC techniques alongside the pre-existing PEEP. Figure 8.1 summarises how the results of Phase 1 and 2 contributed to the select of the BC techniques.

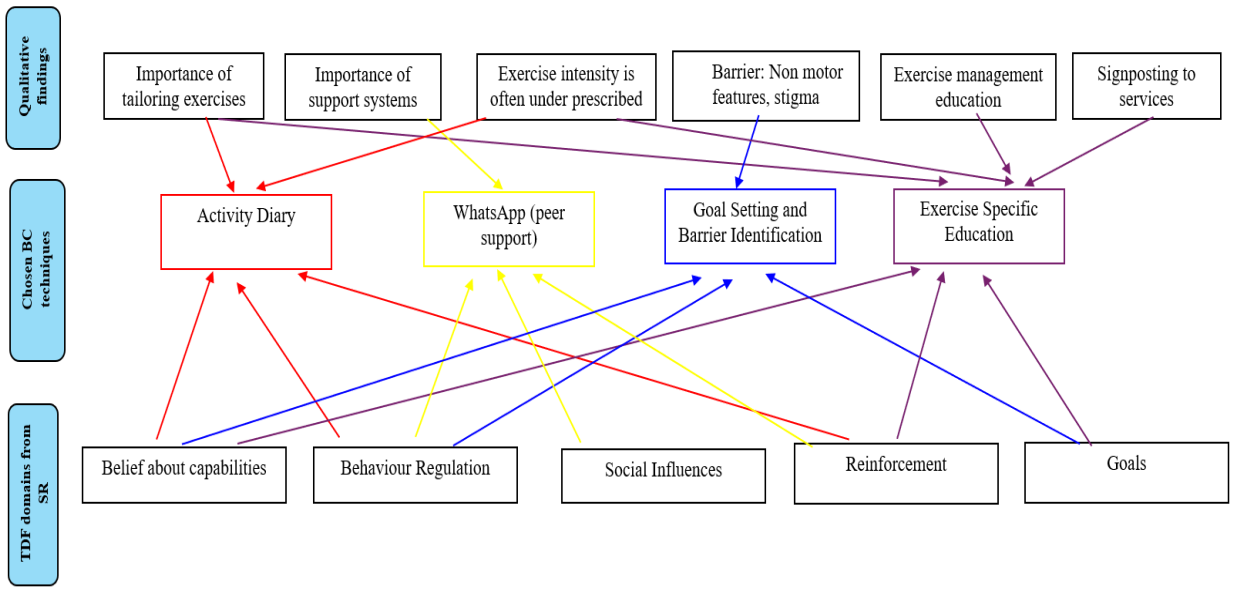


Figure 8.1: Explanation for selection of BC techniques

8.2.2 Rationale for the intervention

Phase 3 aimed to test the feasibility of incorporating BC techniques into the PEEP programme to improve physical activity, function, and self-efficacy in PwPD (Chapter 9/10). A randomised controlled feasibility study was conducted in two groups; group 1: PEEP with behaviour change techniques (PEEP + BC) and group 2: PEEP only (Chapter 10). Exit interviews were completed with the intervention group only, exploring their experience of the BC techniques.

8.2.3 Rationale for the study design

It was clear from the systematic review that research is limited in this area. The most effective techniques were unidentifiable, and the modes of delivery varied. Therefore, it was appropriate

to conduct a feasibility test, to further explore the BC techniques and to gather both qualitative and quantitative data to indicate their impact and value.

A randomised controlled study was conducted instead of a pre-post study for three reasons. Firstly, this would give us the opportunity to observe contamination, and recruitment rates to prepare for a larger pilot study. Secondly, even in a feasibility study, randomisation provides preliminary data on the outcome measures in terms of the direction of the effect of the intervention compared to a control group, and offers insights into the potential effect size and variability, helping to determine whether the intervention is ready to be tested through a pilot study.[228] Lastly, randomisation provides critical data on recruitment, retention, adherence (especially when comparing across both arms), and the logistics of conducting a future pilot study in the target population with realistic timelines and resource allocation.[228] While a pre-post study would have provided some useful information about the intervention's acceptability and preliminary outcomes, it would have offered less guidance on how to structure a future pilot study, especially regarding randomization and control measures.[228]

8.2.4 Rationale for usual care exercise program

The intervention duration was selected at 12 weeks because this is deemed the optimal duration to improve cardiorespiratory fitness[229] and walking economy.[230] Singh *et al.*[227] through their systematic review found that the effectiveness of the physical activity intervention decreased with durations greater than 12 weeks among people with depression, anxiety and distress disorders. Forty-five minutes was selected as the exercise class duration because the World Health Organization physical activity guidelines recommend 150 mins of moderate to vigorous activity per week. Scheduled for one hour, each session allowed forty-five minutes of exercise and fifteen minutes for paced breaks to ensure safety. In addition to the weekly group class, participants were instructed to perform the exercises twice weekly at home, accumulating close to the recommended 150 minutes of activity per week.

8.2.5 Rationale for behaviour change components

The systematic review showed the effective behaviour change domains were *behaviour regulation*, *belief about capabilities*, *social influences*, r*einforcement* and *goals*. The qualitative interviews highlighted differences in exercise preferences existed between men and women, and individuals expressed a strong desire to be more involved in planning their own exercise programme, including being involved in the development and progression of exercise programmes, having some responsibility (with the physiotherapist) in self-management. Therefore, this intervention included four behaviour change techniques (activity diary, peer support, exercise specific education, goals setting and barrier identification), additional to an existing 12-week Parkinson's exercise and education program.

8.2.6 Rationale for the outcome measures

The selected primary performance outcome measures were walking activity measured using the Modus Health StepWatch4 Activity Monitor (SAM), exercise self-efficacy measured using the exercise self-efficacy scale (ESES), aerobic endurance using the six-minute walk test and gait and balance using the APDM Mobility Lab system™. The SAM device was chosen as these were readily available within the University College Cork and have been validated in PwPD.[231] Exercise self-efficacy was chosen because self-efficacy is a strong predictor of exercise adherence in PwPD.[107] The exercise self-efficacy scale (ESES) was selected because it is validated and reliable among people with neurological conditions.[232]

Another common exercise self-efficacy scale is the self-efficacy for exercise scale (SEE).[233] The SEE focuses on overcoming extrinsic barriers to exercise or the practical aspects of maintaining an exercise routine[234], while the ESES focuses on intrinsic motivation and self-management by assessing one's confidence in performing specific exercise behaviours, such as the intensity or duration of exercise, or how to overcome barriers or challenges.[233] It often targets older adults or specific populations where the goal is to assess confidence in maintaining

an exercise routine under challenging conditions.[233] The six-minute walk test and APDM Mobility Lab system™ are validated in PwPD.[235,236]

The project progression is displayed in Figure 8.2 (phase 3 highlighted in orange).

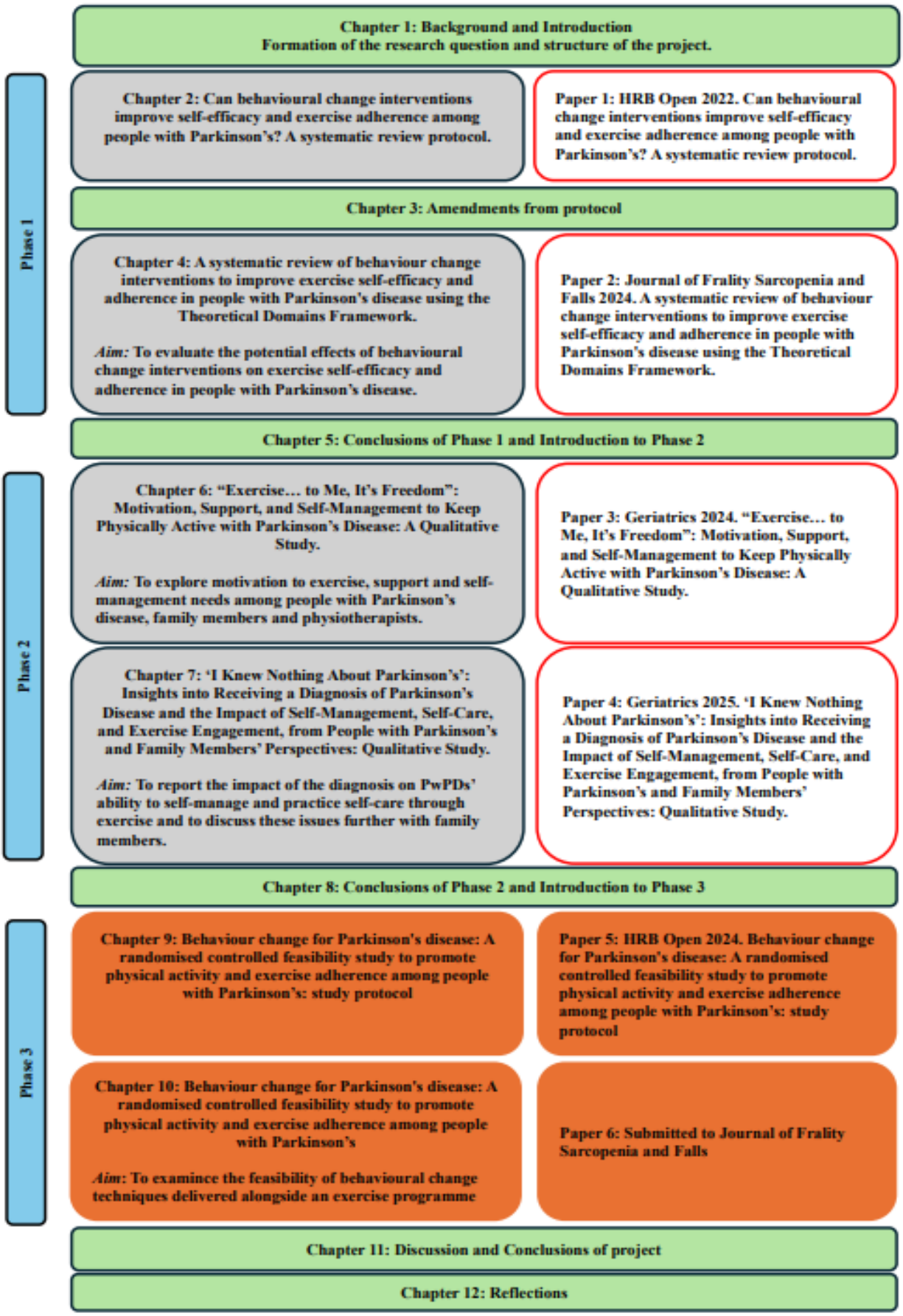


Figure 8.2: Project structure (Phase 3)

Chapter 9

Behaviour change for Parkinson's disease: A randomised controlled feasibility study to promote physical activity and exercise adherence among people with Parkinson's disease: study protocol

Abstract

Background: Parkinson's disease is a common progressive neurological condition characterised by motor and non-motor deficits. Physical activity and exercise can improve health, but many people with Parkinson's disease (PwPD) have trouble reaching the recommended dosage. Our recent literature review found improvements in exercise adherence with behaviour change interventions, but it remains unclear which are most effective. Further qualitative research and patient and public involvement has informed a novel behaviour change intervention to be tested alongside an existing exercise program. ***Objective:*** To examine the feasibility of behaviour change techniques delivered alongside an exercise programme to improve physical activity, function, and self-efficacy in PwPD (and study procedures) to inform a future pilot RCT. ***Methods:*** A parallel-arm, single-blinded randomised feasibility study. Twenty participants with Parkinson's disease (Hoehn and Yahr stage 1-3) will be recruited from a physiotherapy primary care waiting list. Following written consent, and baseline assessment, the participants will be randomly allocated to the intervention (n=10) or the control group (n=10). Both groups will receive usual care, which includes a weekly programme of a multidisciplinary education, a supervised exercise class and a prescribed home exercise program. The intervention group will receive additional behaviour change techniques, targeting behaviour regulation, belief about capabilities and social influences. Class and home exercise adherence, behaviour change technique uptake and adherence, and negative events will be

recorded. Outcomes will include enrolment and maintenance rates, physical function, falls, physical activity, and exercise self-efficacy measured pre- and post- the 12-week programme (in person). Surveys will be used to compare experiences and satisfaction between groups. Exit interviews will be completed with the intervention group only, exploring their experience of the behaviour change techniques. ***Discussion:*** The results will help inform a future pilot RCT, based on the intervention acceptability, consent rate, maintenance, and protocol integrity. ***Trial Registration***: ClincialTrials.gov NCT06192628

Keywords: Parkinson's disease, Behaviour change intervention, Exercise self-efficacy, Exercise adherence, Physiotherapy, Theoretical Domains Framework.

9.1 Introduction

Parkinson's disease is a progressive neurological condition characterised by both motor and non-motor features. Worsening motor features including balance, postural and gait impairments can lead to a sedentary lifestyle, which deteriorates with disease progression[5] , contributing to poor quality of life[6] , loss of functional independence[6] and reduced physical condition[6]. Exercise is important for people with Parkinson's disease (PwPD) to help control motor and non-motor symptoms[11], improving sleep, mood, and memory; it may have a neuroprotective effect, possibly slowing disease progression.[12,13] Leisure-time physical activity has been found to reduce motor symptoms, regardless of nigrostriatal degeneration.[175] Despite this growing evidence, as little as 30% of PwPD achieve the World Health Organisation recommended activity levels[5,15], some are inactive for 70% of the day, and most are one-third less active than age-matched peers.[15,16]

Ellis *et al.*[237] has identified self-efficacy and outcome expectations as strong predictors of exercise adherence. However, PwPD have reported that one of the primary reasons for poor participation in regular physical activity is lack of motivation.[23] Dopamine function, which is

associated with motivated behaviour[24] , is affected in Parkinson's disease thus compromising behaviour-reward processing in PwPD.[25,26] With Parkinson's disease progression, there is reduced dopaminergic innervation of the ventral striatum, which is connected to motivational functions.[32] This may affect PwPDs' well-being, compliance with and participation in exercise programmes and inclination to engage in physical activity.[35] It is thus necessary to develop programmes that can motivate people to engage in physical activity.

Such programmes, promoting engagement and adherence to physical activity and exercise in PwPD, are limited, and few studies have investigated interventions consistent with behaviour change. Speelman *et al.*[51] has shown that behaviour techniques (coaching, goal setting, use of activity monitors) are widely accepted by participants, with 90% reporting benefits from the intervention and 73% reporting they would recommend it to other PwPD[51] ; the activity monitor being identified as the most useful tool.[51] The ParkFit trial[166], a 2-year, multi-centred, randomised controlled trial comparing physical therapy emphasising behaviour change (ParkFit program), with matched physical therapy emphasizing safety (ParkSafe program) in people with Parkinson's, reported no improvement in physical activity, measured by a self-report questionnaire (their primary outcome measure).[166] However, both the activity diary and the activity monitor data suggested significantly more physical activity in ParkFit participants compared to the ParkSafe group.[166] Ellis *et al.*[52] implemented a single arm clinical study, with a virtual activity coach to promote daily walking. They showed that encouraging walking, monitoring progression, and overcoming barriers with collaborative problem-solving, was well accepted among participants, and led to improvements in adherence to walking, and improved walking speed.[52] We recently conducted a systematic review to examine the effects of behaviour change interventions on exercise self-efficacy and adherence in PwPD.[59] We found that behaviour change methods combined with exercise showed no effect on exercise self-efficacy but brought small improvements in exercise adherence, quality of life and physical

function compared to exercise alone.[59] Furthermore, by mapping the data to the Theoretical Domains Framework[53] we identified *belief about capabilities*, *goals*, *behaviour regulation*, *social influences* and *reinforcement* as the five most effective domains, which healthcare providers should encompass when developing a behaviour change programme.[59]

Limitations in the available literature includes inadequate sample sizes, with the majority of the studies being non-randomised trials, and limited reporting of the theoretical perspectives, key barriers to implementing the intervention, and rationale for the intervention dose and type of activity.[52,166] To date, there is only one definitive multi-centred randomised controlled trial (RCT)[166] investigating the effectiveness of a behaviour change intervention on exercise adherence among PwPD, highlighting the need for more large-scale RCTs. Furthermore, this RCT[166] did not assess exercise self-efficacy, which has been identified as a strong predictor of exercise adherence.[52] Our recent qualitative research[210] displayed difference exercise preferences between men and women (such as setting, type, group vs individual) and motivators to exercise, which we will further examine in this study. Clinicians should develop exercise programmes targeting individual's motivators and perceived needs, thus improving long term participation.[210]

The Parkinson's disease Exercise and Education Programme (PEEP) is an on-going programme run in a primary care centre in Cork city. Informed by existing literature, the programme was developed by the first author (LA) in 2021 and modified according to physiotherapy colleagues' and patients' reviews. The programme is targeted for PwPD, at Hoehn and Yahr stage 1-3 (i.e., still physically independent). The programme runs for 12 weeks and consists of weekly disease self-management education (45-minutes) an exercise component (45-minutes) and a prescribed home exercise plan.

9.1.1 Research objectives

The aim of this study is to examine the feasibility and acceptability of adding behaviour change techniques to an existing Parkinson's disease exercise and education programme for people with mild-to-moderate Parkinson's disease and the study procedures for a future pilot trial. The behaviour change techniques are designed to improve their confidence in managing and progressing their exercise and physical activity independently.

Using mixed methods, the research objectives are:

a) To evaluate the recruitment process and resulting sample characteristics (screen failures, consent refusals).
b) To examine the feasibility of the data collection procedures and outcome measures.
c) To explore the acceptability and suitability of the intervention and the study procedures to participants.
d) To assess the time resources required to manage and implement the study and intervention.
e) To explore the trends in outcome measures in terms of range and variability across the entire group.

9.2 Methods

This protocol is reported in line with the SPIRIT 2013 Statement: Defining standard protocol items for clinical trials guidelines[238,239] and the intervention description is guided by the Template for Intervention Description and Replication (TIDieR).[240] The protocol is reported according to the Consolidated Standards of Reporting Trials (CONSORT) statement extension for randomised pilot and feasibility studies.[241]

9.2.1 Patient and public involvement (PPI)

We held two one-hour meetings with a PPI group (consisting of 4 PwPDs; 3 female and 1 male). In one meeting, the findings of our systematic review and qualitative study were presented, and we gained their input on the draft design for the feasibility intervention. In the second meeting, the PPI group read and provided feedback on the participant information sheet and consent form.

9.2.2 Study design

A parallel single-blinded feasibility study comparing an existing Parkinson's disease Exercise and Education Programme (PEEP, control) and an augmented Parkinson's disease Exercise and Education Programme with behaviour change techniques added (PEEP + BC, intervention). Ethical approval has been granted from the local research ethics committee (CREC registration number: ECM 4 (m) 20/06/2023 & ECM 5 (4) 06/07/2023).

9.2.3 Participants and recruitment

Participants will be recruited from the current waiting list to attend the existing PEEP program. We plan to recruit 20 participants (10 in each arm) – to optimise numbers while keeping safety paramount in the classes (n=5 per class). We will aim to recruit an equal representation of both sexes (based on self-report). We estimate an attrition rate of 20%, based on previous PEEP programmes and available literature.[242,243] Prior to random concealed allocation, a member of the research team (LA) will screen participants for eligibility, as follows:

- Diagnosis of idiopathic Parkinson's disease, confirmed by neurologist or geriatrician.
- Early Stages of Parkinson's disease, as determined by Hoehn & Yahr Stage 1-3 using the United Parkinson's disease Rating Scale[7])
- Ability to drive or obtain transport that will drop and collect at the health centre.

- Ability to independently walk (with or without a walking aid)
- Reported by the referring healthcare provider or carer as able to follow instructions and carry out the exercise programme independently at home.

Participants will be excluded if they have:

- A diagnosis of atypical Parkinson's (e.g., progressive supranuclear palsy, multiple system atrophy, etc) or vascular Parkinsonism or drug-induced parkinsonism
- Previously completed the PEEP program.
- Had a hospital admission < 6 weeks ago.
- Immobility, or are a wheelchair-user.
- Severe visual or auditory impairment
- Serious medical conditions in major organs (heart, lung, or kidney) or other illnesses which prevent independent ambulation or safe exercise.
- Been identified as a high falls risk (identified during the pre-screening using objective measure the Short Physical Performance Battery (a score of ≤ 6 indicates a higher fall risk in old adults[244]) and subjective reporting of two or more falls in the past year.

All participants must provide GP clearance letters deeming them medically safe to partake in the exercise component prior to enrolling in the study. Written consent will be obtained from the participants (by LA) before data collection. Participants will be informed that they may withdraw from the study at any time for any reason.

9.2.4 Randomisation

Following written consent and baseline assessment (to ensure blinded assessment), a research staff member (RMcC), not involved in the screening or data collection, will randomly assign eligible participants in a 1:1 ratio, stratified by sex, using a computer-generated randomisation

sequence and concealed allocation (sealed envelopes), to the PEEP or the PEEP + BC group. Outcome assessors will be blinded to group allocation. Study participants will be instructed not to share any information on group allocation with the assessor or with other PwPD outside the intervention. Every attempt will be made to ensure the assessor is not unblinded; if this occurs, a substitute assessor will be used. The assessor will not be in the facility while the programme is being delivered. A full CONSORT[241] flow diagram is presented in Figure 9.1 and will be populated throughout the study. The participant timeline is documented in Table 9.1.

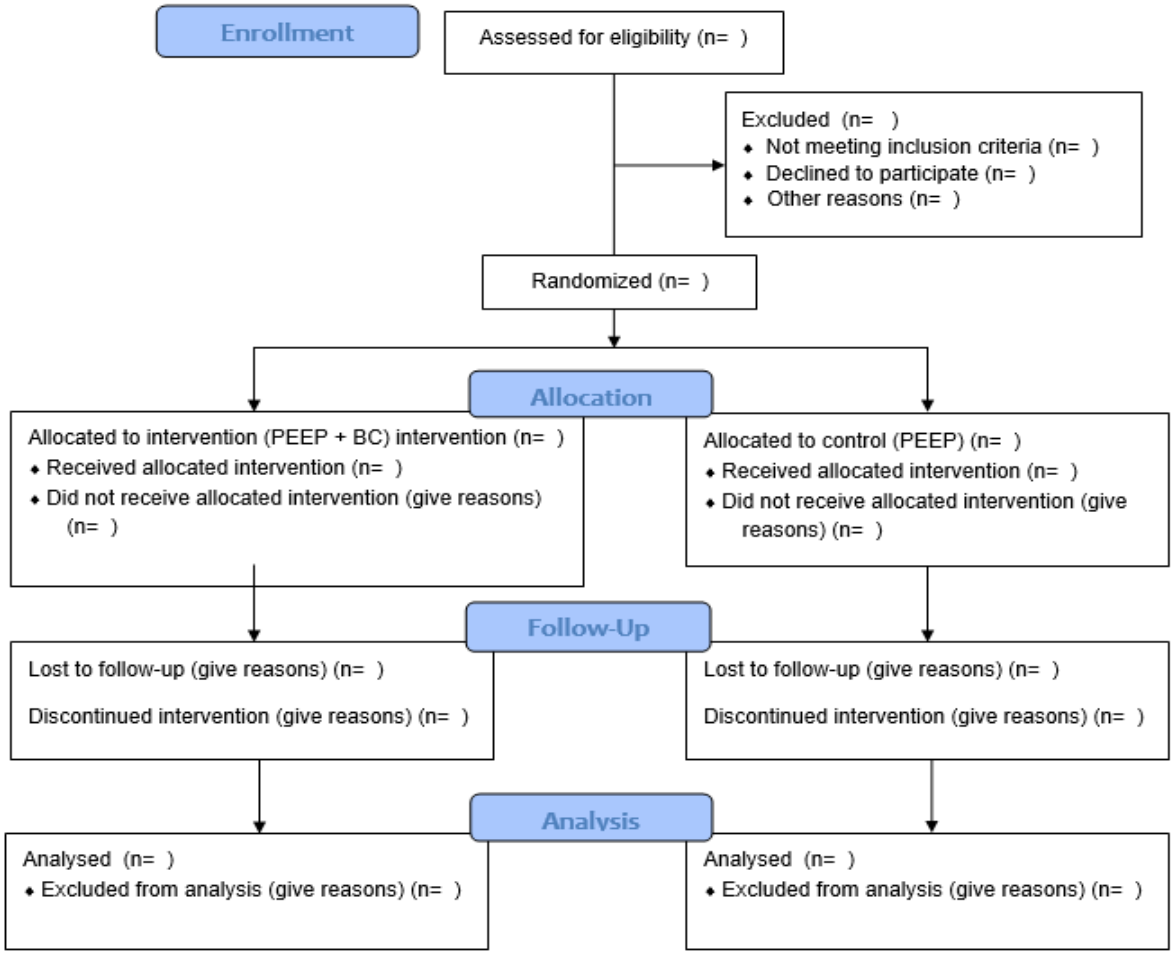


Figure 9.1: Consort flow diagram detailing the participants planned pathway through the trial.[242]

Table 9.1: Participant Timeline

	Enrolment		Allocation	Post Allocation	
Timepoint	$-T_2$ (two weeks before baseline)	$-T_1$ (Week before baseline)	0	T_0 (baseline)	T_1 (post-intervention – Week 12)
Enrolment:					
Eligibility Screen	X				
Informed Consent	X				
StepWatch Activity Monitor distributed to participants		X			
Baseline Assessment		X			
Group Allocation			X		
Intervention:					
PEEP + BC				O———	———O
PEEP				O———	———O
Primary Outcome measures:					
Walking Activity (SAM)				X	X
Gait and Balance (APDM Mobility Lab system™)				X	X
Exercise self-efficacy (ESES)				X	X
Secondary Outcome measures:					
Physical Endurance (6MWT)				X	X
Quality of Life (PDQ-39)				X	X
Exit Interviews					X
Safety					X

SAM: StepWatch Activity Monitor; **ESES**: Exercise self-efficacy scale; **6MWT**: 6-minute walk test; **PDQ-39**: Parkinson's disease Questionnare-39 **Safety**: Falls, hospitalisation, muscle soreness

Usual care and intervention details

Materials include gym and exercise equipment [chairs, steps, resistance bands, ankle weights, water bottles (will be used as hand weights)], an activity diary *[Appendix C1]* and a behaviour change template *[Appendix C2]*. One registered physiotherapist (LA) with a special interest in Parkinson's disease will be leading the programme, as part of their doctorate training. A physiotherapy assistant, with additional training as a Postural Stability Instructor will be

present at all the exercise sessions to ensure safe, correct exercise completion, which will allow the physiotherapist to focus on the behaviour change techniques.

9.2.5 Usual care: Parkinson's disease Exercise and Education Programme (PEEP).

The usual care consists of three components:

(1) Weekly group exercise class. Classes will be delivered in a primary care physiotherapy gym. They will last approximately 45 minutes, including a five-minute warm-up and cool-down. The exercises class will include eight different exercises (focusing on strength, dynamic balance, coordination, flexibility, and dual tasking). The exercise type will remain consistent throughout the 12 weeks (to aid memory retention), however the progression of exercises will be tailored to each participant's capability, weekly, by increasing the number of repetitions and step height, heavier resistance bands, addition of hand and ankle weights and adding a cognitive element while performing the exercises. Thus, adjustments in intensity or complexity will be tailored to the individual and progressed with time. Participants will be asked to attend for one hour, to allow 15 minutes for people to settle in, and give an opportunity to socially engage before the exercise class begins. During this time, the physiotherapist (LA) will have a brief 1:1 conversation with each participant about adverse events that may have occurred that week (see section *Safety).*

(2) Twelve weekly 45-minute group education sessions will be delivered by a range of healthcare professionals and guest speakers including a physiotherapist, speech and language therapist, an occupational therapist, dietician, geriatrician, Parkinson's disease specialist nurse, psychologist, social prescriber, and social worker.

These sessions will be delivered in a conference room located next to the physiotherapy gym in the primary care centre and will include general information to signpost people to services, the role of the healthcare profession in question. Education is provided on medication, symptoms, diet, and aids, but information that could improve exercise self-efficacy and self-management of exercise programmes (such as rest, pacing, goal setting etc) is not provided. Following each education session, a hardcopy of the lecture presentation will be provided, and any pamphlets and leaflets recommended by the speaker. The education sessions will be delivered to both groups together, on the day of the usual care group's exercise classes (the intervention group will have their exercise class on a separate day). All efforts will be made to keep contamination to a minimum as the participants will sit with their own group and will be asked not to discuss the exercise classes with others, and staff will be monitoring conversations in the room. Family members will also be encouraged to attend the education sessions.

(3) At home, the participants will be expected to independently complete the exercises twice weekly, and this will be discussed at each exercise class with the registered physiotherapist.

9.2.6 Intervention: Parkinson's disease Exercise and Education Programme with the Behaviour Change techniques (PEEP + BC)

The BC intervention will consist of usual care and four additional techniques to address behaviour regulation, belief about capabilities, goals and peer support.

(1) *Exercise specific education:* during the weekly exercise class, the intended functional benefit of the exercises will be explained to everyone. Support will be given to self-select personal exercise intensity and to manage their own exercise and progressions at home.

Peer support, competition, reward, and fun will be strongly encouraged and supported by the registered physiotherapist and physiotherapy assistant. By week six, the participants will be

invited to lead the class, with the class leader rotating each week, aiming to be independently managing the class by week 12.

(2) An *activity diary* to be completed independently at home daily *[Appendix C1]*. Details will include the type of exercise or physical activity of choice, and its duration and intensity (using Borg Rating of Perceived Exertion Scale[197]). Furthermore, they will be asked to reflect on the exercise; their confidence/skill completing the activity, consequences of the activity (both positive and negative) and reasons for non-completion. Daily diary completion will take less than 5 minutes.

(3) Individual one-to-one weekly conversations between the registered physiotherapist and the participant, covering the domains of behaviour regulation, peer support, goals and belief about capabilities. The conversations will be held before each weekly exercise class, when the participants are coming into the gym, while others are settling into the room. All topics will be covered frequently but not weekly, to avoid repetition *[Appendix C2].* The conversation will last two to five minutes per person (approximately 15 minutes in total per class). During this time, the participant's activity diary will be reviewed with the physiotherapist to support the participant to explicitly reflect on progress and their expectations, to *identify solutions to any barriers*, and to *set activity goals* for the following week.

(4) Peer support will be further supported with the suggestion of a *WhatsApp group*. To encourage self-management and to limit the influence of sharing their personal information, the physiotherapist will suggest this at the first visit, when, if possible, a participant will volunteer to lead the WhatsApp group. From this point onwards, the physiotherapist will remain uninvolved but will ask about the use of group chat in the individual conversation.

All participants will be asked to continue their usual exercise during the study period.

Outcomes measures

9.2.7 Feasibility outcomes

Feasibility outcomes of interest include methodological, procedural and clinical uncertainites[57,241,245], examination of recruitment rates, consequences of eligibility criteria, attrition once recruited, data collection completion, resources needed to complete the intervention and the data collection, participant adherence to the intervention, and acceptability of the intervention and study procedures to participants. Feasibility outcomes are shown in Table 9.2.[246]

9.2.8 Process outcomes

The following will be collected to indicate the study process feasibility:

1. Fidelity of delivery of exercise-only and exercise-behaviour change classes (duration; range of exercises included progressing intensity as per plan, etc)
2. Class attendance; drop-out rates; set-up administrative time required (participant queries between classes, room preparation, etc)
3. Completion of home-based (self-reported) exercise activity (exercise type, number of repetitions, intensity)
4. Fidelity and barriers of delivery of the behaviour change intervention (review of the records of one-to-one discussions *[Appendix C2]* and researcher completion of a reflective log after each exercise session.

Acceptability

The acceptability of the class and independent exercise (both groups) will be explored by surveys *[Appendix C3]*, and the behaviour component will be explored through additional exit interviews, using a semi-structured interview, with the intervention group only *[Appendix C4]*.

Safety

Falls (number and frequency), injuries (cuts, bruises, muscle pains, other injuries), emergency department attendance or hospitalisation, and death will be considered as adverse events and will be discussed and recorded during the weekly conversations held before each exercise class. If a participant does not attend (without prior explanation) they will be contacted. Family members will be contacted if the participant does not answer over one week, for those who do not have family, the GP will be contacted. Any serious adverse events will be reported to the Chief Medical Officer of UCC.

Table 9.2: Overview of feasibility outcomes.[245]

Outcome	Evaluation
Recruitment and eligibility	- Number of patients on current waitlist - Percentage assessed for eligibility; fulfilling inclusion criteria, and included (of total number identified) - Ambiguities regarding eligibility criteria - Reasons for ineligibility - Reasons for non-participation
Data Collection	- Percentage of completed assessments. - Ease of completion and number of missing items - Types and number of potential clinical uncertainties in interviews
Attrition	- Rate of study dropout - Rate of intervention dropout
Resources needed to complete the study and intervention	Length of time required for: - Participants to work through intervention. - Participants to complete questionnaires and interviews - Study personnel to administer the study
Adherence to the intervention	Number of: - Completed activity diaries. - Exercise classes attended. - Education sessions attended.
Acceptability and experience of the intervention and data	- Reasons for poor attendance and withdrawal from the study and intervention

collection and exploration of mechanisms of impact	- Experience and perception of the behaviour change intervention (including positive and negative consequences) - Perceived value of completing home exercise diaries - Perceived value of WhatsApp group - Perceived value of one-to-one conversations at each exercise class - Perceived confidence in self-management - Number and severity of negative events

9.2.9 Performance outcomes

For performance outcomes see Table 9.1 We will complete all mobility-related assessments during the participants' ON phase for consistency (i.e., 1–2 hours post medications, and stated "good time of day")

Walking activity and falls events

The Stepwatch Activity Monitor will be used to measure step-count and physical activity. This is a validated accelerometer, with excellent accuracy in PwPD.[231] The device is ankle-worn and is fully waterproof, allowing seven days of uninterrupted data collection. Participants will be asked to wear the accelerometer for the week before the programme begin, and again, for the final week of the programme. Within-person differences in average daily step count will be used to examine changes in physical activity. As it is well known that activity diaries are unreliable measures of activity[247], we will focus on accelerometery data only as a measure of physical/walking activity.

Falls and 'near falls' are the only measures that will be taken from the activity diary. These events will be discussed in both groups during weekly one-to-one discussions about adverse event with all participants (at the beginning of the exercise class) and recorded.

Gait and balance

Physical performance will be measured objectively before and immediately after the programme using the APDM Mobility Lab system™ (http://www.apdm.com/mobility/). The APDM Lab system uses coordinated, wearable inertial sensors to precisely analyse quality of gait and balance.[235] It is a portable gait and balance laboratory and allows streamlined gait and balance assessment by making it easy to collect, store, analyse, and interpret balance and gait data from a large set of prescribed tasks.[235] It is a validated device to objectively measure walking and balance in PwPD.[235] Five Opals™ (accelerometers) will be attached to participants two feet (ankles) and two arms (wrists) and one at the waist using Velcro straps (provided). The participants will be asked to stand, walk a 3-metre distance, turn around, walk back to the chair, and sit down (Timed Up and Go Test (TUG)). A 2-minute free walk (at the participants self-selected pace) will be recorded also to examine stride length and turns specifically.

Exercise self-efficacy

Exercise self-efficacy will be measured using the Exercise Self-Efficacy Scale[234] (ESES) at baseline, immediately post-intervention. The ESES is a self-report instrument, validated in PwPD[232], containing ten statements about how confident the person is performing physical activity and exercise.[234] Responses are chosen from a four-point scale with 1 = not at all true to 4 = always true (score range 10–40, higher indicating more confidence.[234])

Secondary outcome measures.

We defined two secondary measures:

Aerobic endurance

Aerobic endurance will be measured with the six-minute walk test[248] (6MWT) at baseline and post-intervention. Participants walk continuously for six minutes at their self-selected pace. As

recommended, an indoor hallway with the 10m distance will be used, and total distance will be recorded.

Quality of life (QoL)

QoL will be measured using the Parkinson's disease Questionnaire[249] (PDQ-39) at baseline, and post-intervention. The PDQ-39 assesses Parkinson's disease-specific health-related QoL in the previous month across eight dimensions of daily living[249], with specific dimensions of functioning and wellbeing.[249]

9.2.10 Data collection

Baseline data will include personal information such as demographics (including age and self-reported sex), social history, medical history, disease severity (using the United Parkinson's disease Rating Scale – motor exam) and medication history will be collected before randomisation by the research physiotherapist (LA) and the Stepwatch Activity Monitor will be programmed and, as per the manufacturer's instructions, attached to the participants ankle at the end of the assessment. They will be instructed to wear the accelerometer continuously for seven days, until they return the following week, when the device is removed the data will be downloaded onto a password protected file on the research laptop. Participants will be encouraged to contact the research physiotherapist with any concerns about the accelerometer during the week, and a courtesy call will be made during the week to ensure data collection.

Similarly, the participants will be asked to wear the accelerometer for the final week of the program. On the last day of the program, the accelerometer will be removed, and the data will be downloaded. The outcome assessments will be completed by a blinded registered physiotherapist, who is fully trained in the completion of the assessments.

Adherence

Full adherence to the intervention will be defined as follows: 1) attending the baseline and immediate post-intervention assessments, 2) completing 12 weekly activity diaries and 3) attending all 12 exercises classes, attending all 12 education sessions. Attendance at the exercise classes and education sessions will be documented each week by the registered physiotherapist. Activity diaries will be viewed each week during the weekly one-to-one weekly conversations between the registered physiotherapist and the participant before each exercise class.

Qualitative process evaluation

All participants will be asked to complete a feedback survey *[Appendix C3]* with open-ended questions exploring what they liked/disliked about the PEEP program, elements of the programme they felt were not required, or elements they believe should have been included in the programme, and their opinions of the topics covered during the education sessions. On-line semi-structured interviews exploring the acceptability of the behaviour change techniques will be conducted by a research physiotherapist (RMcC) with the PEEP+BC participants only, immediately post-intervention (12 weeks). They will be asked to discuss the perceived impact and value, and how the intervention addressed barriers to exercise and physical activity. The interview guide will be informed by previous research examining the acceptability of BC interventions[250-252] coded under the domains of the Theoretical Domains Framework[53] *[Appendix C4]*.

9.2.11 Data analysis

Quantitative analysis

With small numbers in each group, we will present and treat all continuous data as non-parametric data. Suitable summary statistics (e.g., median, interquartile range, and frequency, percentages) will be provided for all outcomes.

These summary statistics will be used to assess the feasibility of the intervention. Potential ambiguities regarding standard safety procedures, types and numbers of measures undertaken to assure participant safety, and types and numbers of unforeseen safety issues will be reported and disaggregated by sex. We will analyse the results according to a modified intention-to-treat principle, whereby we will exclude only participants with no follow-up measurements at all.

Qualitative analysis

Data from the semi-structured interview questions will be video recorded, transcribed verbatim, and analysed with the data from the surveys using qualitative content analysis. Difference between the sexes will be carefully considered.

9.3 Discussion

This intervention has been informed from our previous systematic review[59] and qualitative studies[210] with participants and healthcare providers. These studies showed us that people want to exercise but are frustrated by the barriers and reliance on healthcare providers or family to manage or motivate them to exercise. We propose to examine the feasibility of a behaviour change intervention to address behaviour regulation, belief about capabilities, goals and peer support by encouraging self-progression, reflection, competition, fun and reward to drive adherence and self-management of exercise behaviours.

The results of this feasibility study will inform a future pilot trial, by examining responsiveness of outcome measures, consent rate, and qualitatively exploring acceptability and experiences of the intervention which will help to refine the intervention and may explain uptake and adherence rates. We will consider sex differences, if any that emerge from the qualitative interviews.

The effects of behaviour change intervention on exercise adherence and exercise self-efficacy remains unclear. There is a clear need for participatory research to design interventions that help PwPD to maintain health and wellbeing. While not definitive, this study will help further behaviour change intervention design informed by the published literature, stakeholder input and PPI involvement.

9.4 Extended data

Dryad: Extended Data for Behaviour change for Parkinson's disease: A randomised controlled feasibility study to promote physical activity and exercise adherence among people with Parkinson's disease: study protocol, https://doi.org/10.5061/dryad.prr4xgxt5.[253]

9.5 Reporting guidelines

Zenodo: SPIRIT checklist for 'Behaviour change for Parkinson's disease: A randomised controlled feasibility study to promote physical activity and exercise adherence among people with Parkinson's disease: study protocol', https://doi.org/10.5281/zenodo.10407626.[254]

Chapter 10

Behaviour change for Parkinson's disease: A randomised controlled feasibility study to promote physical activity and exercise adherence among people with Parkinson's disease

Abstract

Background: Exercise and physical activity may improve mobility and health related quality of life in people with Parkinson's Disease. However, adhering to it can be challenging. ***Objective:*** To evaluate recruitment, study procedures/resources, acceptability of interventions, trends in physical activity, and self-efficacy measures. ***Methods:*** A mixed methods parallel-arm, single-blinded, randomised feasibility study. Participants (Hoehn and Yahr stage 1-3) were randomly allocated to intervention or control. Both groups received 12-weeks of education, supervised exercise, and twice-weekly home exercises. The intervention group received additional behaviour change techniques to enhance behaviour regulation, belief about capabilities, goals and social influences. Enrolment, attendance, adherence and serious adverse events were recorded. Primary outcome measures were walking activity, gait, balance, falls, aerobic endurance, strength, and exercise self-efficacy. Surveys and exit-interviews examined acceptability, satisfaction, and experience of the interventions. ***Results:*** Twenty-six people were screened; sixteen were randomised, fourteen completed (both drop-outs were in the intervention group). These dropouts led to reduced attendance to the sessions in the intervention group. However, attendance in both groups was high (76% (146/192)(Total number of exercise + education classes attended/Total number offered), and adherence to the twice-weekly home-exercises (intervention, 70% (135/192); control, 63% (120/192)). No serious adverse events were detected. Time resources were deemed acceptable by the participants. Physical activity

and aerobic endurance were the most responsive measures reaching previously described minimally important differences. Interviews indicated that participants enjoyed the group dynamic, and gaining knowledge and skills were perceived as important. Feedback on the intervention will help improve acceptability. Preferences emerged, suggesting that profiling exercise preferences could improve tailoring of the intervention. ***Conclusion:*** The study and intervention are feasible and acceptable. Preference profiling may improve the intervention. ***Trial registration:*** ClincialTrials.gov NCT06192628. Registered 5th January 2024, https://clinicaltrials.gov/study/NCT06192628

Keywords: Parkinson's disease, Information Motivation Behaviour Skills Model, Self-efficacy, Exercise therapy.

10.1 Key Messages

- Exercise and behaviour change techniques were considered feasible and acceptable by the participants. The group dynamic was universally enjoyed.

- Physical activity data, and measures of aerobic endurance were most sensitive to change.

- Clinicians may find it useful to profile an individual's motivation type and baseline understanding of exercise to select the appropriate behaviour change technique.

10.2 Introduction

Parkinson's disease is a progressive neurological condition involving motor and non-motor symptoms. Deteriorating symptoms can lead to a sedentary lifestyle[5], leading to further functional dependence.[6] Exercise can relieve symptoms in people with Parkinson's disease (PwPD)[11], with emerging evidence suggesting a possible neuroprotective effect.[12,13] However, as

few as 30% of PwPD attain the recommended activity guidelines[5,16]; most PwPD are one-third less active than age-matched peers.[15,16]

Self-efficacy and outcome expectations are stronger predictors of sustained exercise adherence than disease severity.[237] PwPD report that lack of motivation prevents regular physical activity.[23] Dopamine depletion associated with disease progression may result in lack of motivation (apathy), loss of interest in pleasurable activities, and pessimistic views of exercise capability.[33,34] However, expectations of enjoyable and valuable exercise can drive motivation.[43,44]

We recently completed a systematic review of intervention studies relating to exercise-related behaviour change in PwPD.[59] It showed that limited research has examined behaviour change interventions to improve physical activity and exercise adherence in PwPD. Compared to exercise alone, behaviour change techniques with exercise showed no effect on self-efficacy, but gave small improvements in exercise adherence, quality of life and physical function.[59] When mapping to the Theoretical Domains Framework[53] the data suggested belief about capabilities, goals, behaviour regulation, social influences and reinforcement are the five most effective domains of exercise-related behaviour change in Parkinson's disease.[59] The only large, multi-centered randomised controlled trial (RCT) of behaviour change interventions for PwPD found was the ParkFit trial.[166] This two-year trial found no difference in self-reported physical activity between physical therapy emphasizing behaviour change (ParkFit program), versus physical therapy emphasizing safety in PwPD (ParkSafe program).[166] Further exploration of the intervention to motivate exercise and improve exercise self-management is needed.

10.2.1 Research objectives

Based on the review findings, and previous qualitative work exploring exercise motivation and supports[210], we aim to test the feasibility of additional behaviour change (BC) techniques, delivered alongside an existing 12-week exercise and education intervention called the

Parkinson's disease Exercise and Education Programme (PEEP). The BC techniques aim to improve self-efficacy and self-management of exercise/physical activity.

Using mixed methods, the objectives were to:

a) Examine recruitment process, and resulting sample characteristics (screen failures, consent refusals)
b) Feasibility test the study procedures: time, equipment, data collection procedures, and set-up administration time
c) Examine attendance, adherence and safety of the program
d) Explore the acceptability of the intervention and the study procedures
e) Estimate the responsiveness of measures to change.

10.3 Methods

10.3.1 Study design

A detailed description of the trial protocol has been presented previously.[255] A parallel single-blinded feasibility study comparing the PEEP Programme (PEEP; control) with the same programme augmented with behaviour change techniques (PEEP+BC; intervention). The study received local ethical approval (ECM 5 (4) 06/07/2023) and was conducted from September 2023 to January 2024. This study is reported in line with the Consolidated Standards of Reporting Trials (CONSORT) statement extension for randomised pilot and feasibility studies.[241] The intervention description, guided by the Template for Intervention Description and Replication (TIDieR)[240] is previously published.[255] The study is registered on ClinicalTrials.gov (NCT06192628).

10.3.2 Subjects and recruitment

We aimed to recruit 20 participants from the existing PEEP programme waiting list, estimating a 20% attrition rate based on previous PEEP programmes and the available literature.[242,243] The stop-go criteria was implemented for recruitment, the pre-determined thresholds were; go (90-100% of the target), amend/monitor (60-89% of the target) and stop (<60% of the target). Participants were screened using the following eligibility criteria:

- Diagnosis of idiopathic Parkinson's disease, confirmed by neurologist or geriatrician.
- In the early stages of Parkinson's disease, as determined by Hoehn & Yahr Stage 1-3 using the Unified Parkinson's disease Rating Scale[7])
- Able to walk independently (with/without a walking aid)
- Able to attend classes, follow instructions and complete the exercises independently at home (as self-reported, or reported by the referring healthcare provider/carer).
- Participants must be stable on their medications (i.e. no changes to medication or dosage in past three months).

Exclusion criteria:

- Diagnosis of atypical Parkinson's disease (e.g., progressive supranuclear palsy, multiple system atrophy), vascular parkinsonism or drug-induced parkinsonism
- Completed the PEEP programme previously
- Hospital admission < 6 weeks ago
- Serious medical conditions/illnesses preventing safe exercise
- Identified as a high falls risk, at pre-screening, using the Short Physical Performance Battery (a score of ≤ 6 indicates falls risk in old adults[244]) and/or subjective reporting of frequent falls in the past year (two or more falls).[85]

10.3.3 Recruitment and baseline assessment procedure

The waiting list for the PEEP programme was used to identity suitable participants, who were screened and invited to participate by phone. If eligible, the study was explained to them, and a copy of the participant information leaflet [*see Appendix C6]* was sent to them by post. Those that were interested were invited for assessment. Confirmation of the screening and baseline data was completed one week before the programme, at the primary care centre. Those who did not reach eligibility were offered alternative appropriate treatments. The participants were given the opportunity to ask further questions, and written consent was sought before baseline data was gathered. Participants were assessed one week before the 12-week programme by a member of the research team (LA). Baseline data included demographics, medical, medication, social history, and disease severity (UPDRS–motor exam). All assessments were completed in one hour, and during the participants ON phase (medication is effectively reducing symptoms, allowing smoother movement) for consistency (i.e., 1-2 hours post medications, at their stated "good time of day"). The SAM was programmed as per manufacturer instructions to each participant and worn on the dominant ankle continuously for seven days.

The participants were then randomised using a computer-generated randomisation sequence and sealed envelopes (see below). Those assigned to the intervention group were given an activity diary showed how to complete it and informed it would be reviewed each week. Participants were also taught how to record any falls and/or near fall events in the activity diary.

10.3.4 Randomization process

Randomisation was conducted by a member of the research team not involved in the assessment or delivery of the program. Eligible participants were allocated in a 1:1 ratio, stratified by sex, using a computer-generated random number sequence (Excel, Microsoft Corporation) and sealed envelopes, to the PEEP or the PEEP+BC group. To limit

contamination, study participants were asked not to share information on group activities with other PwPD.

10.3.5 Intervention for PEEP and PEEP+BC groups

Usual Care: Parkinson's disease Exercise and Education Programme (PEEP):

The Parkinson's disease Exercise and Education Programme (PEEP) is an on-going 12-week programme run in an urban primary care centre in Ireland. A detailed description of the interventions is described in Ahern *et al*.[255] Briefly, the programme, informed by existing literature, was developed (LA) in 2021 and modified with physiotherapy colleagues' and patients' reviews. The programme is targeted for PwPD at Hoehn and Yahr Stage 1-3 (i.e., physically independent).

The classes and education sessions were each provided once weekly for twelve weeks. The exercise classes were 45 minutes in duration including strength, balance, functional and dual tasking exercises. Home exercises were individually prescribed, to be completed twice weekly. The education sessions were delivered by different healthcare professionals explaining their role and signposting to services.

Intervention: Parkinson's Exercise and Education Programme with the Behaviour Change techniques (PEEP+BC)

Similarly, the PEEP+BC is described in detail in Ahern *et al*.[255] The PEEP+BC incorporated four behaviour change techniques to promote exercise self-efficacy and self-management; (1) *Exercise specific education*: the participants were explicitly taught the functional benefit of each exercise, participants were educated how to monitor and progress their own program, including monitoring exercise intensity, logging sets and reps and progressing and regressing exercises. (2) *Activity diaries* were completed weekly at home, reflecting on progress, expectations, (3) *solutions to barriers*, and to *set activity goals* for the following week and, (4) finally, a *WhatsApp group* was encouraged to drive peer-support and self-management. The

activity diary completion was monitored and reviewed by LA each week during a brief weekly discussion prior to the exercise classes.

Intervention group attended their exercise class on a separate day to the usual care group. To prevent the repetition of the weekly education sessions, both the PEEP and PEEP+BC attended the same education sessions. Every attempt was made to keep the groups separate.

10.3.6 Time and equipment resources for the study

Each arm was split into two groups of four participants, to allow space and safety (four classes weekly (n=4 per class), two classes per arm). The required equipment was routine; chairs, steps (10cm and 15cm), varying resistance bands, and weights. Forty-five minutes provided for warm-up, cool down and a five-minute break between the exercise and education sessions worked well. The additional debriefing sessions before the classes were feasible and straightforward.

10.3.7 Set-up administration time required

Administration per person in either arm of the study was the same, taking approximately two hours, organization of education sessions and guest speakers took approximately four hours with additional time for printed handouts, pamphlets, and session information (approx. 20-30 mins per session).

10.3.8 Outcome assessment procedure

Participants were assessed one week after the programme (Week 13) by the same member of the research team (LA). All assessments were completed in one hour, and during the participants ON phase (exactly 13 weeks after the baseline assessment, on the same day and time.) The SAM was programmed as per manufacturer instructions, participants were asked to wear the accelerometer for the final week of the programme (week 12) on the dominant

ankle continuously for seven days (returned on the assessment day, week 13). Activity diaries and feedback surveys were also collected on the assessment day (week 13).

10.3.9 Outcomes

The study used quantitative and qualitative data to evaluate the feasibility of the intervention, while outcome data was used to estimate its effects.

The quantitative measures to examine feasibility included:

- Recruitment and retention rates: The numbers approached, screened and consented.
- Feasibility of the intervention and research procedures: The adherence to in-class and home exercises, data collection completeness, staff and equipment resources were examined. Full adherence to the programme was defined as: 1) attendance at all assessments, 2) completion (at least 50% completion rate) of twelve, weekly activity diaries and 3) documented attendance at 12 exercise/education sessions. The weekly activity diaries completion was recorded as follows: 0% complete: no activities documented; 50% complete: some exercise details provided but feelings after exercise/reasons for not exercising not provided and 100% complete: included detailed exercises description: time, place, reps, sets and intensity, feelings after exercising and reasons for not exercising.
- Programme safety: This was checked weekly against a predetermined list of serious adverse; (falls [number and frequency], injuries [cuts, bruises, muscle pains]), emergency department attendance or hospitalization, and death). All unaccounted non-attendances were followed up.

The qualitative data to examine the feasibility (acceptability) included:

- All participants completed a feedback survey *[see Appendix C3]* with open-ended questions exploring the acceptability and suitability of the programme, elements of

the programme they felt were not required, or elements they believe should have been included in the programme, and their opinions of the topics covered during the education sessions. The week after the programme, online semi-structured interviews conducted with the intervention participants only by an independent interviewer (RMcC) to prevent the physiotherapist-patient relationship affecting open dialogue and participant responses. The interviews explored the acceptability and perceived impact of the BC techniques among the PEEP+BC participants only. The interview guide *[see Appendix C4]* was informed by our systematic review and previous research examining the acceptability of BC techniques[250-252], coded under the domains of the Theoretical Domains Framework.[53]

The quantitative measures to estimate the effects of the intervention included:

- Measures of physical activity, function and self-efficacy (detailed under section 10.3.10 Outcome measures) were examined to explore their responsiveness to change, and floor and ceiling effects. Within group differences were compared to published minimal important differences, as significant differences between groups were not anticipated with low numbers.

10.3.10 Outcome measures

The primary outcome measures included walking activity, gait, balance, aerobic endurance and exercise self-efficacy.

Walking activity

We used the Modus Health™ Stepwatch4 Activity Monitor (SAM), to compare 7-day average daily step-count from baseline to the last week of the programme. This ankle-worn, waterproof accelerometer has excellent accuracy in PwPD.[231] The SAM was worn continuously for seven

days. A courtesy call was made mid-week, and participants were encouraged to contact the researcher with any concerns.

Falls

Falls and 'near falls' were self-reported in the activity diary weekly. Participants were asked to document if they had a fall. Participants were also asked about falls every week, during the weekly discussions before the exercise class, and the activity diary were updated as required.

Gait, balance and strength

We used the validated[235] APDM Mobility Lab system™ to objectively measure a Timed Up and Go Test (TUG) and a 2-minute free walk test (at the participants self-selected pace). Five Opals™ (accelerometers) were attached at the ankles, wrists, and waist.

Aerobic endurance was measured with the six-minute walk test[248] (6MWT) at a self-selected pace. A 10m indoor hallway was used, and total distance was recorded.

Five time sit-to-stand (5TSTS) was used to measure functional mobility and lower limb strength.[256] JAMAR handheld-dynamometer was used to measure grip strength.

Exercise self-efficacy and Quality of life (QoL)

Self-efficacy was measured using the Exercise Self-Efficacy Scale[234] (ESES). The Parkinson's disease Questionnaire[249] (PDQ-39) was used to assess Parkinson's disease-specific health-related QoL[249], both of which are validated in PwPD.[234,249]

10.3.11 Data analysis

Quantitative analysis

Attendance rates were determined for each group for the 12-week programme. Attendance was calculated as the percentage of the number of classes attended relative to the number of classes

offered (i.e. Total number of exercise + education classes attended/Total number of exercise + education offered).

Given the small number of participants, we treated all continuous data as not normally distributed (see Table 10.1), non-parametric t-tests were used to analyse the quantitative measures for pretest and post-test evaluation data.

Qualitative analysis

Content analysis methods were used with qualitative data from the surveys. The recordings from the semi-structured interview were transcribed verbatim, with thematic analysis of the coded transcripts.

10.4 Results

10.4.1 Participants

Twenty-six people were invited to participate. Three did not fit the eligibility criteria, and seven were not interested (Figure 10.1). Sixteen participants were randomised and commenced the intervention (PEEP n=8; PEEP+BC n=8). Group demographics and baseline scores are presented in Table 10.1.

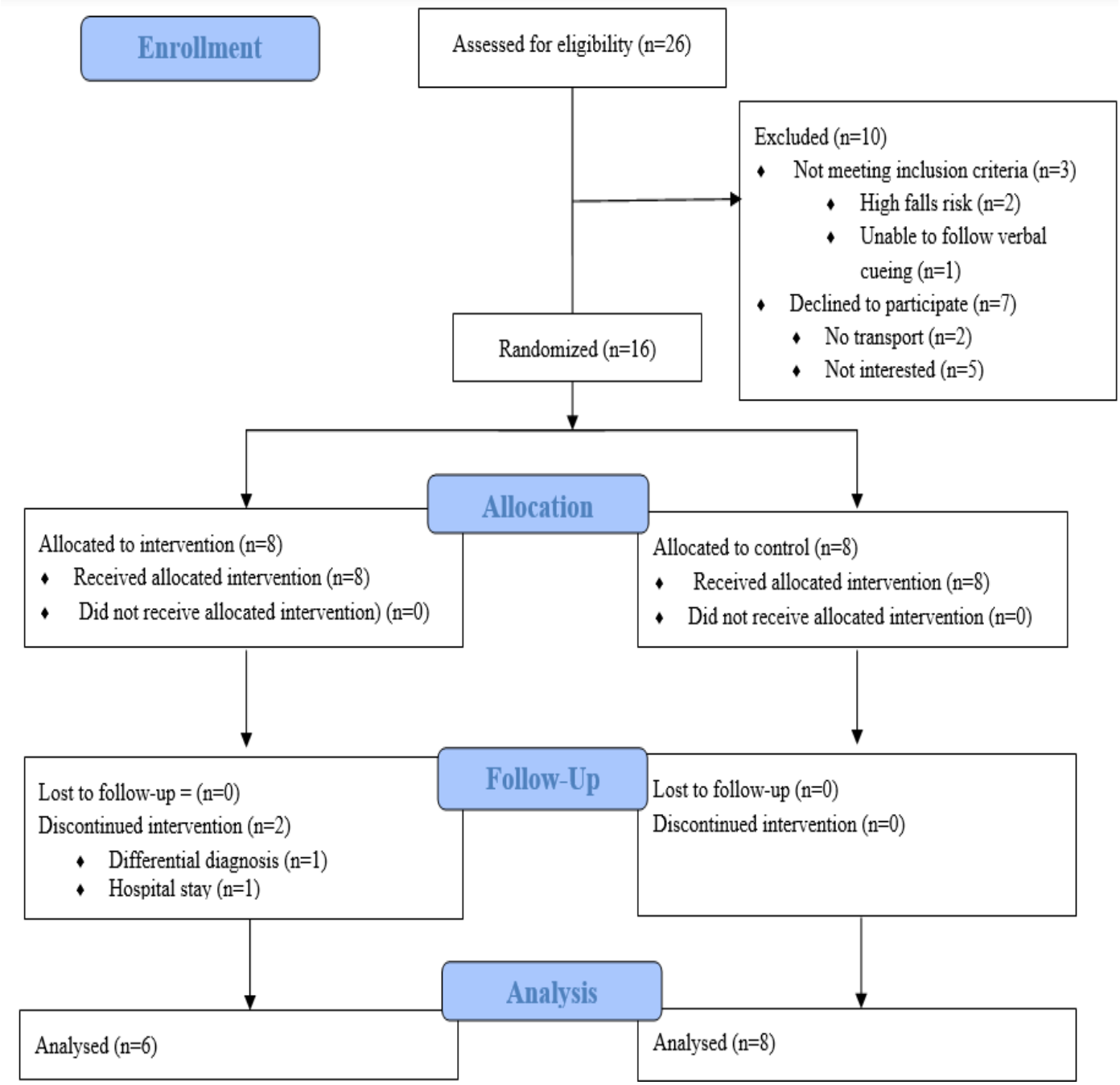


Figure 10.1: CONSORT Flow Diagram

Table 10.1: Baseline Demographics and baseline outcomes

	PEEP+BC (n=8) Median [IQR]	PEEP (n=8) Median [IQR]
Age *(years)*	72 [66.3 - 77.8]	68.5 [56.5-81.5]
Height *(cm)*	172.5 [165.3-179.8]	175.5 [172.6-178.4]
Weight *(kg)*	78.1 [66.6-89.6]	91.9 [79.2-104.6]
Sex *(M/F)*	6/2	6/2
UPDRS Part III Motor Exam	14.5 [3-26]	12 [20.5-3.5]
PDQ-39 SI	2.5 [-1.9-6.9]	5.5 [2.5-8.5]
ESES	31 [25.8-36.3]	34 [25.5-42.5]
SPPB	11 [7-15]	10 [8.8-11.3]
TUG (*seconds)*	9.9 [4.5-15.2]	10.0 [7.8-12.2]
5TSTS *(seconds)*	13.7 [8.6-18.8]	12.1 [5.8-19.3]
6MWT *(m)*	337.5 [268.5-406.5]	337.5 [222.8-452.3]
Walking activity (SAM) *(average daily step-count)*	7880.5 [2755.3-13005.8]	8594 [2286.2-14901.8]
Grip strength *(kg)*	R 25.9 [19.9-31.0] L 20.9 [17.1-24.7]	R 26.6 [15.2-38.0] L 25.8 [18.9-32.7]

IQR = interquartile range, **cm** = centimetre, **kg** = kilogram, **M** = male, **F** = female,
UPDRS = Unified Parkison's disease rating scale (range 0-132, ≤32 indicates mild disease)[257]
PDQ-39 SI = Parkinson's disease Questionnaire-39 Summary Index (range 0-19.5, higher indicates worse)[249]
ESES = Exercise Self-Efficacy Scale (range 10- 40, higher indicates better)[234]
SPPB = Short Physical Performance Battery (range 0-12, higher indicates better)[244]
TUG = Timed Up and Go (<10 seconds indicates normal mobility; >11.5 seconds indicates a falls risk in Parkinson's disease)[258],
5TSTS = Five time sit to stand (> 16 sec indicates falls risk in Parkinson's disease)[256]
6MWT = 6-minute walk test, **m** = metres, **R** = right, **L** = left.

10.4.2 Recruitment process and resulting sample characteristics

Overall, the recruitment process was satisfactory with an uptake rate of 62% (see Figure 10.1, seven declined to participate (five were not interested and two had no transportation). Participants (age 56.5 - 81.5 years) were mostly male (75%), with low levels of disability, and relatively high self-efficacy and quality of life (see Table 10.1). The control group were heavier in weight (median +14kg heavier) and walked more (median +713 steps per day) at baseline, suggesting they may have been a more robust group.

10.4.3 Feasibility of study procedures

Baseline data collection took approximately 30 minutes per visit (total 15 hours), and methods were acceptable for both staff and participants. Two participants found the phrasing of the PDQ-39 and ESES questionnaires unclear, but with simple explanations,

could complete them independently. Three needed assistance to write answers.

We used the SAM and APDM to measure outcomes. The SAM were easy to use, requiring little set-up time. One participant found the SAM uncomfortable at night, hence they removed it nightly. We used the APDM to measure gait and balance. The time to calibrate, set-up and analyze the data was lengthy, and did not provide any additional data than a simple timed test.

10.4.4 Adherence and fidelity to the programme

Overall, attendance (exercise and education) for both intervention and control groups was high (see Table 10.2, Figure 10.2, Figure 10.3). Reasons for non-attendance included personal reasons (35%), illness (31%), unavailability (27%) and unspecified reasons (15%). Attendance showed that the PEEP group attended their education sessions (71% (68/96) noticeably less than their exercises sessions (81% (78/96)). Home exercise adherence showed considerable differences between the groups. The PEEP+BC participants adhered better to the twice-weekly prescribed home exercises than the PEEP group (70% (135/192) vs 63% (120/192)). Furthermore, most PEEP+BC participants completed additional home exercises, exercising at least four times weekly by the end of the programme. Conversely, some PEEP participants did not complete any of their home programme (n=3); while the rest remained at twice weekly sessions (n=5).

Table 10.2: Participant level attendance

PEEP + BC			
Participant ID	% exercise attended (classes offered, n=12)	% education attended (classes offered, n=12)	% Overall Attendance (exercise + education classes offered n=24)
ID1	83	83	83
ID2	75	92	83
ID3	92	92	92
ID4	100	92	96
ID5	50*	8*	29
ID6	92	92	92
ID7	50**	33**	42
ID8	92	92	92
% Total PEEP+BC class attendance (total number of classes attended/total number of classes offered)	79	73	76
% PEEP+BC class attendance *excluding dropouts (ID5 and ID7)*	89	90	90
PEEP			
Participant ID	% exercise attended (classes offered, n=12)	% education attended (classes offered, n=12)	% Overall Attendance (n=24 exercise + education classes)
ID9	67	58	63
ID10	83	75	79
ID11	100	92	96
ID12	83	42	63
ID13	92	75	83
ID14	67	75	71
ID15	75	67	71
ID16	83	83	83
% Total PEEP class attendance (total number of classes attended/total number of classes offered)	81	71	76

*ID5 100% (6/6) attendance to exercise; 17% attendance for education (1/6) before excluded at week 7 with a serious medical condition preventing safe exercise
**ID7 100% (6/6) attendance to exercise; 67% attendance for education (4/6) before excluded at week 7 with a diagnosis of atypical Parkinson's disease

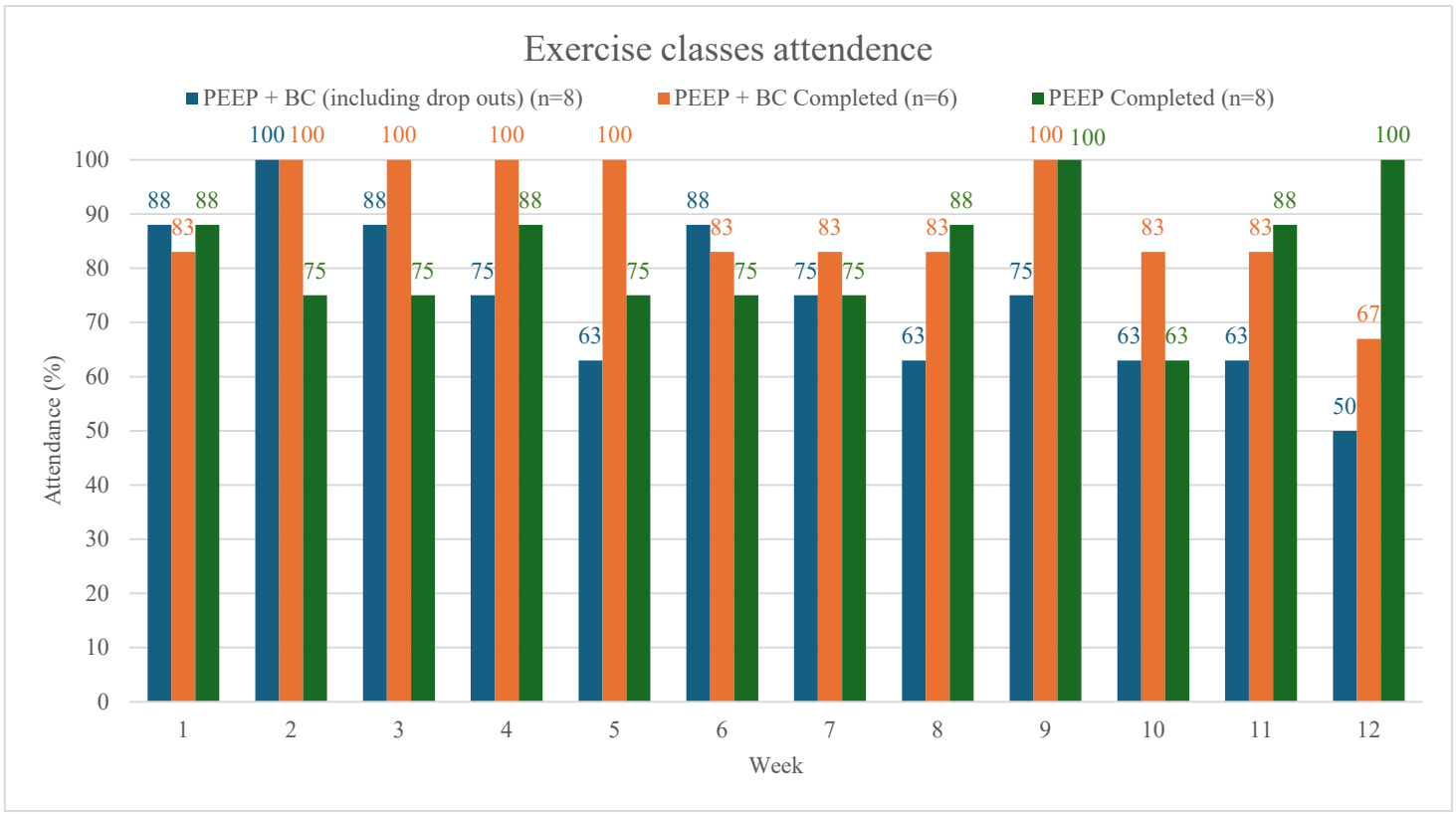


Figure 10.2: Attendance rate per group (exercise classes)

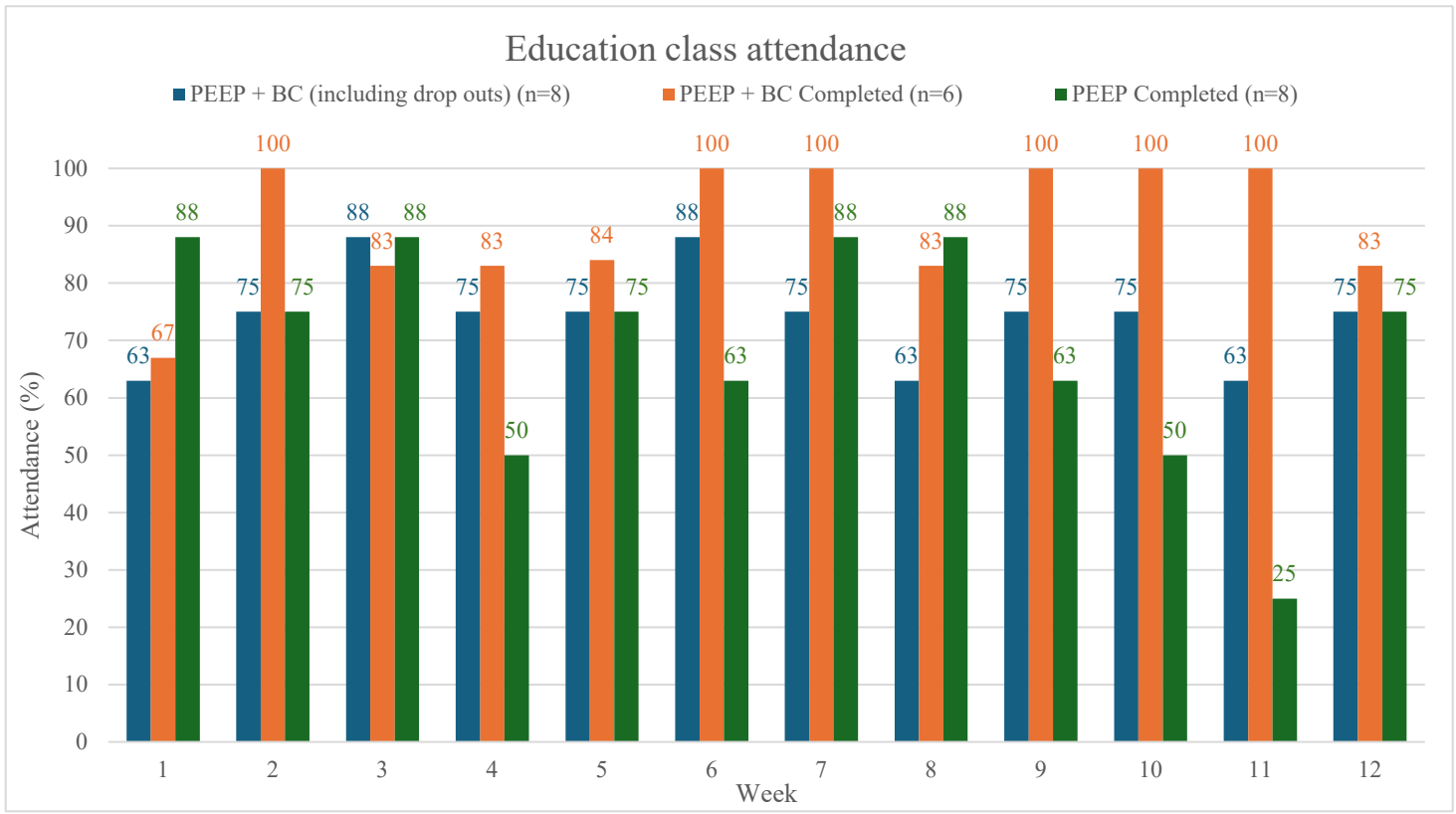


Figure 10.3: Attendance rate per group (education classes)

In the exercise class, PEEP+BC participants showed improving confidence with the weekly exercise progressions (any progressions were noted in the exercise logs); at Week 6, participants started leading the classes with some prompting. By Week 10, the participants were fully leading the exercise classes with supervision only, while PEEP participants required encouragement and prompting through the programme entirety.

10.4.5 Acceptability of the exercise intervention

The feedback surveys and exit interviews showed that all participants enjoyed the exercise programme, e.g. *"it is the best exercise class I have been to since [diagnosis]…. other classes…aren't hard enough"* and would recommend it to others. Most reported they would continue with the classes if available, and all reported they plan to continue exercising after the programme. All participants agreed that 12 weeks was appropriate for the programme. *"…the 12 weeks is fine, to make it any shorter wouldn't do it justice. There is a lot in the programme, and I think the progressions are nice and subtle every week".* Any longer *"would be taxing"* and *"would lose the focus".* All participants reported enjoying the group classes, e.g. *"there was a good spirit generated ……there was a very, very good atmosphere, a kind of a fun atmosphere."* Some found peer support in class was key to maintaining exercise intensity, e.g. "*It was never hard [exercising at home] because you were doing it on your own…you would be nice to yourself … as opposed to in the class"* and *"I was glad to [have] monitoring there. It kept you going."* and *"…being in the group was very helpful*." Most PEEP+BC participants enjoyed the additional dual-cognitive tasks in the last six weeks, *"And then when we did the cognitive bit…that was excellent…it made it a bit more interesting."*

10.4.6 Acceptability of the multidisciplinary education

The results of the survey showed that all participants indicated the sessions were appropriate and helpful (12/12 100%). In the exit-interviews, most preferred the exercise and education

classes on the same day, especially those who travelled a distance. Other suggestions included: limiting the education sessions to fortnightly (on the same day as the exercise classes); combining some education sessions; making them interactive; including support services education for carers; and a debrief session (facilitated by the physiotherapist) after the education sessions in smaller groups to discuss the information they learned.

10.4.7 Acceptability of behaviour change techniques (PEEP+BC only)

Completion of the ***activity diary*** was mixed (one was 0% completed, two were 50% completed, and three were 100% completed), with all but one returned post-assessment, but with varying levels of completion. Many reported it as most important as it created "*structure", "routine"* and *"accountability".* Participants *"did not want to leave a blank space".* Despite it being viewed as a "*chore*" by some, it was valued, and they suggested changes in wording, removal of unimportant headings, and the use of more tick boxes.

Most participants reported the ***WhatsApp group*** as the least important and used it to enquire rather than for peer support. Barriers included difficult with texting, *"not good with technology".* All the participants preferred the peer support in class; reporting the break time between sets helped build a rapport. "*You know, I think among the three of us, there was a good relationship, and I just feel we didn't need the WhatsApp you know."*

One participant reported ***education*** as most important because *"it provided understanding why…and provided context and meaning".* However, some keen exercisers, reported *"no real benefit"*; *"I suppose we all had a fair idea…before we started*".

Only two participants reported **goal setting** as the most important behaviour change technique, they *"liked the accountability of having the goals reviewed"* and enjoyed *"learning the skills to adapt and modify goals".* However, difficulties remembering their goals existed also.

Most participants showed good ***self-management skills*** by completing their exercise logs independently from Week 4 onwards, with many documenting sets and reps at home. Most found the **Rate of Perceived Exertion scale** very helpful to determine the exercise intensity and planned to continue its use. Three participants enjoyed taking responsibility in leading the classes as the programme progressed "*it brought a fun competitive atmosphere" and "ownership of a particular exercise*". "*Testing your cognitive function as well as your physical fitness…I really enjoyed that*".

Safety

No serious adverse events (e.g., falls, injuries) occurred in the classes. Two reported delayed shoulder and arm muscle soreness, which fully resolved. Beyond the classes, muscle soreness (unattributed to the programme) (n=1), non-injurious falls (n=1), and a fall with a long lie resulting in hospital admission (n=1) were reported.

10.4.8 Trends in the outcomes (Table 10.3)

The ***SAM, 6MWT, TUG*** and ***5TSTS*** tests detected within-group improvements. The PEEP+BC ***SAM*** showed increased walking activity (+1697 steps), reaching the minimal clinical importance difference (MCID) of 800 steps/day.[259] Furthermore, the group walked notably faster (+0.22 m/s), reaching the MCID for a large improvement of 0.22m/s.[260] No notable changes were detected in PEEP group ***SAM*** data (+97 steps/day).

The ***6MWT*** detected improved walking endurance in both groups (PEEP +56m; PEEP+BC +43m), both exceeding the MCID of 30.5m.[236] ***TUG*** improvements did not reach the MDC of 3.5 secs (PEEP -1.06 secs; PEEP+BC -1.05 secs).[258] The ***5TSTS*** improved in both groups, (PEEP -3.7 secs; PEEP+BC -2 secs); with only the PEEP group reached the MCID of 2.4 secs.[261] Similarly, the ***SPPB*** showed clinically meaningful (MCID of 1)[262] improvements in the PEEP group only (PEEP +1.5; PEEP+BC +0.5).

The ***PDQ-39 SI*** scores, near minimal scores at baseline, showed small changes in both groups. Similarly, the ***ESES***, near maximum score at baseline, detected only small changes, with slight improvements in the PEEP+BC group (+1.67), and declines in the PEEP group (-0.875). These extreme scores in the ***PDQ-39 SI*** and ***ESES*** at baseline may have limited their scope to detect improvements. Issues in scheduling, transport and illness led to APDM Mobility Lab system^{TM} data being collected on three participants only (n =2 in PEEP + BC group; n = 1 in PEEP group) Therefore, this limited data was not used in the analysis. The simple timed results are presented in *Appendix C5*.

Table 10.3: Overview of assessments

	PEEP + BC (n = 6)		PEEP (n = 8)	
Outcome Measure	Post-intervention Median (IQR)	Δ	Post-intervention Median (IQR)	Δ
PDQ-39 SI [0-19]	2.75 [0.2-5.4]	+0.3	4.07 [2.4-5.8]	-1.4
PDQ-Mob	12.5 [-6.9-31.9]	+5.0	18.75 [-1.3-38.8]	-7.5
PDQ- ADLs	6.24 [2.0-10.4]	+4.2	14.59 [5.2-24.0]	0
PDQ- Emot Well	31.25 [9.4-53.2]	+10.4	25 [17.7-32.3]	-10.3
PDQ- Stig	6.25 [-7.9-20.4]	-12.5	12.5 [-7.8-32.8]	0
PDQ- SS	8.32 [2.0-14.6]	+8.3	8.33 [-8.0-24.6]	-4.2
PDQ- Cog	12.5 [0-25]	-6.5	21.88 [-0.02-43.9]	-9.5
PDQ- Comm	12.5 [-7.6-22.6]	-8.5	25 [22.9-27.1]	+8.3
PDQ- Body Dis	16.67 [-6.2-39.6]	-0.2	29.17 [12.3-46.6]	-12.5
ESES [0-40]	32.5 [26.3-38.8]	+1.5	30.5 [26.8-32.3]	-3.5
SPPB [0-12]	12 [0]	+0.5	11.5 [9.8-13.3]	+1.5
TUG (secs)	7.15 [6.1-8.3]	-1.1	8.52 [6.4-10.6]	-1.4
5TSTS (secs)	9.77 [8.4-11.1]	-2.0	8.43 [6.4-10.5]	-3.7
6MWT (metres)	399 [361.5-436.5]	+43	393.5 [314.3-472.8]	+56
Walking Activity (steps/day)	11074 [5559.2-16588.8]	+1697	8691 [7157.2-10224.8]	+97
Gait Speed (m/s)	1.28 [1.0-1.6]	+0.2	1.26 [1.0-1.6]	+0.2
Grip Strength (kg)	R 23.8 [14.9-32.7]	+0.1	R 26.7 [17.0-36.4]	+0.1
	L 23.3 [9.4-37.2]	+2.6	L 25.7 [20.0-31.3]	-0.1

PDQ-39 SI = Parkinson's disease Questionnaire-39 Summary Index (0-19.5, higher indicates worse)[249] **Mob** = Mobility, **ADLs**= Activity Daily Living, **Emot Well** = Emotional Wellbeing, **Stig** = Stigma, **SS** = Social Support, **Cog** = Cognition, **Comm** = Communication, **Bod Dis** = Bodily Discomfort, **ESES** = Exercise Self-Efficacy Scale (10- 40, higher indicates better)[234], **SPPB** = Short Physical Performance Battery (0-12, higher indicates better, MCID=1)[244], **TUG** = Timed Up and Go (<10 seconds indicates normal mobility; 11.5 seconds indicates a falls risk in Parkinson's disease, MDC 3.5)[258], **5TSTS** = Five time sit to stand (normative values 60-69 yrs: 11.4 seconds; 70-79 yrs: 12.6 seconds; 80-89 yrs: 14.7 seconds, > 16 sec indicates falls risk in Parkinson's disease)[256] **6MWT** = 6-minute walk test (metres) (MCID 30.5m)[248]. **IQR** = Interquartile range, **m** = metres, **m/s** = metres per second, **kg** = kilogram, **R** = right, **L** = left, Cohens' d = Effect size (small (d = 0.2), medium (d = 0.5), and large (d = 0.8)) * = significance level p< 0.05

10.5 Discussion

This study aimed to examine the feasibility and acceptability of adding BC techniques to an existing exercise and education programme. Recruitment was feasible, at 62% (16/26), the time and staff resources are acceptable and similar to routine care. The overall programme is acceptable and safe, with good adherence and no clear concerns about adverse events. Qualitative data showed that it was acceptable with positive feedback and good suggestions from participants. Outcome measures are feasible, and the most sensitive measures have been identified.

10.5.1 Recruitment

Recruitment rates were good (62%, 16/26). However, at baseline participants reported good exercise self-efficacy and low impact of Parkinson's disease on their QoL, and a low score in the UPDRS Motor Exam. These factors may have hindered the ability to detect improvements in QoL and self-efficacy. Therefore, future studies should widen the sample of participants, by recruiting through Parkinson's disease support-groups (and the health services) and recruit people with poorer physical function. We will consider involving family members/carers, to allow familiarity with the exercises and to encourage family support when exercising at home.

10.5.2 Behaviour change techniques

The ***activity diary*** was viewed cumbersome by some but as the most important BC technique by most participants. Helpful suggestions included providing tick box exercise options; and embedding the goals into the activity diary to help self-monitoring of progress.

The exit-interviews gave useful insights into the individual's motivation to exercise. Some women explained how the weekly diary review encouraged exercise (extrinsic motivator) while others (both men and women) found it stimulated routine, accountability and the "*feel*

good factor" (intrinsic motivator). Good self-efficacy at baseline may have hindered detection, but the BC techniques appeared to influence self-efficacy. While ***most*** of the control group reported lower self-efficacy, ***most*** in the intervention group reported higher self-efficacy (they displayed extrinsic motivation in the interviews). Haughton McNeil *et al*.[263] highlighted a positive association between intrinsic motivation and self-efficacy, suggesting that enhancing exercise self-efficacy and identifying motivation type is important when considering BC techniques.

Social engagement during the in-person group sessions helped all participants to push themselves and it made the sessions enjoyable. The WhatsApp group seemed superfluous.

Goal setting was deemed important by two participants; reporting it promoted exercise adherence. Research has highlighted a strong association between goal setting, physical activity, and self-efficacy.[264,265] Hence it will be reviewed to make it meaningful and continued as good practice.

Participants who were keen exercisers did not value the ***exercise specific education*** as much as others. Self-selecting and recording exercise intensity/progression at home was mixed, suggesting lack of confidence, or lack of interest. More support to participants to independently record sets and repetitions will be developed for future studies. Most participants highly valued the Rate of Perceived Exertion[196] (RPE) to monitor their exercise intensity. Collado-Mateo *et al*.[266] found improved knowledge and skills about exercise improves self-efficacy[267,268], which can lead to better adherence.[269,270] Therefore, the education should be tailored to the patients baseline knowledge, and tools such as the RPE can be valuable.

Our ***outcome measures*** included SAM (walking activity), ESES (exercise self-efficacy), 6MWT (aerobic endurance), SPPB (balance), and PDQ-39 (QoL). The PEEP+BC group

showed small improvements in walking activity, aerobic endurance and balance. However, both the ESES and PDQ39 SI showed floor/ceiling effects, as the participants had low disability. Generic measures may detect improvements better, such as the exercise self-regulation questionnaire which can also indicate motivation type and the EQ5D to measure health status. The APDM would not be used in future studies, and is more suited to monitor disease progress, as recommended.[235]

10.5.3 Strengths and limitations

This study aimed to test the feasibility and acceptance of the programme with BC techniques. Outcome assessments were not blinded. Although efforts were made to limit contamination, we cannot guarantee it did not occur; we would consider cluster randomization or separate educational sessions for both groups in future studies. Participant numbers were low, the small sample size of both groups limits the transferability of this study. However, the interviews with the PEEP+BC group gave good insight into their experience of the programme, with a direct comparison of the different behaviour change techniques. The effect of external factors, such as unrelated health issues, and emotional or social supports should also be monitored more closely.

The 6MWT was conducted over 10m because a 30m walkway was not available. However, Beekman *et al*.[271] found that people with COPD walked 42.5m less when the test was completed over 10m compared to 30m.[271] This may have impacted our findings, PwPD can experience issues with freezing of gait and difficulty with turning. Therefore, for future studies we will conduct the 6MWT using the recommended 30m walkway.

10.5.5 Future directions

The next step is a larger feasibility study with a larger (e.g., n=60, thirty in each arm, as recommended[272]), more diverse sample (in terms of activity levels). We aim to review and

test more behavioural change techniques aligned to exercise knowledge, preferences and motivations. A longer follow-up period will allow for power calculations. We will aim to recruit a sex balanced sample to further explore the relationship with sex differences and exercise preferences. The activity diary will be altered in line with the participants' feedback, embedding goals within the diary, refining the headings to streamline its completion, providing videos of the exercises and demonstrating to the family members to ensure correct technique is completed at home. The WhatsApp group will be discontinued. The APDM would not be used as it did not provide any further data, and generic measures such as the EQ5D and the exercise self-regulation questionnaire will replace the PDQ-39 and ESES to overcome their ceiling effect.

10.6 Conclusion

The amalgamation of behaviour change techniques with the PEEP Programme was deemed to be feasible and acceptable among PwPD. The addition of the BC techniques showed promise of improvements in physical activity, and feedback was positive. Identifying the participants' type of motivation, and their baseline knowledge about exercise are important when considering BC preferences. The activity diary was deemed the most important activity but requires careful redrafting. The WhatsApp peer support group was considered the least helpful. The participants' suggestions will help refine the intervention, including adaptations to the activity diary, encompassing goal setting, providing videos of the exercises, involving family members more, reducing the number of education sessions, and including information about available support services.

10.7 Data availability

The data sets used and analyzed during this study are available from the corresponding authors on request.

10.8 Funding

This research was co-funded by the Irish Research Council and the Parkinson's Ireland through the Enterprise Partnership Scheme (EPSPG/2021/77).

10.9 Competing interests

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest. The funders had no role in the design of the study; in the collection, analyses, or interpretation of data; in the writing of the manuscript; or in the decision to publish the results.

10.10 Ethics approval and consent to participate

The study was conducted in accordance with the Declaration of Helsinki, and approved by the Clinical Research Ethics Committee of University College Cork [ECM 5 (4) 06/07/2023]

10.11 Consent for publication

Informed consent was obtained from all subjects involved in the study. Written informed consent has been obtained from the patient(s) to publish this paper.

10.12 Trial registration

This study with registered on ClincialTrials.gov NCT06192628. Registered 5th January 2024, https://clinicaltrials.gov/study/NCT06192628

10.13 Acknowledgements

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10.14 Author contribution

Conceptualization, L.A., S.T., S.L. and R.McC.; methodology L.A., S.T., S.L. and R.McC., formal analysis, L.A. and R. McC.; writing—original draft preparation, L.A.; writing—review and editing, R.McC. S.T. and S.L.; supervision, S.T., R.McC. and S.L.; project administration, L.A. and R.McC. All authors have read and agreed to the published version of the manuscript.

Chapter 11

Discussion and Project Conclusions

The overarching aim of this project was to design, develop and test the feasibility of a tailored exercise intervention incorporating behaviour change (BC) techniques to improve self-management, exercise accessibility and adherence in people with Parkinson's disease (PwPD).

In order to achieve this, the project was divided into include three sequential phases.

11.1 Phase 1: Systematic Review

This review aimed to evaluate the potential effects of behaviour change interventions on exercise self-efficacy and adherence in PwPD. Nine databases were searched. Randomised and non-randomised studies reporting the effects of behaviour change on exercise self-efficacy, quality of life, physical function and/or exercise adherence were included. Data was extracted and mapped to the Theoretical Domains Framework (TDF).[53]

The systematic review highlighted the novelty of this concept in exercise therapy for PwPD. Of the eleven studies included, many were at the exploratory phases (n=4 feasibility studies), with small sample sizes ($n \leq 20$ in six studies), or poorer study design (n=2 n-RCT). Interventions were very heterogenous, varying in duration, delivery and BC techniques used. Subsequently, synthesis was challenging, and there is insufficient high-quality evidence to recommend the most effective BC intervention to promote exercise adherence among PwPD. While effective *interventions* could not be identified, the analysis using the TDF brought structure to the synthesis, and helped highlight the *domains* that brought about behaviour change in the studies included.

While the evidence base is weak and novel, by using the TDF, the five domains that brought about behaviour change were identified: *behaviour regulation*, *belief about capabilities*, *social influences*, *reinforcement* and *goals*. The mode of delivery, and duration varied greatly, so to recommend its method of application was not possible. Future work needs to further explore the application of these domains, evaluating their impact and exploring PwPD's perception of their value. A key limitation of using the TDF in this thesis is its limited capacity to capture the dynamic shifts in behavioural determinants over time. In the context of Parkinson's, where both physical function and psychosocial priorities can change, there is a need for more flexible and temporally sensitive approaches. Future work may benefit from integrating TDF with repeated qualitative analysis to guide intervention adaptations that respond to the evolving nature of self-efficacy and adherence. Using theoretical models, such as the self-determination theory can help to guide the adaptations. Furthermore, future trials should be sufficiently powered, with diverse populations recruited, and sufficient follow-up periods to give data on the sustained level of exercise adherence.

This is the only systematic review to date that explored exercises interventions combined with BC techniques to improve exercise adherence among PwPD. A previous meta-analysis conducted by Tennigkeit *et al.*[58] found that BC interventions combined with multi-component disease self-management programmes improved health, mobility, QoL, as well as self-efficacy and depression. However, it remained unknown whether the BC techniques further led to better exercise adherence and more physical activity. Through a small qualitative study with PwPD (n=4) and their caregivers (n=4), Crizzle *et al.*[201] found the main motivators for a hydrotherapy exercise programme included constant reassurance and support from the exercise leader, group structure and group support (extrinsic motivators), and perceived benefits in psychological well-being (intrinsic motivator).[201] However, the focus was on hydrotherapy, and the sample

was small, including people at H&Y stage 2 and 3[201], therefore, missing the perspectives of those with H&Y stage 4 and 5 who may have more difficulties engaging in exercise.[201]

In this thesis, both exercise self-efficacy and self-management were positioned as central outcomes in supporting sustained physical activity among people with Parkinson's. These constructs are interrelated: self-efficacy reflects an individual's confidence in their ability to perform and persist with exercise[61,273], while self-management encompasses the skills and behaviours required to plan, monitor, and adapt physical activity over time.[274] Crucially, both are shaped by underlying motivational processes. The intervention design was primarily informed by Bandura's Self-Efficacy Theory[275,276], which emphasises the role of confidence, mastery experiences, and perceived control in behaviour change. Behaviour change techniques such as goal setting, feedback, and social support were selected for their potential to strengthen self-efficacy and support the development of self-management behaviours.[136]

While Self-Efficacy Theory explains the value of capability as a driver of behaviour change, it does not explain the impact of motivation as a driver of sustained behaviour. Reflecting on this, elements of Self-Determination Theory may have offered a valuable complement. According to Self-Determination Theory, intrinsic motivation — engaging in behaviour for its inherent enjoyment and satisfaction — is strengthened when individuals experience competence, autonomy, and relatedness.[277,278] Therefore, the behaviour change techniques used in the intervention may have also brought about these basic psychological needs. In turn, greater intrinsic motivation would reinforce both self-efficacy and sustained self-management. This relationship is dynamic and reciprocal, and may fluctuate with changing physical capacity, emotional challenges, and shifting personal priorities.[237] Therefore, interventions must be adaptive and personalised, addressing not only behavioural skills but also the motivational mechanisms that sustain engagement over time.

11.2 Phase 2: Qualitative Study

The systematic review identified the five domains that were most effective to promote behaviour change in the included studies. We acknowledge that the research has identified that PwPD have trouble exercising as often as recommended by the World Health Organisation (WHO) guidelines[15] (150 minutes of moderate-vigorous activity per week, 2-3 strength sessions and 1-2 flexibility sessions)[279], and the importance of support systems (family, friends, healthcare professionals) to encourage and facilitate exercise.[60,61,201] Therefore the aim of this second phase was to explore motivation to exercise, and support and self-management needs among PwPD, as indicated by the patients, their family members, and physiotherapists. The TDF was used to structure the discussion and topic guide around their perceptions and views of motivations, barriers, and facilitators of exercise and the needed support systems for long term exercise adherence and physical activity engagement. Discussions on motivation led the questioning to their relationship and experience of exercise suggesting that those who were intrinsically motivated required less external support and encouragement to maintain exercise habits compared to those who were extrinsically motivation. The PwPD discussed how exercise is important, supports are essential but there can be challenges when the person and physiotherapists are not focused on the same goals.

Similar to Crizzle *et al.*[201], this qualitative study only represents high-functioning PwPD which would limit the transferability and generalizability of these findings to the wider Parkinson's disease community. As previously mentioned, the small sample size of both interview groups further limits the transferability of this study. For future studies, a larger sample of family members and physiotherapists should be recruited, by increasing the recruitment time period, and by recruiting through Parkinson's disease support groups (as well as the health services) and private physiotherapy clinics, and recruit people with poorer physical function.

Ultimately, the take home findings from this phase were that PwPD expressed a strong desire to self-manage their condition and voiced the need for healthcare professionals to provide them with the adequate information, skills and tools to give them some ownership and independent self-management of their exercise programmes (under the guidance of the physiotherapist) rather than creating a dependence on services.

11.3 Phase 3: Feasibility Study

The systematic review showed the effective BC domains were *behaviour regulation, belief about capabilities, social influences*, *reinforcement* and *goals*. The qualitative interviews highlighted that differences in exercise preferences existed between men and women, and individuals expressed a strong desire to be more involved in planning their own exercise programme. The findings from the systematic review and the qualitative research together informed the selection of the BC techniques. Therefore, the intervention included four BC techniques (activity diary; peer support; exercise-specific education; goal setting and barrier identification) added to an existing 12-week Parkinson's exercise and education programme.

The feasibility study aimed to examine the feasibility of implementing additional BC techniques within a pre-existing Parkinson's disease exercise and education programme. The findings showed that the intervention is feasible and well accepted among PwPD.

The findings from this feasibility study offer valuable insights to help refine future interventions aimed at improving exercise adherence in people with Parkinson's. While the pilot intervention was grounded in Bandura's Self-Efficacy Theory[275] and showed promise in targeting exercise self-efficacy and behavioural capability, the qualitative feedback suggests a need to revisit the intervention design through a more dynamic and person-centred theoretical lens. Incorporating elements of Self-Determination Theory[277] may strengthen the motivational

foundations of the intervention by addressing intrinsic motivation and the psychological needs of autonomy, competence, and relatedness.

For example, the activity diary was identified by participants as one of the most important components, particularly in fostering structure, routine, and accountability — core features that align with both self-regulation (Self-Efficacy theory) and autonomous engagement (Self-Determination Theory). However, its framing as a "chore" by some suggests that it may need to be re-imagined supporting enjoyment, flexibility, and autonomy; possibly by integrating goal-setting more fluidly or by making the format more user-friendly (such as a tick-box layout as suggested).

Similarly, the WhatsApp group was deemed least useful, largely due to technological barriers and a preference for in-person peer support. This suggests that future interventions should de-emphasise digital platforms and favour of in-person, relational support mechanisms that promote relatedness — a key Self-Determination Theory construct.

The exercise specific education was valued only by those less familiar with exercise, indicating the need personalise these components based on participants' prior knowledge and needs. Likewise, goal setting was positively received when it involved ongoing review and skill-building, supporting its continued inclusion — ideally paired with tailored support to maintain a sense of progress and autonomy.

Further suggestions for adaptation included involving family members in the exercise, to help encourage the home exercises, offering exercise videos, and including information on available local support services for family members, all of which may help reinforce self-efficacy while also aligning with Self-Determination Theory as motivational strategies. Taken together, these findings highlight the need to tweak, tailor, and in some cases re-imagine intervention

components to more effectively meet the changing needs, preferences, and motivational drivers of individuals with Parkinson's.

However, the addition of the BC techniques showed promise in terms of improvements in physical activity, and feedback was positive. The most important aspect to consider when selecting BC preferences is identifying the participant's motivation type, their baseline knowledge about exercise and their exercise preferences. Based on these findings, a flow diagram of the most appropriate BC techniques matched to the corresponding type of motivation was created (Figure 11.1). This flow diagram is only a preliminary guideline for clinicians to help identify specific BC techniques, and tailor the treatment plan to each individual. The type of education and level of detail would be dependent on the individual's baseline knowledge about exercise. The "*other exercise factors"* are key discussion points that should be discussed between the clinician and the individual to allow for a shared role in the development of a treatment plan. The aim is for the individual to lead the discussion regarding their exercise preferences and to identify ways to improve their accessibility, overcome barriers to exercise and for the clinician to facilitate with evidence-based practice regarding the most appropriate type of exercise and exercise intensity.

On reflection, it is important to view these BC techniques not as isolated components, but as interacting elements within a broader system. In this thesis, BC techniques were selected based on theoretically mapped domains; however, the impact of the techniques are most likely influenced by the interaction between the techniques, and also by the individual and their situation. For example, techniques such as goal setting, action planning, and self-monitoring may be more impactful when paired with feedback and social support. Moreover, these interactions do not occur in a vacuum. The success of a given combination of BC techniques may vary depending on the individual's cognitive and physical capacity, emotional readiness, stage of disease progression, and environmental context (e.g., availability of exercise facilities,

carer support, or digital access). This highlights the importance of adopting a dynamic and context-sensitive approach when designing interventions — one that can accommodate the changing needs, preferences, and lived experiences of people with Parkinson's. Future work might explore how adaptive intervention models or iterative co-design methods can complement the structured approach provided by the TDF.

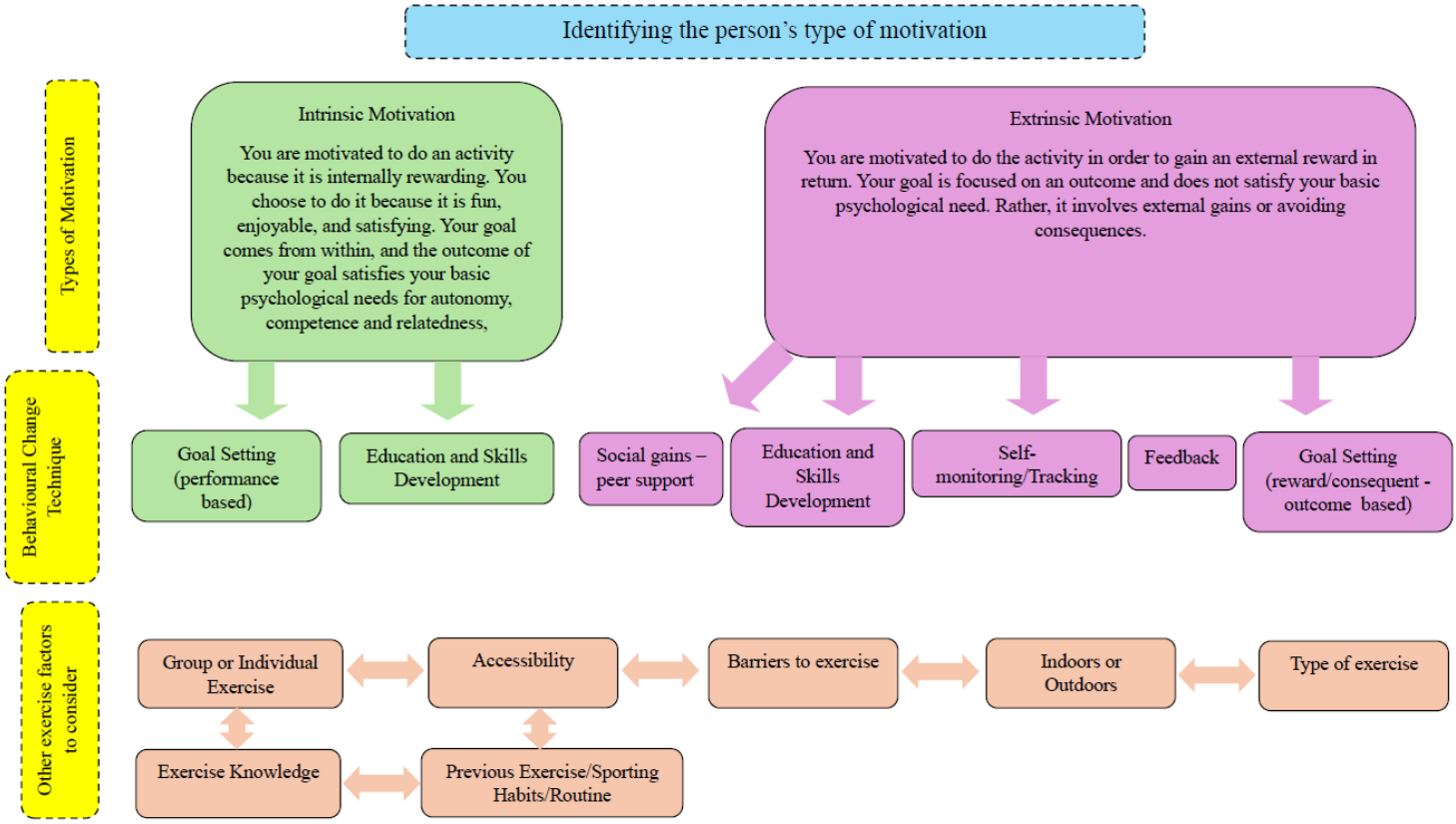


Figure 11.1: Flow Diagram of BC technique matched to motivation type.

The participants for this feasibility study were recruited from the waiting list of the pre-existing Parkinson's disease Exercise and Education Programme (PEEP). While this limits generalisability, it made the study more feasible within the time restrictions of the project, and referrals to the service come from different primary care centres in Cork, GP clinics and acute services. The programme was conducted in the primary care centre, where the PEEP programme has been running 2-3 times a year since 2021 (five previous programmes were

conducted). The recruitment rate for the study was 62% (16/26). The recruitment rate is likely to be slower at other primary care sites, because the study was conducted at the main centre for primary care neurological rehabilitation. Although, there was the wide range of the participants included in the programme, a multi-centre trial, including primary care sites from a wider catchment area is required to confirm generalisability of the results.

The participants recruited to this study showed differences at baseline, especially in weight (kg; PEEP group were a median 14kg heavier) and exercise (the PEEP group walked a median of 713 steps more per day), possibly indicating the PEEP group were more robust and active. Minimal differences were observed in the other measures at baseline (TUG, 5TSTS and 6MWT). A larger sample in future studies will help balance potential confounders, and multivariable analysis may adjust for potential confounders.

Chapter 12

Reflections

12.1 Phase 1: Systematic Review

Since the review was completed, an updated search of the literature did not identify any new publications. The quality of the studies in the review were poor, limiting the ability to conduct a meta-analysis. However, expanding the eligibility criteria would have lost focus of the research question. The use of the Theoretical Domains Framework helped to structure the analysis and identified the most promising domains. On reflection, I would not change the topic of the systematic review as I believe it provided valuable insights which structured the subsequent phases of this project.

To gain insight into people's perceptions of, or the barriers and facilitators to, behaviour change, a qualitative evidence synthesis of PwPD's perceptions of exercise would be valuable. Furthermore, some of the interventions were designed using BC theories, models or frameworks. A systematic review exploring these would provide a deeper theoretical understanding of behaviour change for exercise.

12.2 Phase 2: Qualitative Study

Although the qualitative study conducted a novel approach of exploring motivation, support and exercise self-management needs in people with Parkinson's disease through multiple viewpoints, the findings could be strengthened by increasing the sample size for all cohorts in the study (PwPD, family members, and physiotherapists). In addition to increasing the sample size, a greater diversity of the sample should be recruited, with the aim to recruit *keen exercisers*

and *not keen exercisers*, individuals at different stages of disease progression, male and female physiotherapists, and physiotherapists working in the private sector, from multiple sites.

The TDF was used to structure the topic guides. We focused on the five domains identified from the systematic review, however as the findings of the review are not conclusive, we included the other domains to ensure a comprehensive in-depth exploration of the behaviour change techniques. A framework analysis using the Theoretical Domains Framework was initially planned. However, upon analysing the data, it became evident that the data did not align with the framework, hence thematic analysis was used instead.

12.2.1 Credibility

The interviews (SSIs and group interviews) were conducted by the PhD student, who also works clinically as a physiotherapist. The PhD student has experience of working with PwPD as a physiotherapist and has developed the ability to build a good rapport with the participants to help understand their perspectives and gain nuanced insights into their experiences, behaviours, and beliefs. Although an independent experienced non-physiotherapist interviewer may have reduced bias, the individual's lack of knowledge around the specialist topic could prevent iterative questioning and reduces reflexivity.[280]

To increase credibility, the interviews were video recorded and field notes were taken (triangulation). All interviews began with a brief outline of the study aims and the participants were encouraged to speak openly.

12.2.2 Transferability

Participants were recruited from both urban and rural settings. However, the sample mainly included high functioning individuals, missing those who do not engage in physical activity regularly. The physiotherapists included all worked for the national public health system and did not include those working in the private sector.

12.2.3 Dependability

During data collection dependability was enhanced, interviews were video recorded and transcribed verbatim, with transcripts including non-verbal data in brackets to further illustrate the discussion. A comparison between transcripts and video recordings was conducted to ensure data was correctly interpreted. Dependability was enhanced during data analysis; the data was peer-reviewed by members of the research team when collected. An audit trail of the research decisions, changes, and data analysis processes throughout the study were documented.

12.2.4 Confirmability

Throughout the data collection process, three additional research team members continuously reviewed emergent topics through critical peer review.

During data analysis, credibility and dependability were enhanced; an independent initial coding was conducted by three members of the research team. After this, a consensus meeting discussing emerging themes took place. This process was repeated after recoding and then a peer-review of the final themes took place. A reflexive journal was kept by the PhD student throughout the project.

12.3 Phase 3: Feasibility Study

We chose to conduct a RCT feasibility study for reasons previously outlined in Chapter 8 and 11. However, upon reflection, a feasibility pre-post study may have been more appropriate. The aim of the feasibility study was to determine the feasibility of additional BC techniques to a pre-existing evidence-based programme. I believe implementing the BC techniques and conducting qualitative interviews with all 16 participants would have provided more valuable data regarding the acceptability of the BC techniques and given a better opportunity to explore motivation and BC technique preferences. However, this randomised controlled feasibility

study has demonstrated that for a future trial, randomisation was feasible, and we did not detect deviations from the protocol or contamination between groups. People were willing to be randomised and receive either intervention. To the best of our knowledge no new research has been conducted which would change the findings of this study.

12.4 Clinical implications

There is insufficient high-quality evidence to recommend the most effective BC intervention to promote exercise adherence among PwPD. Future research will examine multi-component BC interventions encompassing the five most effective TDF domains (*behaviour regulation*, *belief about capabilities*, *social influences*, *reinforcement* and *goals*).

Interviews have shown that prompt information sharing and signposting about the condition and available services would be highly valued in a follow-up appointment by PwPD. Prompt access to physiotherapy at the time of diagnosis for early education about exercise self-management, (not after a functional deterioration), may help promote motivation to engage in exercise. In line with the literature, family members are crucial to support exercise, and physiotherapists rely on them especially in cognitive decline. However, frustration can arise when they are "pushing" exercise, rather than supporting exercise.

Explaining the rationale for tailored exercises is important, but people value having ownership and guided independent self-management of their exercise programmes. Exercise intensity is often under prescribed, missing the opportunity to guide people to high intensity exercise, which may have a neuroprotective effect, slowing disease progression. Highly functioning, motivated people feel excluded from challenging exercise. They are signposted to community-based classes or neurological gyms, where they feel underchallenged. When designing a BC exercise programme, differences in exercise patterns and preferences between sexes as well as

the five TDF domains should be considered (targeting an individual's intrinsic motivators and perceived needs).

BC techniques combined with a pre-existing evidence-based exercise programme were considered feasible and acceptable by the PwPD. The group dynamic was universally enjoyed. Clinicians may find profiling the individual's motivation type useful to consider their baseline understanding of exercise to select the appropriate behaviour change technique (e.g. focus on education and goal setting for intrinsically motivated participants; focus on group setting, action planning and exercise logs for those extrinsically motivated).

12.5 Implication for future practice

Originally, we planned for a pilot study as the next step. However, after reflection, I believe another feasibility study is the more appropriate. The intervention is not fully explored or finalised to conduct a pilot study.

Our primary outcome measures were physical activity/exercise adherence and self-efficacy but as the project developed, motivation to exercise emerged as a more important contributing factor than exercise self-efficacy. Additionally, I aim to explore other BC techniques, such as exercise buddies, and provide targeted education to family members on home exercise routines to emphasise consistent at-home exercise. I also would seek to educate physiotherapists on BC training and motivational interviewing. Exploring these aspects is important because BC techniques and motivational interviewing have been shown to enhance patient adherence to exercise programmes[136], particularly in chronic conditions like Parkinson's disease.[237] By educating family members, a supportive home environment that can reinforce daily exercise habits can be prescribed. Engaging physiotherapists through training and interviews will not only deepen their understanding of these techniques but also identify practical challenges and

solutions for integrating them into clinical practice, leading to more effective patient outcomes. Conducting qualitative interviews with physiotherapists about the application of BC techniques and motivational interviewing in clinical settings could yield valuable insights to this research.

Following the larger/modified feasibility study, the next step would be a pilot study with a larger (e.g., n=60), more diverse sample (in terms of activity levels) and longer follow-up period to allow for power calculations, with the aim to recruit a more sex-balanced sample by recruiting from Parkinson's disease support groups and health services to further explore the relationship with sex differences and exercise preferences.

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Appendices

Appendix A

Table A1: PRISMA-P (Preferred Reporting Items for Systematic review and Meta-Analysis Protocols) 2015 checklist: recommended items to address in a systematic review protocol[281]

Section and topic	Item No	Checklist item
ADMINISTRATIVE INFORMATION		
Title:		
Identification	1a	Identify the report as a protocol of a systematic review
Update	1b	If the protocol is for an update of a previous systematic review, identify as such
Registration	2	If registered, provide the name of the registry (such as PROSPERO) and registration number
Authors:		
Contact	3a	Provide name, institutional affiliation, e-mail address of all protocol authors; provide physical mailing address of corresponding author
Contributions	3b	Describe contributions of protocol authors and identify the guarantor of the review
Amendments	4	If the protocol represents an amendment of a previously completed or published protocol, identify as such and list changes; otherwise, state plan for documenting important protocol amendments
Support:		
Sources	5a	Indicate sources of financial or other support for the review
Sponsor	5b	Provide name for the review funder and/or sponsor
Role of sponsor or funder	5c	Describe roles of funder(s), sponsor(s), and/or institution(s), if any, in developing the protocol
INTRODUCTION		
Rationale	6	Describe the rationale for the review in the context of what is already known
Objectives	7	Provide an explicit statement of the question(s) the review will address with reference to participants, interventions, comparators, and outcomes (PICO)
METHODS		
Eligibility criteria	8	Specify the study characteristics (such as PICO, study design, setting, time frame) and report characteristics (such as years considered, language, publication status) to be used as criteria for eligibility for the review
Information sources	9	Describe all intended information sources (such as electronic databases, contact with study authors, trial registers or other grey literature sources) with planned dates of coverage
Search strategy	10	Present draft of search strategy to be used for at least one electronic database, including planned limits, such that it could be repeated
Study records:		
Data management	11a	Describe the mechanism(s) that will be used to manage records and data throughout the review
Selection process	11b	State the process that will be used for selecting studies (such as two independent reviewers) through each phase of the review (that is, screening, eligibility and inclusion in meta-analysis)
Data collection process	11c	Describe planned method of extracting data from reports (such as piloting forms, done independently, in duplicate), any processes for obtaining and confirming data from investigators

Data items	12	List and define all variables for which data will be sought (such as PICO items, funding sources), any pre-planned data assumptions and simplifications
Outcomes and prioritization	13	List and define all outcomes for which data will be sought, including prioritization of main and additional outcomes, with rationale
Risk of bias in individual studies	14	Describe anticipated methods for assessing risk of bias of individual studies, including whether this will be done at the outcome or study level, or both; state how this information will be used in data synthesis
Data synthesis	15a	Describe criteria under which study data will be quantitatively synthesised
	15b	If data are appropriate for quantitative synthesis, describe planned summary measures, methods of handling data and methods of combining data from studies, including any planned exploration of consistency (such as I^2, Kendall's τ)
	15c	Describe any proposed additional analyses (such as sensitivity or subgroup analyses, meta-regression)
	15d	If quantitative synthesis is not appropriate, describe the type of summary planned
Meta-bias(es)	16	Specify any planned assessment of meta-bias(es) (such as publication bias across studies, selective reporting within studies)
Confidence in cumulative evidence	17	Describe how the strength of the body of evidence will be assessed (such as GRADE)

Table A2: Results of the RoB 2 tool[155]

Author(s) (yr)	Random Sequence Generation	Deviations from intended intervention (assignment to intervention)	Deviations from intended intervention (adherence to intervention)	Missing Data	Bias in outcome measurements	Selective Reporting	High/Moderate/Low Risk
Ellis et al. (2019)[159]	Low	Low	Some concerns	Low	Low	Low	Low
Peteet (2002)[165]	High	High	High	Low	Low	Low	High
Tickle-Degnen et al. (2010)[91]	Low	Some concerns	Some concerns	Low	Some concerns	Low	Moderate
van Nimwegen et al. (2013)[166]	Low	Some concerns	Some concerns	Low	High	Low	Moderate

Table A3: Results of ROBINS-I scale[156]

Author (year)	Confounding Effect	Bias in selection of participants	Bias in classification of interventions	Bias due to deviation from intended intervention	Bias due to missing data	Bias in measurement of outcomes	Bias in selection of reported results	Overall bias High/Moderate /Low Risk
Colón-Semenza et al. (2018)[158]	Y	N	NA	N	N	PN	PN	Moderate
Ellis et al. (2013)[52]	PN	PY	N	PN	N	PY	PY	Moderate
Hermanns et al. (2019)[160]	PN	PN	N	PN	NA	N	N	Low
Lai et al. (2020)[161]	PN	N	PN	N	N	N	N	Low
Landers and Ellis (2020)[162]	N	N	N	PN	N	Y	N	Moderate
Lee et al. (2019)[163]	Y	N	N	PN	Y	PY	PY	High
Long (2020)[164]	Y	PY	NA	N	N	PY	N	Moderate
Y=Yes; PY=Partially yes; N=No; PN=Partially No; NA=Not applicable; NI=No information								

Table A4: TDF domains mapped for included studies

Author (year)	Knowledge	Skills	Memory, attention and decision processes	Behaviour regulation	Beliefs about capabilities	Beliefs about consequences	Social/ professional role and identity	Emotion	Intentions	Reinforcement	Goals	Optimism	Environmental context resources	Social Influences
Colón-Semenza et al. (2018)[158] USA														
Ellis et al. (2013)[52] USA														
Ellis et al. (2019)[159] USA														
Hermanns et al. (2019)[160] USA														
Lai et al. (2020)[161] USA														
Landers and Ellis (2020)[162] USA														
Lee et al. (2019)[163] South Korea														
Long (2020)[164] USA														
Peteet (2002)[165] USA														
Tickle-Degnen et al. (2010)[91] USA														
van Nimwegen et al. (2013)[166] Netherlands														
Total	**6/11**	**8/11**	**3/11**	**11/11**	**11/11**	**7/11**	**5/11**	**3/11**	**6/11**	**10/11**	**8/11**	**0/11**	**8/11**	**11/11**
Bold =studies with significantly positive findings														

Table A5: TDF domains and component constructs identified in the included studies.

TDF Domain	COMPONENT CONSTRUCTS
Knowledge	**Education of condition[160,164,165], communication[91], mobility[91], exercise and physical activity[91,164,166]**
Skills	**Skill development[52,91,160,164,166], self-management skills[52,91,160,164,166], coping strategies[91,160,165], competence[161,162,164], transfer training[35]**
Memory, attention, and decision processes	**Decision making[163,165], problem solving[52,165]**
Behaviour regulation	**Action planning[91,161-165], activity tracking[52,158,160,164,166], self-monitoring[159,162,164,166], breaking habit[163,166], feedback[158,159,164,166]**
Beliefs about capabilities	**Perceived competence[52,158-162,164-166], empowerment[52,158,159,162,165 19,36,37,40,41,43], identification of prompts/cues for successes[163], self-confidence[52,158,159,161,162,164,165], self-efficacy[158,163], beliefs[91,161,164,166] pleasant change[163]**
Beliefs about consequences	**awareness of actions[52,91,158,164], negative consequences[91,163,164,166], unpleasant change[163]**
Social/ professional role and identity	**Leadership[91,160,165], Group Identity[91], Organizational commitment[91,160,163,166], Professional role[160,163-166]**
Emotion	**Stress management[91], relaxation[91,165]**
Intentions	**Promote health behaviour change[52], transtheoretical model of change[164-166], stages of change[164], theory of planned behaviour[91]**
Reinforcement	**Incentives[158,159], reinforcement[52,159-162,164,166], rewards[163]**
Goals	**Long[52,166] and short-term goal setting[52,158,159,161,163,164,166], goal setting[91]**
Optimism	
Environmental context resources	**Barrier identification[52,91,158,161,163-166]**
Social Influences	**Recruiting social supports[166], social support[52,158,159,162-164,166], social comparisons[158,165,166], online support group[160], online verbal support[161], feedback[163-165]**

Table A6: Results for studies investigating quality of life and physical function outcomes.

Article Author (year)	Outcomes Outcome(s) of interest	Conclusions Results
Ellis et al.(2013)[52] *Multi-component Behaviour Change Components: Technology + Support Groups*	6MWT; Gait speed; Self-selected walking speed	Walking distance improved significantly in the 6-MWT, from a mean (SD) distance of 459.5 (91.9) m at baseline to 484.1 (85.3) m after the intervention (P=0.02). Self-selected walking speed improved from a mean (SD) of 1.19 (0.2) m/sec at baseline to 1.26 (0.18) m/sec after the intervention (P=0.02). In addition, the baseline maximum walking speed improved from 1.66 (0.32) m/sec to 1.77 (0.32) m/sec after the intervention (P=0.02). On the basis of minimal clinically important differences of 50 m for the 6-MWT and 0.1 m/sec for the 10-m walk test derived from the geriatric population, the results in this study reveal a clinically meaningful change of 0.11 m/sec in the maximum walking speed. Changes of 24 m in the 6-MWT and 0.07 m/sec in the 10-m self-selected condition did not exceed the minimal clinically important difference.
Ellis et al. (2019)[159] *Behaviour Change Component: Technology*	PDQ-39 6MWT	*Quality of Life* PDQ-39 mobility domain scores for the mHealth group declined from baseline to 12 months, which reflected improved mobility (−1.7 points, 95% CI=−4.4 to 1.1). While the active control group scores increased by 2.1 points (95% CI=−0.76 to 5.0). The between-group difference did not cross the threshold level of .05 α (estimated mean change: −3.8 points, 95% CI=−7.8 to 0.2; p=0.06); however, the magnitude of the difference was clinically meaningful. Participants with lower activity at baseline reported better mobility-related quality of life in the mHealth condition compared with the active control condition, with a statistically significant and clinically meaningful difference in the change in PDQ-39 mobility over 12 months between groups (−8.2 points, 95% CI=−15.4 to −0.9; p=0.03). *Physical Function* The change in 6MWT from baseline to 12 months (3.8 m 95% CI=5.1-62.5) was statistically significant (p =0.02) and could be considered clinically meaningful for the mHealth group but not the Active control group (5.3 m, 95% CI=−25.6 to 36.2) However, the difference in the change scores between groups was not statistically significant (28.5 m, 95% CI=−14.4 to 71.5; p =0 .19). *Less active participants* There was a nonsignificant between-group difference in improved distance walked (23.4 m, 95% CI=−49.4 to 96.3; P=.51); however, within-group changes in the mHealth group were similar to those in the whole sample (29.1 m, 95% CI=−16.8 to 75.0; P=.20) although this improvement was not significant.
Hermanns et al. (2019)[160] *Multi-component Behaviour Change Components: Technology + Support Groups*	Functional Assessment of Cancer Therapy-General	Percentage of change findings suggested that the physical activity tracker and electronic tablet intervention did not have a significant effect on participants' QoL (percentage change: -3.18).
Lai et al. (2020)[161] *Behaviour Change Component: Technology*	Walking Capacity	All TAE participants exhibited a small to moderate increase (range: 2-101 m) in distance achieved on the 6MWT, with a mean increase of 35 m from baseline. TAE participants also displayed improvements in comfortable walking speed and fastest walking speed with a mean change of 0.31 (0.77) m/sec and 0.16 (0.63) m/sec from baseline respectively. Whereas SRE participants appeared to have a more variable response (changes in walking distance ranged from -67 to 83 m), with a mean increase of 1.35 m from baseline. SRE displayed decreases in comfortable walking speed and fastest walking speed with a mean change of -0.11 (0.67) m/sec and -0.002 (0.41) m/sec from baseline respectively.
Landers and Ellis (2020)[162]	PDQ-8	*Quality of Life* The PDQ-8 improved from the baseline, mean 6.8 (SD 5.0), to the 8-week measurement, mean 4.1 (SD 5.0; P= 0.01; Hedges g=0.53; 95% CI 0.14-0.94). At the 8-week point, 6/28 (21%)

Behaviour Change Component: Technology	**30-second STS** **Timed Up and Go**	**improved beyond the MDC on the PDQ- 8.** **The results of the ANOVAs (baseline, 8-week, and 12-week measurements) suggest that there were no additional improvements from the 8-week to the 12-week measurement points for the PDQ-8 (P=0.94).** **There were no statistically significant interactions for the factorial ANOVAs to test dosing effect: STS (P=0.39), TUG (P=0.41), and PDQ-8 (P=0.86). Likewise, there were no statistically significant correlations for the average time of app exercise usage and change scores on the STS (r=-0.148, P=0.45), TUG (r=0.113, p=0.57), and PDQ-8 (r=-0.017, P=0.93).** ***Physical Function*** **There was a statistically significant improvement at both 8 and 12 weeks. The STS improved from the baseline, mean 11.6 (SD 4.0), to the 8-week measurement, mean 14.3 (SD 4.7; p=0.01; Hedges g= 0.59; 95% CI 0.16-1.04). At the 8-week point, 15/28 (54%) improved beyond the MDC on the STS.** **The TUG improved from the baseline, mean 11.2 (SD 3.9), to the 8-week measurement, mean 8.5 (SD 2.6; P<0.001; Hedges g=.80; 95% CI 0.46-1.18). At the 8-week point, 8/28 (29%) improved beyond the MDC on the TUG.** **The results of the ANOVAs (baseline, 8-week, and 12-week measurements) suggest that there were no additional improvements from the 8-week to the 12-week measurement points for the STS (P > 0.99), TUG (P > 0.99),**
Lee et al. (2019)[163] **Behaviour Change Component: Support Groups**	**PDQ-39** **30-second STS** **TUG** **Berg Balance Scale** **6MWT**	***Quality of Life*** **The intervention group displayed overall improvements health-related QoL from baseline (38.75 (20.28)) to postintervention (32.63 (17.99)) to 16-week follow-up (30.45 (14.52)). While the control group displayed poorer QoL from baseline (26.72 (13.47)) to postintervention (32.55 (19.84)) to 16-week follow-up (30.11 (16.47)). There was a significant difference found between the groups for overall health related QoL (p=0.012) and the subscales of stigma (p=0.023), cognition (p=0.028), communication (p=0.014) and social support (p=0.003)** ***Activities of Daily Living*** **The intervention group displayed improvement in ADLs from baseline (76.36 (23.21)) to postintervention (81.58 (13.02)) to 16-week follow-up (82.63 (14.85)). The control group displayed a smaller improvement from baseline (80.00 (14.91)) to postintervention (84.67 (15.52)) with a small decline from postintervention to 16-week follow-up (82.94 (10.47)). There were no significant differences found between the groups (p=0.406)** ***Functional Fitness*** **The intervention group displayed improvements in leg strength (baseline: 12.48 (2.98); postintervention 13.67 (2.57); 16-week follow-up 13.28 (2.95)), mobility (baseline: 9.44 (1.52);** **postintervention 8.08 (1.66); 16-week follow-up 8.27 (1.85)), balance (baseline: 52.32(2.77); post intervention 53.63 (3.00); 16-week follow up 53.63 (2.69)) and cardiopulmonary endurance (baseline: 398.04 (75.81); postintervention 427.05 (82.98); 16-week follow-up 434.34 (82.52)) from baseline to 16-week follow-up** **While the control group also displayed improvements in leg strength (baseline: 11.28 (3.30); postintervention 12.27 (3.65); 16-week follow-up 15.44 (2.56)), mobility (baseline: 9.41 (2.83); postintervention 8.75 (2.02); 16-week follow-up 6.95 (1.56)), balance (baseline: 51.89 (3.40); postintervention 52.87 (4.42); 16-week follow-up 54.12 (2.26)) and cardiopulmonary endurance (baseline: 401.69 (72.24); postintervention 433.89 (82.12); 16-week follow-up 460.15 (72.55)) from baseline to 16-week follow-up. There were no significant differences found between the groups for any of these variables (Leg strength p=0.874, mobility p=0.541, balance p=0.699 and cardiopulmonary fitness p= 0.258)**

Peteet (2002)[165] **Behaviour Change Components: Behaviour Techniques and Education**	**Functional Reach Test** **Timed Up and Go Test** **Berg Balance Scale**	***Physical Function*** **Both experimental and control groups did not demonstrate a statistically significant change between the two groups in either the Timed Up and Go test (p=0. 126) or the Functional Reach test (p= 0.135)**
Tickle-Degnen et al. (2010)[91] **Behaviour Change Component: Education**	**PDQ-39**	***Quality of Life*** **Those who overall HRQOL scores improved when receiving rehabilitation (18 or 27 hours) were compared with those whose scores improved when receiving no intervention (0 hours).** **A decrease of at least 5.39 points on the summary index (a reduction in problems) was used as the criterion for clinically relevant improvement. Rates of improvement were greater for rehabilitation versus no rehabilitation at post and 6 months follow-up, with a smaller difference at 2 months.** **At immediately post-test,54% of participants in rehabilitation were improved versus 18% receiving no rehabilitation. The difference of these two rates is 36%, the absolute benefit increases due to rehabilitation (95% CI 5 20- 53%; p < 0.0001)).** **At 2 months follow-up, 34% of participants in rehabilitation were improved versus 20% of those who did not receive rehabilitation (p=0.11)** **At 6 months, 38% who received rehabilitation were improved versus 10% of those who received no rehabilitation (p < 0.001).**
van Nimwegen et al. (2013)[166] ***Multi-component Behaviour Change Components: Technology + Behaviour Techniques + Education + Support Groups***	**PDQ-39** **6MWT**	***Quality of Life*** **Quality of life did not differ between the groups (adjusted group difference -0.9 points, 95% CI -2.1 to 0.3; p =0.14)** ***Physical Function*** **ParkFit participants increased their physical function compared with controls (6MWT adjusted group difference 4.8 m, 95% CI 0.1 to 9.6; p=0.05).**

SD=standard deviation; PD=Parkinson's disease; 6MWT=6-minute walk test; PDQ-39=Parkinson's disease Questionnaire-39; PDQ-8=Parkinson's disease Questionnaire-8; 95% CI=95% Confidence Interval; NR=Not reported; STS=sit to stand; QoL=Quality of life; HRQoL=Health-related quality of life; EQ-5D= European Quality of Life Five Dimension; TAE=Telecoach-assisted exercise; SRE=Self- regulated exercise; MDC=Minimal Detectable Change; TUG=Timed Up and Go; ADLs =Activities of Daily Living; M=Mean;
m/sec=metre per second; s=seconds; ns=Non-significant, Bold=studies with significantly positive findings.

Appendix B

B1: Participant Information Sheet (Person with Parkinson's disease)

Study Title: Exploring Perceptions and Understandings of the Role of Physical Activity and Exercise in the Management of Parkinson's disease: A Qualitative Study

For permission to participate in an interview to discuss your thoughts and opinions about exercise as you live with Parkinson's disease.

Study Number (if applicable): Participant Name:

Name of Chief Investigator: Dr Ruth McCullagh **Contact Number:** XXX

Name of PhD Researcher: Leanne Ahern **Contact Number:** XXX

You are being asked to participate in a research study. To decide whether or not you want to be a part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This information sheet gives detailed information about the research study. The research team will also discuss the study with you in detail.

When you are sure you understand the study and what will be expected of you, you will be asked to sign a consent form if you wish to participate. Before you decide whether you wish to take part, please read the information provided below carefully. Discuss this with your family, or friends, if you wish. Take time to ask questions – do not feel rushed or under pressure to make a quick decision.

We are asking your permission to discuss your thoughts and opinions about exercise as you live with Parkinson's disease. This information will allow us to examine how valuable and accessible exercise is to you, and how we can help people with Parkinson's disease to exercise well.

Please take your time to read this information sheet and ask any questions.

NATURE AND DURATION OF PROCEDURE(S):

The aim of the study is to determine the potential barriers and motivators to exercise faced by people with Parkinson's disease. If you agree, we would like to invite you to participate in a one-to-one interview to discuss your thoughts and experiences.

This will involve a one-to-one interviews (led by a registered physiotherapist) where you can share your personal thoughts and experiences. The interview will take place in person (socially distanced) in XXX Primary Care Centre or online depending on COVID-19 guidelines.

The interview will discuss your perceptions of the value of exercise, its value to you, and any barriers you experience to exercising. The interview will be video recorded and will last for about 50-60 minutes. The results of the study will be published and may contain important statements made by you. However, all statements included will be anonymised to avoid revealing identity.

The following details will be discussed:

- Barriers and motivators you have faced with regards to engaging in exercise,
- Symptoms you experience, and how you manage them
- The relationship between your symptoms and exercise
- Your thoughts and understanding of the role of exercise in the self-management of Parkinson's disease
- Exercise you take, what form and how frequently
- Your exercise preferences
- The value of exercise to you
- How challenging it is to exercise, including issues such as geographical location, isolation, exercising alone, symptoms, and motivation
- What encourages you to keep exercising, self-management strategies
- Any possible solutions – how can we help?
- Your awareness of available services for people with Parkinson's disease.

BENEFITS

This information will allow us to examine how valuable and accessible exercise is to you, and how we can help people with Parkinson's disease to exercise well. We hope the results of these interviews will provide us with a better understanding for why people with Parkinson's disease engage or do not engage with exercise. We hope to use the information we gather from your interviews to design a novel exercise intervention to improve accessibility for people with Parkinson's disease to exercise services, to optimise their self-management strategies and adherence to exercise.

RISKS

The main risk you may be exposed to is confidentiality. To minimise this risk, the information will be kept confidential.,

1. Only the researcher and supervisors at University College Cork (UCC) will have access to the information.
2. No identifiable information will be stored.
3. The anonymised data will be stored on a computer on a password protected file.
4. The data will not be given to any other party.

POSSIBLE ALTERNATIVES

Participation in this study is voluntary; you can choose to withdraw from the study at any time without question. Withdrawal from the study will not restrict your access to health care services normally available to you. If you do not want to discuss specific topics, you can refuse to do so. You will not be penalised in any way if you refuse to participate or change your mind. You will be given the opportunity to review to amend your interview transcript. If you change your mind, your recording can be deleted up to two weeks after the completion of the interview and information discussed during your interview will not appear in published work, however after this time period the data cannot be revoked. All data discussed in published work will be anonymised.

While we may not be able to find solutions to the issues you discuss there and then, it will help us to examine how we can help people with Parkinson's disease in general.

If you have any questions about this interview, please contact:

Name of Chief Investigator: Dr Ruth McCullagh, Lecturer, Physiotherapy, School of Clinical Therapies, University College Cork.
Contact Number for Chief Investigator: XXX
Email: XXX

Name of PhD researcher: Ms Leanne Ahern, PhD researcher, Physiotherapy, School of Clinical Therapies, University College Cork.
Contact Number for PhD researcher: XXX
Email: XXX

Data Protection Notice

At University College Cork, we treat your privacy seriously. Any personal data which you provide to the University will be treated with the highest standards of security and confidentiality, in accordance with Irish and European Data Protection legislation. This notice sets out details of the information that we collect, how we process it and who we share it with. It also explains your rights under data protection law in relation to our processing of your data.

Who we are?

Throughout this Notice, "we," "us" and "our" refers to University College Cork, as study sponsor. For more information about us, please refer to our website: *www.ucc.ie*

How we will use your personal data

By participating in the study, information from you (also called "personal data") will be collected for the study purposes mentioned in the Participant information leaflet above.

Personal data collected at any time during the study will be kept strictly confidential. To ensure confidentiality, the data generated during the study is **coded** with a number that will identify you in the study. A list or 'key' linking your study number to your name will also be kept securely (locked cupboard in a room with restricted access) by the investigator.

Who will access my personal data?

Your uncoded data will only be accessible to the study investigator and study staff. Results of the study will be provided to the Clinical Research Ethics Committee of the Cork Teaching Hospitals (CREC) in compliance with national and international regulations on clinical studies.

The purpose and legal basis for collecting your data

Any personal data you provide to us during this study will be processed fairly and lawfully.

Signing the Informed Consent Form means that your personal data will be used for the purposes outlined in the Participant information leaflet (PIL).

Personal data collected during this study and the results of the study may be presented for scientific purposes. However, you will never be identified individually during these presentations. Your identity will not be revealed in any reports or publications.

The investigator will use your personal data within the scope defined above.

The General Data Protection Regulation allows us to process your data because you have provided your consent. You are entitled to withdraw your consent at any time.

How long we will keep your data

The personal data collected in the study will be kept for a period of at least 10 years after the end of the study. Thereafter, they may be stored for a further period of time for legal reasons (e.g. revised retention obligations), or more if required by law.

Your rights

You have various rights under data protection law, subject to certain exemptions, in connection with our processing of your personal data, including the right:

- to find out if we use your personal data, access your personal data, and receive copies of your personal data;
- to have inaccurate/incomplete information corrected and updated;
- in certain circumstances, to have your details deleted from systems that we use to process your personal data or have the use of your personal data restricted in certain ways;
- to object to certain processing of your data by UCC;
- to exercise your right to data portability where applicable (i.e. obtain a copy of your personal data in a commonly used electronic form;
- to withdraw your consent to the processing of your data at any time without giving a reason by notifying your decision to the investigator. This will not affect the lawfulness of processing data about you based on your consent before the withdrawal. If you withdraw your consent for data processing, your participation in the study stops and no further data will be collected from you. Your study physician will present you the options you have concerning your personal data.
- Along with study withdrawal, you have the right to request the deletion of data about you if your data are no longer necessary for the purposes of processing or there is no other legal ground for their further processing.

If you wish to exercise any of these rights, please address your request to the study research team or the Information Compliance Manager, University College Cork (details below).

Questions or Complaints

If you have any queries in relation to this study, please contact Dr Ruth McCullagh, Discipline of Physiotherapy, University College Cork. Email: XXX Telephone: XXX

If you have any complaints in connection with our processing of your personal data, you can contact UCC's Information Compliance Manager: **Information Compliance Manager, Office of Corporate & Legal Affairs, University College Cork, Western Road, Cork E: foi@ucc.ie Tel: +353 21 4903949**

You also have the right to lodge a complaint with the Data Protection Commission if you are unhappy with our processing of your personal data. Details of how to lodge a complaint can be found on the Data Protection Commission's website (www.dataprotection.ie), or by telephoning 1890 252 231.

Name of Participant _____Date _____

Signature of Participant _____Date _____

Name of Informant _____Date _____

Signature of Informant _____Date _____

B2: Participant Consent Form (Person with Parkinson's disease)

Study Title: Exploring Perceptions and Understandings of the Role of Physical Activity and Exercise in the Management of Parkinson's disease: A Qualitative Study

For permission to participate in a one-to-one interview to discuss your thoughts and opinions about exercise as you live with Parkinson's disease.

Principal Researcher: Dr Ruth McCullagh, Lecturer in Physiotherapy. Contactable by email (XXX) or by phone XXX

PhD Researcher: Leanne Ahern, PhD researcher. Contactable by email (XXX) or by phone XXX

Name_____
Date_____

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all your questions.

Statement of Consent

I am aware that participation is voluntary and that I may withdraw my consent at any time. I am aware that my decision not to participate or to withdraw will not restrict my access to health care services normally available to me. Confidentiality of records concerning my involvement in this project will be maintained in an appropriate manner. If required, the records of this research may be reviewed by government agencies, the research sponsors, and the clinical research ethics committee of the Cork Teaching Hospitals.

I have read the information sheet and received a copy of this consent form for my records. I have asked questions and discussed what is involved. I understand that if I have any further questions concerning this research, I can contact the Chief Investigator listed below. I understand that the study has been approved by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (CREC) and if I have further queries concerning my rights in connection with the research, I can contact CREC at Lancaster Hall, 6 Little Hanover Street, Cork, 021 4901901 or email crec@ucc.ie.

I understand that I will be interviewed in a local community setting or online, the interview will be video recorded, and the information will be analyzed for research. By signing this consent form, I have not waived any of my legal rights.

Please tick one of the following boxes
I can partake in the interview alone. ☐
I require a family member in the interview with me to help me understand and/or answer the questions. ☐

Please answer yes or no to the following questions:

- I have read the information sheet and understand the study: Yes/No
- I agree to participate in this research Yes/No
- I understand that I can withdraw permission to use my data within 2 weeks of the interview, in which case the material relating to me will be deleted. Yes/ No
- I agree to quotation/publication of extracts from my interview Yes/No

Participant's signature_____
Participant's printed name: _____
Date _____

Researcher's signature_____
Researcher's printed name: _____
Date _____

If you have any questions, please do not hesitate to contact the chief investigator or the researcher.

Name of Chief Investigator: Dr Ruth McCullagh
Contact Number for Chief Investigator: XXX
Email: XXX

Name of PhD researcher: Ms Leanne Ahern
Contact Number for PhD researcher: XXX
Email: XXX

B3: Participant Information Sheet (Family Member/Carer of a Person with Parkinson's disease)

Study Title: Exploring Perceptions and Understandings of the Role of Physical Activity and Exercise in the Management of Parkinson's disease: A Qualitative Study

For permission to participate in a focus group and to be interviewed about your experiences of caring for someone with Parkinson's disease and your thoughts on the value of exercise in the management of Parkinson's disease.

Study Number (if applicable): Participant Name:

Name of Chief Investigator: Dr Ruth McCullagh **Contact Number:** XXX

Name of PhD Researcher: Leanne Ahern **Contact Number:** XXX

You are being asked to participate in a research study. To decide whether or not you want to be a part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This information sheet gives detailed information about the research study. The Chief Investigator will also discuss the study with you in detail. When you are sure you understand the study and what will be expected of you, you will be asked to sign a consent form if you wish to participate. Before you decide whether you wish to take part, please read the information provided below carefully.

We are asking your permission to interview you about your experience of caring for someone with Parkinson's disease and your thought of the value of exercise in the management of Parkinson's disease. This information will allow us to examine how valuable and accessible exercise is to people with Parkinson's disease, and how we can help them to exercise well.

Please take your time to read this information sheet and ask any questions.

NATURE AND DURATION OF PROCEDURE(S):

The aim of the study is to determine the potential barriers and motivators to exercise faced by people with Parkinson's disease. If you agree, we would like to invite you to participate in a focus group, with about 6 - 8 other family members and/or carers of people with Parkinson's disease. This will involve group interviews (led by a registered

physiotherapist and one other researcher will observe and take notes but will not partake in the discussion) where you can share your personal thoughts and experiences. The interview will take place in person (socially distanced) in ***XXX Primary Care Centre*** or online depending on COVID-19 guidelines. At present the ***provisional date*** for this group interview is ***Thursday 24th of November 2022 at 12pm – 1pm***

The focus group will be video recorded and will last for about 40-50 minutes. Your name will not be recorded. The results of the study will be published and may contain important statements made by you. However, all statements included will be anonymised to avoid revealing your identity.

The following details will be discussed:

- Your experience of living with a person with Parkinson's disease.
- The challenges that Parkinson's disease brings to exercise.
- Your thoughts and understanding of the role of exercise in the self-management of Parkinson's disease
- Barriers and possible solutions to helping to exercise
- Motivational technique you find beneficial to use to encourage exercise,
- Strengths and weaknesses to your role in helping to exercise
- "Too much." When you find you cannot help more?
- Your awareness of available services for people with Parkinson's disease

BENEFITS

This information will allow us to examine how valuable and accessible exercise is to people with Parkinson's disease, and how we can help them to exercise well. We hope the results of these focus groups with provide us with a better understanding for why people with Parkinson's disease engage or do not engage with exercise. We hope to use the information we gather from your interviews to design a novel exercise intervention to improve accessibility to exercise services, to optimise self-management strategies and adherence to exercise.

RISKS

The main risk you may be exposed to is confidentiality. To minimise this risk, the information will be kept confidential.,

5. Only the researcher and supervisors at University College Cork (UCC) will have access to the information.
6. No identifiable information will be stored.
7. The anonymised data will be stored on a computer on a password protected file.
8. The data will not be given to any other party.

POSSIBLE ALTERNATIVES:

Participation in this study is voluntary; you can choose to withdraw from the study at any time without question. Withdrawal from the study will not restrict your family members access to health care services normally available to them. If you do not want to discuss specific topics, you can refuse to do so. You will not be penalised in any way if you refuse to participate or change your mind. Unfortunately, we will be unable to delete any participation in the focus group once the recording has started, as each member's contribution will be anonymous.

While we may not be able to find solutions to the issues you discuss there and then, it will help us to examine how we can help people with Parkinson's disease in general.

If you have any questions about this interview, please contact:

Name of Chief Investigator: Dr Ruth McCullagh, Lecturer, Physiotherapy, School of Clinical Therapies, University College Cork.
Contact Number for Chief Investigator: XXX
Email: XXX

Name of PhD researcher: Ms Leanne Ahern, PhD researcher, Physiotherapy, School of Clinical Therapies, University College Cork.
Contact Number for PhD researcher: XXX
Email: XXX

Data Protection Notice

At University College Cork, we treat your privacy seriously. Any personal data which you provide to the University will be treated with the highest standards of security and confidentiality, in accordance with Irish and European Data Protection legislation. This notice sets out details of the information that we collect, how we process it and who we share it with. It also explains your rights under data protection law in relation to our processing of your data.

Who we are?

Throughout this Notice, "we," "us" and "our" refers to University College Cork, as study sponsor. For more information about us, please refer to our website: *www.ucc.ie*

How we will use your personal data

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Personal data collected at any time during the study will be kept strictly confidential. To ensure confidentiality, the data generated during the study is **coded** with a number

that will identify you in the study. A list or 'key' linking your study number to your name will also be kept securely (locked cupboard in a room with restricted access) by the investigator.

Who will access my personal data?

Your uncoded data will only be accessible to the study investigator and study staff. Results of the study will be provided to the Clinical Research Ethics Committee of the Cork Teaching Hospitals (CREC) in compliance with national and international regulations on clinical studies.

The purpose and legal basis for collecting your data

Any personal data you provide to us during the course of this study will be processed fairly and lawfully.

Signing the Informed Consent Form means that your personal data will be used for the purposes outlined in the Participant information leaflet (PIL).

Personal data collected during this study and the results of the study may be presented for scientific purposes. However, you will never be identified individually during these presentations. Your identity will not be revealed in any reports or publications.

The investigator will use your personal data within the scope defined above.

The General Data Protection Regulation allows us to process your data because you have provided your consent. You are entitled to withdraw your consent at any time.

How long we will keep your data

The personal data collected in the study will be kept for a period of at least 10 years after the end of the study. Thereafter, they may be stored for a further period of time for legal reasons (e.g. revised retention obligations), or more if required by law.

Your rights

You have various rights under data protection law, subject to certain exemptions, in connection with our processing of your personal data, including the right:

- to find out if we use your personal data, access your personal data, and receive copies of your personal data;
- to have inaccurate/incomplete information corrected and updated;
- in certain circumstances, to have your details deleted from systems that we use to process your personal data or have the use of your personal data restricted in certain ways;
- to object to certain processing of your data by UCC;

- to exercise your right to data portability where applicable (i.e. obtain a copy of your personal data in a commonly used electronic form;
- to withdraw your consent to the processing of your data at any time without giving a reason by notifying your decision to the investigator. This will not affect the lawfulness of processing data about you based on your consent before the withdrawal. If you withdraw your consent for data processing, your participation in the study stops and no further data will be collected from you. Your study physician will present you the options you have concerning your personal data.
- Along with study withdrawal, you have the right to request the deletion of data about you if your data are no longer necessary for the purposes of processing or there is no other legal ground for their further processing.

If you wish to exercise any of these rights, please address your request to the study research team or the Information Compliance Manager, University College Cork (details below).

Questions or Complaints

If you have any queries in relation to this study please contact Dr Ruth McCullagh, Discipline of Physiotherapy, University College Cork. Email: XXX Telephone: XXX

If you have any complaints in connection with our processing of your personal data, you can contact UCC's Information Compliance Manager: **Information Compliance Manager, Office of Corporate & Legal Affairs, University College Cork, Western Road, Cork E: foi@ucc.ie Tel: +353 21 4903949**

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Name of Participant _____Date _____

Signature of Participant _____Date _____

Name of Informant _____Date _____

Signature of Informant _____Date _____

B4: Participant Consent Form

(Family Member/Carer of Person with Parkinson's disease)

Study Title: Exploring Perceptions and Understandings of the Role of Physical Activity and Exercise in the Management of Parkinson's disease: A Qualitative Study

For permission to participate in a focus group and to be interviewed about your experiences of caring for someone with Parkinson's disease and your thoughts on the value of exercise in the management of Parkinson's disease.

Principal Researcher: Dr Ruth McCullagh, Lecturer in Physiotherapy. Contactable by email (XXX) or by phone XXX

PhD Researcher: Leanne Ahern, PhD researcher. Contactable by email (XXX) or by phone XXX

Name_____
Date_____

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all your questions.

Statement of Consent

I am aware that participation is voluntary and that I may withdraw my consent at any time. I am aware that my decision not to participate or to withdraw will not restrict my family members access to health care services normally available to them. Confidentiality of records concerning my involvement in this project will be maintained in an appropriate manner. If required, the records of this research may be reviewed by government agencies, the research sponsors, and the clinical research ethics committee of the Cork Teaching Hospitals.

I have read the information sheet and received a copy of this consent form for my records. I have asked questions and discussed what is involved. I understand that if I have any further questions concerning this research, I can contact the Chief Investigator listed below. I understand that the study has been approved by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (CREC) and

if I have further queries concerning my rights in connection with the research, I can contact CREC at Lancaster Hall, 6 Little Hanover Street, Cork, 021 4901901 or email crec@ucc.ie.

I understand that I will be interviewed in a local community setting or online, the focus group will be audio recorded, and the information will be analyzed for research. By signing this consent form, I have not waived any of my legal rights.

Please answer yes or no to the following questions:

- I have read the information sheet and understand the study: Yes/No
- I agree to participate in this research Yes/No
- I understand that I can withdraw permission to use my data within 2 weeks of the interview, in which case the material relating to me will be deleted. Yes/ No
- I agree to quotation/publication of extracts from my interview Yes/No

Participant's signature_____
Participant's printed name: _____
Date _____

Researcher's signature_____
Researcher's printed name: _____
Date _____

If you have any questions, please do not hesitate to contact the chief investigator or the researcher

Name of Chief Investigator: Dr Ruth McCullagh
Contact Number for Chief Investigator: XXX
Email: XXX

Name of PhD researcher: Ms Leanne Ahern
Contact Number for PhD researcher: XXX
Email: XXX

B5: Participant Information Sheet (Physiotherapist)

Study Title: Exploring Perceptions and Understandings of the Role of Physical Activity and Exercise in the Management of Parkinson's disease: A Qualitative Study

For permission to participate in a focus group and to be interviewed about your perception of the barriers to exercise, the value of exercise in the management of Parkinson's disease, the available services for People with Parkinson's disease, the need for new services.

Study Number (if applicable): Participant Name:

Name of Chief Investigator: Dr Ruth McCullagh **Contact Number:** XXX

Name of PhD Researcher: Leanne Ahern **Contact Number:** XXX

You are being asked to participate in a research study. In order to decide whether or not you want to be a part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This information sheet gives detailed information about the research study. The Chief Investigator will also discuss the study with you in detail. When you are sure you understand the study and what will be expected of you, you will be asked to sign a consent form if you wish to participate. Before you decide whether you wish to take part, please read the information provided below carefully.

We are asking your permission to interview you about your experience of working with people with Parkinson's disease, your perception of barriers to exercise, the value of exercise in the management of Parkinson's disease, the available services for People with Parkinson's disease, the need for new services and the accessibility and feasibility of providing the new services. This information will allow us to examine how valuable and accessible exercise is to people with Parkinson's disease, and how we can help them to exercise well.

Please take your time to read this information sheet and ask any questions.

NATURE AND DURATION OF PROCEDURE(S):

The aim of the study is to determine the potential barriers and motivators to exercise faced by people with Parkinson's disease. If you agree, we would like to invite you to participate in a focus group, with about 6 -8 other physiotherapists who work with people with Parkinson's disease. This will involve group interviews (led by a registered physiotherapist and one other researcher will observe and take notes but will not partake

in the discussion) where you can share your personal thoughts and experiences. The interview will take place in person (socially distanced) in XXX Primary Care Centre or online depending on COVID-19 guidelines. At present the ***provisional date*** for this group interview is ***Thursday 1st of December 2022 at 10am – 11am***

The focus group will be video recorded and will last for about 40-50 minutes. Your name will not be recorded. The results of the study will be published and may contain important statements. However, all statements included will be anonymised to avoid identity.

The following details will be discussed:

- Your perception of your role
- Your relationship with people with Parkinson's disease
- Common challenges to exercise, and how you help overcome them
- Barriers that you find challenging to overcome
- Solutions/Strategies you have discovered or suggestions you may feel worthwhile.

BENEFITS

This information will allow us to examine how valuable and accessible exercise is to people with Parkinson's disease, and how we can help them to exercise well. We hope the results of these focus groups with provide us with a better understanding for why people with Parkinson's disease engage or do not engage with exercise. We hope to use the information we gather from your interviews to design a novel exercise intervention to improve your accessibility to exercise services, to optimise your self-management strategies and adherence to exercise.

RISKS

The main risk you may be exposed to is confidentiality. In order to minimise this risk, the information will be kept confidential.,

9. Only the researcher and supervisors at University College Cork (UCC) will have access to the information.
10. No identifiable information will be stored.
11. The anonymised data will be stored on a computer on a password protected file.
12. The data will not be given to any other party.

POSSIBLE ALTERNATIVES:

Participation in this study is voluntary; you can choose to withdraw from the study at any time without question. If you do not want to discuss specific topics, you can refuse to do so. You will not be penalised in any way if you refuse to participate or change your mind. Unfortunately, we will be unable to delete any participation in the focus group once the recording has started, as each member's contribution will be anonymous.

While we may not be able to find solutions to the issues you discuss there and then, it will help us to examine how we can help people with Parkinson's disease in general.

If you have any questions about this interview, please contact:

Name of Chief Investigator: Dr Ruth McCullagh, Lecturer, Physiotherapy, School of Clinical Therapies, University College Cork.
Contact Number for Chief Investigator: XXX
Email: XXX

Name of PhD researcher: Ms Leanne Ahern, PhD researcher, Physiotherapy, School of Clinical Therapies, University College Cork.
Contact Number for PhD researcher: XXX
Email: XXX

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Personal data collected during this study and the results of the study may be presented for scientific purposes. However, you will never be identified individually during these presentations. Your identity will not be revealed in any reports or publications.

The investigator will use your personal data within the scope defined above.

The General Data Protection Regulation allows us to process your data because you have provided your consent. You are entitled to withdraw your consent at any time.

How long we will keep your data

The personal data collected in the study will be kept for a period of at least 10 years after the end of the study. Thereafter, they may be stored for a further period of time for legal reasons (e.g. revised retention obligations), or more if required by law.

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You have various rights under data protection law, subject to certain exemptions, in connection with our processing of your personal data, including the right:

- to find out if we use your personal data, access your personal data and receive copies of your personal data;
- to have inaccurate/incomplete information corrected and updated;
- in certain circumstances, to have your details deleted from systems that we use to process your personal data or have the use of your personal data restricted in certain ways;
- to object to certain processing of your data by UCC;
- to exercise your right to data portability where applicable (i.e. obtain a copy of your personal data in a commonly used electronic form;

- to withdraw your consent to the processing of your data at any time without giving a reason by notifying your decision to the investigator. This will not affect the lawfulness of processing data about you based on your consent before the withdrawal. If you withdraw your consent for data processing, your participation in the study stops and no further data will be collected from you. Your study physician will present you the options you have concerning your personal data.
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If you wish to exercise any of these rights, please address your request to the study research team or the Information Compliance Manager, University College Cork (details below).

Questions or Complaints

If you have any queries in relation to this study, please contact Dr Ruth McCullagh, Discipline of Physiotherapy, University College Cork. Email: XXX Telephone: XXX

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Name of Participant _____ Date _____

Signature of Participant _____Date _____

Name of Informant _____ Date _____

Signature of Informant _____ Date _____

B6: Participant Consent Form (Physiotherapist)

Study Title: Exploring Perceptions and Understandings of the Role of Physical Activity and Exercise in the Management of Parkinson's disease: A Qualitative Study

For permission to participate in a focus group and to be interviewed about your perception of the barriers to exercise, the value of exercise in the management of Parkinson's disease, the available services for People with Parkinson's disease, the need for new services.

Principal Researcher: Dr Ruth McCullagh, Lecturer in Physiotherapy. Contactable by email (XXX) or by phone XXX

PhD Researcher: Leanne Ahern, PhD researcher. Contactable by email (XXX) or by phone XXX

Name_____
Date_____

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Please circle one of the following
I am a qualified **physiotherapist Yes/No**.
I work with people with Parkinson's disease **Yes/No.**

Statement of Consent

I am aware that participation is voluntary and that I may withdraw my consent at any time. I am aware that my decision not to participate or to withdraw will not restrict my access to health care services normally available to me. Confidentiality of records concerning my involvement in this project will be maintained in an appropriate manner. If required, the records of this research may be reviewed by government agencies, the research sponsors, and the clinical research ethics committee of the Cork Teaching Hospitals.

I have read the information sheet and received a copy of this consent form for my records. I have asked questions and discussed what is involved. I understand that if I have any further questions concerning this research, I can contact the Chief Investigator listed below. I understand that the study has been approved by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (CREC) and

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Please answer yes or no to the following questions:

- I have read the information sheet and understand the study: Yes/No
- I agree to participate in this research Yes/No
- I understand that I can withdraw permission to use my data within 2 weeks of the interview, in which case the material relating to me will be deleted. Yes/ No
- I agree to quotation/publication of extracts from my interview Yes/No

Participant's signature_____
Participant's printed name: _____
Date _____

Researcher's signature_____
Researcher's printed name: _____
Date _____

If you have any questions, please do not hesitate to contact the chief investigator or the researcher.

Name of Chief Investigator: Dr Ruth McCullagh
Contact Number for Chief Investigator: XXX
Email: XXX

Name of PhD researcher: Ms Leanne Ahern
Contact Number for PhD researcher:
Email: XXX

B7: Interview Questions: Semi-structured interviews: People with Parkinson's disease

The topic guide for these interviews will be mapped to the 14 domains of the Theoretical Domains Framework (TDF)[53]

Overview

Confirm consent to conduct and record the interview

Introductions and expression of gratitude to the participants

Reiterating the aims of the study

Encourage individuals to be open and honest about their experiences and give as much information as possible

Participant to state name, age, years since diagnosis (first symptoms), and whether they are independent with ADLs and living with someone or alone.

Knowledge, Skills, and Memory, attention, and decision processes (TDF Domains 1, 2 and 10)

1. When you were told you had Parkinson's disease/received your diagnosis did you receive adequate information regarding your diagnosis of Parkinson's disease? How did this effect/influence you/your ability to manage your condition?

1a. Were you surprised? Can you tell me about that?

2. Has anyone talked to you about exercise and physical activity? Can you tell me about that?

Probing Question: Do you think exercise and physical activity is important for you? Why?

Probe their understanding of why exercise is important – is it more on a well-being point of view? Or a neuroprotective point of view.

3. What do you think are the most important things for you when managing your condition?

4. Have you been informed of the role of exercise in the management of Parkinson's disease? If so, by who? How did this impact your outlook?

5. Is exercise important to you? Can you explain why/why not?

6. Do you believe you benefit from exercise? Can you explain?

7. Are you aware of the World Health Organisation's (or any) guidelines on physical Activity? Can you explain this

Belief about capabilities, Optimism, and Belief about consequences (TDF Domains 4, 5 and 6)

8. What activities do you consider to be "exercise"?

9. Do you engage in exercise?

- If no, can you please explain why

- If yes, how many times a week to you exercise? What type of exercise do you enjoy?

10. Do you prefer to exercise alone? With a family member/friend? As part of a group?

11. Other than physically, do you believe you benefit from exercise/how does exercise benefit you? Can you explain?

Symptom Management

12. Can you discuss some Parkinson's disease symptoms (both motor and non-motor) you have experienced? How do you manage these symptoms?

13. Do your symptoms effect your participation in everyday life? Can you explain?
14. How does exercise effect your Parkinson's disease symptoms?
15. How do your symptoms effect your ability to exercise?

Reinforcement, Emotion and Behaviour regulation (TDF Domains 7, 13 and 14)

16. What motivates you to exercise? /What encourages you to engage in exercise?
17. What reduces your motivation?
18. How do you stay motivated (strategies)? What techniques do you use to stay motivated?

19. As healthcare professionals what can we offer you or others to help you stay motivated/improve your motivation?

Barriers and Facilitators

20. Do you find it hard to exercise? If so, why?

Probe both personal and environment factors

Probe both motor and non-motor

Follow up question: How do you overcome this?

21. Do you believe it is easy for you to engage in exercise services in the community? Can you explain?

22. How can we make exercise services more accessible for you?

Intentions and Goals (TDF Domains 8 and 9)

23. Why do you exercise?

Probe the benefits, social element

24. Do you set goals for yourself? Can you give an example?

25. Are you as physically active as you would like to be?
    If no, why not? What can you do to change this?

Environmental context and resources, social influences and social role and Identity (TDF Domains 11, 12 and 3)

26. Do you feel supported by your family and friends? Can you explain?

27. Do you feel supported within your community? Can you explain?

28. Do you believe the people you encounter during your everyday life understand your Parkinson's disease specific needs? Can you explain/How does this effect you?

29. What are the general society beliefs regards Parkinson's disease? How does this effect you?

30. Do you belief society facilitates/provides for your Parkinson's disease specific needs?

31. How can we improve this/What can we do to improve this?

Conclude

32. Ask participant if there is anything else they would like to say/add

33. Thank them for their participation.

B8: Interview Questions; Interview Group 1: Family Member/Carers

The topic guide for these interviews was mapped to the 14 domains of the Theoretical Domains Framework (TDF)[53]. Items covered in this paper are in bold.

Overview

Confirm consent to conduct and record the focus group

Introductions and expression of gratitude to the participants

Reiterating the aims of the study

Encourage individuals to be open and honest about their experiences and give as

much information as possible

Participant to state name, their family-member/participant's name, if they are a family member or carer and how long ago since their family member was diagnosed

Introduction

1. What are your experiences of living/caring for someone with Parkinson's disease?

2. Does your family member engage in exercise? Can you explain (type, duration, frequency)?

3. Do you believe your family member benefits from/enjoys exercise? Can you explain?

4. How important is exercise to your family member?

5. What is your role in helping your family member to exercise/ Do you play a role in helping your family member to exercise?

6. What are the strengths and weaknesses to your role in helping your family member to exercise?

Knowledge and Skills (TDF Domains 1 and 2)

7. When your family member received their diagnosis did you receive adequate information and education regarding the management of Parkinson's disease?

8. Were you educated regarding the role of exercise in the management of

Parkinson's disease? If so, by who? How did this influence your outlook?

9. Is exercise important to your family member? Can you explain why/why not?

10. Do you believe your family member benefits from exercise? Can you explain?

11. What are your thoughts and understanding of the role of exercise in the

management of Parkinson's disease?

12. As healthcare professionals, what can we do to help?

13. Are you aware of the World Health Organisation's guidelines on physical

Activity? Can you explain this?

Reinforcement, Emotion and Behaviour Regulation (TDF Domains 7, 13 and 14)

14. What challenges does Parkinson's disease bring to exercise? How do you help overcome these?

Probe personal and environment factors; motor and non-motor

15. What are the barriers and possible solutions to helping your family member to exercise? How can we help?

16. As healthcare professionals how can we help overcome these challenges?

17. Can you discuss some examples of motivational technique you find beneficial to use to encourage exercise?

Intentions and Goals (TDF Domains 8 and 9)

18. Does your family member set personal goal when it comes to exercise? Can you explain?

19. What role do you play in the goal setting process? Can you explain?

20. Do you think your family member is as physically active as they would like to be? If no, why not? What can you do to help them change this?

Environmental Context and resources, social influences and social role and Identity (TDF Domains 11, 12 and 3)

21. Do you believe it is easy for your family member to access exercise services in the community? Can you explain?

22. Do you feel your family member is supported within your community? Can you explain?

23. What are the general society beliefs regarding Parkinson's disease? How does this influence your family- member?

24. Do you belief society facilitates for people with Parkinson's disease?

25. How can we improve this?

Conclude

26. Ask participants if there is anything else they would like to say/add

27. Thank them for their participation.

B9: Interview Questions Interview Group 2: Physiotherapists

Overview

Confirm consent to conduct and record the focus group

Introductions and expression of gratitude to the participants

Reiterating the aims of the study

Encourage individuals to be open and honest about their experiences and give as

much information as possible

Participant to state name and how many years they have been working with people with Parkinson's disease

Introduction

1. What is your role in helping people with Parkinson's disease to exercise?

2. What are the strengths and weaknesses of your role?

3. Can you describe your Parkinson's disease patient cohort (age, disease severity, sex)?

4. Are your patients with Parkinson's disease physically active? Can you give some examples? Is it the same for both men and women?

5. Are your patients meeting the World Health Organisation's guidelines on physical activity? Can you give some examples? Is it the same for both men and women?

Barriers and Challenges

6. What are common challenges to exercise faced by people with Parkinson's disease? Do these differ for men and women? Can you explain

Follow up question: How do you help overcome them?

7. What barriers do you find challenging to overcome?

8. Can you discuss solutions/strategies you have discovered or suggestions you may feel worthwhile?

Education

9. Do you believe people with Parkinson's disease are well educated regarding the benefits of exercise?

10. Does this influence their outlooks of disease disability?

11. As healthcare professionals how can we improve this?

Role of the family member

12. Does the family member play an important role with regards to exercise among your patients? Can you explain this?

13. Do you believe family members and carers are well educated/understand the benefits of exercise?

14. Do you encourage family members to attend physiotherapy sessions? Can you explain?

Services

15. Do you believe people with Parkinson's disease are well supported within the community?

16. What clinical services do you offer for people with Parkinson's disease? Can you explain? Is access to these services' dependent on referrals? Can people attend these classes without a referral from a healthcare professional?

17. Outside of referral dependent clinically led services are you aware of community exercise services available to people with Parkinson's disease? Can you explain?

18. With the prevention versus treatment approach in mind, how can we improve accessibility to clinically led exercise services for people with Parkinson's disease not currently accessing community services?

Present findings from PwPD and Focus group with family member

19. Discuss the need for this service, accessibility, acceptability, feasibility

Conclude

20. Ask participants if there is anything else they would like to say/add

21. Thank them for their participation

B10: Codes for semi-structured interviews

P1 P2 P3 P4 P5 P6 P7 P8 P9 P10 P11 P12

Relationship with HCPs	Diagnosis	Services	Education	Barriers to exercise	Strategies/motivators to exercise			Meaning of exercise	Exercise Environment/Conditions of exercise/Factors to consider	Other
					Beliefs/Consequences	Motivators	Strategies			
Not being listened to (by HCPs)	Delayed diagnosis	Lack of signpostin g	Lack of education on diagnosis	Barrier to engagement in community services: Social influences (negative) - progression of others	Social/Societal Influences	Persevering through the barriers - routine of exercise	Organised commitment	Exercise is empowerin g	Importance of appropriate exercise environment	Lack of control, people taking independence away
Anger at HCPs	Disbelief at diagnosis - family	Lack of knowledge of services	Lack of education on diagnosis	Barrier: social influences (negative) - being looked at	Understanding/awar eness of consequences (beliefs)	Motivator: fear	Importance of peer support	Benefits of exercise - empowerm ent, sense of control	Importance of language and phrasing used by HCP	Societal connotations
Onus of neurologist responsibility	Misdiagnos ed initially	Self-directed learning of services	Lack of education on diagnosis	Social influences (negative)	Benefits of exercise/beliefs of benefits	Motivator: determination to maintain function/remain well	Recruited local supports	Exercise provides opportuniti es/ participatio n	Variation: online/in person (gym) Outdoors/Indoors Alone/Group	Social identity
Relationship with consultant	Delayed diagnosis	Services not tailored/sui table for all	Lack of education on diagnosis	Exercise classes rules - sense of helplessness, dehumanising, lack of control of own management	Benefits of exercise: belief of capabilities, empowerment, understanding of benefits (knowledge)	Motivator: fear of stopping	Social support	Exercise is personal - music	Role of HCP in exercise environment encouraging vs authoritative	Social influences (negative): others knowing
Difficulty accessing GP	Delayed diagnosis - self unawarenes s	Frustration at healthcare system	Lack of education on diagnosis	Barrier: Social influences (negative)	Benefits of exercise: rewards	Motivator: determination	Mindfulness	Simplicity of exercise	Importance of exercise environment	Awareness of symptoms, social influences
Language and phrasing of HCP - empathy/humanis ing	Lack of knowledge pre diagnosis	Importanc e of prevention - HSE should refocus	Not educated at diagnosis	Lack of accessibility - county living	Benefits of exercise: participation	Motivation: proving others wrong (determination/soc ial influences)	Mindfulness	Communit y engagemen t - sense of belonging ad unity	Role of HCP in exercise environment - lack of freedom to progress, lack of ownership of	Societal factors

									management, lack of control	
Building a rapport with HCP	Unawareness pre diagnosis	Need for early introduction to exercise - HSE pathway	Lack of education - benefits of exercise	Preconceived judgement/lack of access to service for high function	Benefits of exercise: participation	Motivator: benefits of exercise	Body awareness - mindfulness	Importance of exercise	Exercise: importance of fun aspect	Social influences
Importance of staff being educated	Lack of knowledge pre-diagnosis - unawareness	Need for HSE to re-prioritization on their needs	Lack of education: benefits of exercise	Barrier: transport	Understanding of the role of exercise	Motivator: social engagement	Mindfulness	Definition of exercise	Adaptability of exercise (setting/environment)	Societal views
HCP not listening	Diagnosis delivered alone (no family member	Need for HSE pathway - prevention vs treatment	Lack of education: benefits of exercise	Societal factors: societal connotations/beliefs	Motivator: benefits of exercise/adaptability of exercise	Motivator: social aspect, feeling of community involvement	Mindfulness - awareness of body	Benefits of exercise: gaining control	Exercise habits pre-diagnosis	Societal connotations
										Feelings socially normal
	present)									Societal influences
HCP viewing them as a patient not a person - dehumanising	Importance of support at diagnosis	Lack of knowledge of services	Lack of education from HCP: exercise	Societal factor: stigma	Motivator: Benefits of exercise	Motivator: feedback (technology)	Body compared to nature	Exercise should be non-negotiable	Exercises prior to diagnosis	Peer learning
Importance of HCP language and phrasing - delivery of diagnosis	Lack of knowledge prior to diagnosis	Lack of knowledge - fear of unknown	Lack of education: role of exercise	Societal barriers to community services	Motivator: Benefits of exercise	Motivator: exercise a part of daily life (work), exercise built into lifestyle	Mindfulness	Exercise is non-negotiable	Exercised prior to diagnosis	Peer learning
Shock of diagnosis - lack of empathy from HCP	Lack of knowledge pre-diagnosis	Support on diagnosis	Education of exercise	Lack of accessibility - country	Motivator: physical benefits of exercise	Motivator: Benefits of exercise (physical)	Mindfulness	Exercise as part of daily life/routine	Exercised prior to diagnosis	Social isolation
HCP - lack of empathy, lack of professional support on diagnosis		Family support on diagnosis	Lack of education - GP	Unable to self-manage - adapt exercise	Motivator: physical and mental benefits of exercise	Motivator: carer for other, others dependent on you	Body awareness, mindfulness	Importance of exercise	Exercise pre - diagnosis	Societal factors
Importance of language by HCPs		Healthcare system - lack of pathway	Importance of education		Motivator: belief of consequences	Motivator: exercise a part of daily life (work), exercise built into lifestyle	Social comradery	Exercise should be routine - consistency	Enjoyment	Fear of environment, viewed as vulnerable
Instilling hope (HCPs)		Unaware of treatment plan - HCP	Importance of education - exercise		Motivator: benefits of exercise	Motivator: determination	Exercise - fun aspect	Social interaction	Adaptability of exercise	Barriers: societal factors - embarrassment

		not informed								
		Peer support for younger diagnosed	Timing of education piece, presence of family member		Motivator: belief of negative consequences	Motivator: self-want	Importance of goal setting	Meaning of exercise	Importance of appropriate environment and social setting	Barrier: social influences (negative) - embarrassment, others' opinions, disengaging from society, effecting participation
		Feeling vulnerable post diagnosis - no support	Self-education		Awareness of negative consequences	Motivator: determination, goals, perseverance, ambition	Peer/family support	Exercise as part of a routine	Adaptability of exercise - environment and variety	Lack of control, people taking independence away
		Lack of peer support within services	Self - education		Motivator: benefits of exercise	Motivator: determination	Positive mindset - positive thinking - optimism	View of exercise in management of PD	Exercise is adaptable	
		Lack of peer support	Lack of education leading to social disengagement		Motivator: fear of hospital - progression	Internal vs external motivators	Positive reflection	Exercise is personal, individual	Exercise is adaptable	
		Importance of group support	Education on exercise		Belief of capabilities	Motivator: Goals - maintaining function/prevention of progression	Positive outlook	Exercise is personal time	Exercise is adaptable	
		Importance of peer support	Views of exercise - importance of education		Motivator: taking control, self-empowerment	Motivator: determination	Peer support	Exercise is a pleasant experience not a chore	Adaptability of exercise: outdoor vs indoor	
		Lack of support for younger diagnosed	Lack of education - exercise		Motivator: determination, fight, fear of giving up	Motivator: perseverance	Social support	Outlook of exercise	Exercise is adaptable	
		Lack of a pathway - prevention	Lack of knowledge of services		Benefits of exercise: opportunities, participation	Motivator: social comparison	Exercise - fun aspect	Social outlet	Outdoor exercise	
		Personalised approach	Lack of knowledge; belief about capabilities		Belief about capabilities	Motivator: determination, perseverance, awareness	Optimism	Outlook of exercise	Variety in exercise	
		Strategy - possible solution	Lack of education		Intensity of exercise: belief about capabilities	Reason for exercise - maintain function	Motivator: Social pressures	Exercise as part of a routine	Exercise must be meaningful and functional	
		Possible solution: availing of	Lack of education		Motivator: fear of progression	Social comparison - not letting	Peer Support	Simplicity of exercise	Exercise has to be meaningful	

		community halls				Parkinson's be her identity				
		Possible solution/strategy	Importance of education		Benefits of exercise - beliefs about capabilities	Motivator: social influences	Motivator: setting challenging goals	Value of exercise - improved QoL (benefits of exercise)	Exercise - enjoyment	
		Early intervention	Importance of education		Exercise - change of outlook	Motivator: maintain function	Motivator: social influences	Exercise is personal, adaptable, tailored to the individual	Exercise - fun aspect	
		Lack of knowledge of services	Lack of education		Gaining control of management	Parkinson's not defining her	Motivator: social influences - embarrassment	Opportunities of exercise - activity, completing tasks	Exercise classes rules - lack of freedom to progress, lack of control, lack of ownership of self-management	
		Possible solution/strategy	Importance of education		Benefits of exercise: mental	Motivator: maintain function	Strategy: self-talk	Specific, multicomponent exercise	Role of HCP in exercise environment - lack of progression, no ambition	
		Possible solution/strategy	Self-education		Benefits of exercise: non - motor	Motivator: prevent progression	Social support	Participation	Frustration with lack of control with progression at exercise class	
		Lack of knowledge of services	Lack of education		Motivators: benefits of exercise, maintain function	Motivator: knowledge of benefits	Motivator: incentives	Benefits of exercise: self-efficacy, self-esteem, sense of accomplishment	Social "chatting" aspect not as important, exercise is priority	
		Awareness of services	Self-education		Motivator: Main function, prevent progression	Motivator: fear of progression	Reinforcement	Exercise provides opportunities, participation	Social aspect not important	
		Possible solution			Social influences (negative): fear of progression, social comparison	Motivator: maintain, others are depending on your goals	Motivator: everyday goals Exercise as a routine		Variety - understanding of exercise	

		Individual responsibility to find services			Motivator: fear of progression	Motivator: determination	Family understanding, family support, role of the carer	Importance of exercise	Variety of exercise	
		Possible solution - increase knowledge			Benefit of exercise: sense of accomplishment (belief about capabilities)	Motivator: rewards	Strategies	Meaning of exercise	Being physical active	
		Importance of support at diagnosis			Empowerment	Positive effects of exercise - pain relief	Coping mechanism	Individuality of exercise	Environment of exercise - outdoors	
					Sense of accomplishment - empowerment	Motivator: social influences	Social aspect	Exercise is personal	Awareness of health	
					Motivator: fear of progression	Social aspect	Social aspect	Personalised	Impact of symptoms - symptom management	
					Empowerment	Motivator: social aspect	Social/peer support	Exercise as a routine - begin early	Variety of exercise	
					Motivator: fear of progression	Types of motivation/motivators	Motivator - organisational commitment	Importance of regular exercise	Group exercise - support	
						Mental readiness required to be motivated	Societal influences	Exercise - participation	Outdoor environment	
						Motivator: Maintain function	Social/peer support	Simplicity of exercise	Limitations of PD specific classes - not challenging, instructors afraid to progress	
						Motivator: family encouragement	Motivator: goals, self-improvement		More challenging classes - societal views of older people	
						Motivators: social influences (support), belief about capabilities, benefits of exercise and incentives	Strategy: organised commitment		Enjoyment of exercise	
						Social comparisons	Social influences (positive) - encourages exercise		Importance of community involvement	

						Mental and physical benefits of exercise	Social aspect of exercise		Awareness of own exercise habits	
						Motivator: dog (dependency of others)	Societal influences		Variety of exercise	
						Motivator: social influences	Motivator: social influences		Adaptability of exercise	
						Social aspect	Family support		Enjoyment of exercise	
						Motivators: health benefits	Social and societal influences		Importance of enjoying exercise	
						Motivator: maintain function	Individual goals		Adaptability of exercise	
						Benefits of exercise	Social support		Enjoyment, personal (exercise)	
						Correct motivation	Small changes to introduce exercise to non-exercisers		Group vs Individual	
						Motivator: competitiveness	Tips for new exercisers			
						Motivator: incentive/rewards				
						Social aspect of exercise				
						Benefits of exercise: mental				
						Motivator: maintain function, cure for Parkinson's				

B11: Codes for group interview with family members/carers

FM1 FM2 FM3 FM4

Relationship with HCPs	Services	Education	Exercise	Societal factors	Impact on family member
Lack of empathy on diagnosis	Possible solution/strategy	Prevent progression	Variety of exercise Motivational support	Societal views/outlook on Parkinson's Stigma need for public awareness	Open communication
Family members feeling dismissed by HCP	Lack of knowledge of services	Self-educated	Value of exercise	Peer support	Impact on family
Importance of involving the family member in the plan	Lack of signposting	Lack of education for family members	Putting the onus of the PwP to take responsibility	Community involvement	Frustration for family members, missing the past
Dismissed by HCP - not personalized, seen as business	Importance of early diagnosis	Lack of education for family members	Discourages FM from suggesting exercise	Risk of social isolation	Fear of progression
HCPs assuming family members knowledge	Reflect on timely supports early into diagnosis		Organisational commitment, social interaction	Still affected by COVID lockdown	Fear, concern, worry
Dismissed by HCP - not personalized, seen as business	Reflect on the Individualised needs of PwP throughout this paragraph		Family encouraging exercise		Becoming the role of carer
	Possible solution/strategy		Variety of exercise		Concern of progression
	Lack of knowledge of services		Exercise has to be fun		Hiding emotions, determined for partner
			Company, social aspect		Fear for future
			The relationship between exercise and timeliness (progression of illness)		Social support
			Family encouraging exercise		Open communication
			Putting the onus of the PwP to take responsibility		Impact on family
					Frustration for family members, missing the past

PT1
PT2
PT3
PT4
PT5

B12: Codes for group interview physiotherapists

Relationship with HCPs/Role of Physio	Services	Education	Exercise	Societal factors	Role of the family member
Role of physio: introduction to exercise, education regarding exercise	Early physio access	MDT Input	Make exercise a routine	Prejudgement against high functioning patients	Family members: to share information with
Building a trusting rapport with patient	Lack of treatment pathway	Timing of education	Adapting exercise to home environment		Family members: to prompt exercise
Importance of expert knowledge of staff	Perceptions of the role of physio	Education HCPs on available services	Personalised approach		Family members for collateral
Role of physio: introduction to exercise, education regarding exercise	Prevention not seen as a priority	Education regarding accepting assistance	Created routine in a supported environment		
	Lack of staff	Deeper education regarding exercise - identifying barriers, understanding how to exercise	Adapting exercise to the patient		
	Prevention vs cure - early access, early referral, pathway		Barriers: transport		
	Need for a treatment strategy/pathway		Barrier: Fear		
	Technology both aiding and hindering (including and excluding)		Barrier: Non - motor features		
	Prevention vs cure - early access, early referral, pathway		Barrier: health literacy, culture		

Appendix C

C1: Activity Diary

NAME _____

7 – DAY ACTIVITY DIARY

(WEEK 1-12)

SAMPLE DIARY

Day	**What Activity?** **(group or alone)**	**Where?**	**How Long?**	**Difficulty Level** **Light/** **Moderate/** **Hard**	**How did it make you feel?**	**If you had trouble exercising what are the reasons?** **What stopped you from exercising?**
Monday	Walking (with friends) Swimming (alone)	Local Park Local Pool	20 mins 45 mins	Light Moderate	Energised, by body feels less stiff, improved my mood. Felt tired, but in a good way. I did an extra length of the pool today and I feel amazing. Very tired now – but I am delighted with myself.	No trouble exercising today – felt good, felt empowered.
Tuesday	Exercises at home (alone)	Home	5 mins	Hard	Sore, tired, no energy	Feeling sore and tired today, maybe I over did it yesterday. I did not finish my exercises. I wanted to do more but my body is saying no. I am a little disappointed, but today I am going to listen to my body and rest and start again tomorrow or the next day.

Wednesday						
Thursday						
Friday						
Saturday						
Sunday						

C2: Behaviour Change Template

Name _____ ID Code _____

Group Chat ***(Peer support)***	Did they use the group chat? If so, did they find it helpful? What about it was helpful?
Family/friend encouragement ***(Social influences/recruiting supports)***	Are their family/friends encouraging them to exercise? If yes, do they find it beneficial? How do the family members encourage exercise (e.g. exercising with them (as buddies) or providing prompts, nudges to exercise alone) If not, do they think it would help to exercise more (if their family/friends encouraged them). If yes, as the weeks progress are they doing more themselves (without requiring the encouragement)
Activity Diary What motivated them to exercise?	Did they struggle to exercise this week? If yes, what were the reasons? How could they overcome this?

(Barrier Identification, goal setting, self-monitoring, belief about capabilities)	Do they fill out the diary themselves or does someone help them? If no, why aren't they doing it themselves? Could they try fill it out themselves next week? Are they meeting the WHO guidelines – 150 mins per week, 2-3 strength session and 1-2 flexibility sessions? Do they have any goals they would like to set for themselves for next week? Encourage them to plan an exercise schedule.
Education ***(Enhancing knowledge)***	Discuss the importance of exercises: - Strength - Balance - Improve mental health. - Sleep Slow down the progression of symptoms of Parkinson's disease Adverse Effects - Fatigue - Muscle Soreness - Exacerbation of pain
Reflect on their progress to date.	Ask them to reflect on their progress? Do they feel there is a change (improvement, dis-improvement, the same)? Explain

(*Positive reinforcement, belief about capabilities, empowerment)*	Has their ability to set goals changed (improvement, disimprovement, the same)? Explain Do they find they are more motivated to exercise, without others encouraging them? Explain Mention how well they are doing. - Acknowledge the participants' progress in the group classes. - Encourage peer support within and outside the classes. - Encourage participants to explore exercises that may be meaningful or of interest to them (outside the programme).

C3: Parkinson's disease Exercise and Education Programme Feedback Survey

Thank you very much for participating in the programme. I would be grateful if you would complete this survey. Please be as open and honest as possible. Your feedback helps plan future programmes.

Please tick one of the following boxes:

I am a **Class participant** ☐ **Family member** ☐

How many classes did you attend? (Total: 24 for participant; 12 for family member)

Exercise classes ☐ **Education sessions** ☐

Do you believe you benefitted from the programme? Can you explain why?

_____
_____
_____

<u>Family members</u>, please write N/A for the following two questions.

What did you enjoy most about the exercise classes?

_____
_____
_____

What did you enjoy least about the exercise classes? What would you change?

_____
_____
_____

How do you feel about continuing to exercise? What plans have you?

_____
_____
_____

What did you enjoy most about the education classes?

_____
_____
_____

What did you enjoy least about the education classes? What would you change?

_____
_____
_____

Were all the education sessions helpful? Would you drop/change any sessions?

_____
_____
_____

How can we improve this programme? Can you give suggestions?

_____
_____
_____

Is there any other guest speakers/topics that you would have liked to hear from/learn about?

_____
_____
_____

Thank you for your feedback. I hope you enjoyed the program.

C4: Topic Guide: Qualitative interview to explore the patients' experience and acceptability of the Behaviour Change Techniques with Exercise

Activity Diary (TDF Domain 14: Behaviour Regulation, TDF Domain 4: Belief about capabilities)

1. What are your opinions on using the **activity diary**? [probe its impact on self-efficacy and exercise adherence]
2. Will you continue to use the activity diary, why?
3. [the research physiotherapist] tried to get you to lead the classes as the weeks progressed. How do you feel that went? [probe further about self-efficacy and self-management
4. Is there a better way of doing this/ delivering this?
5. Or a better way of getting you confident about exercising with less guidance?
6. When we are running the programme again, do you think this element should be included or changed?

Peer Support (TDF Domain 12: Social Influences)

1. What are your opinions about the group dynamics within the class?
2. What are your opinions/experience on using **the WhatsApp group**? [probe its impact on self-efficacy and exercise adherence]
3. Will you continue to use the WhatsApp group, why?
4. Is there a better way to deliver this?
5. When we are to run the programme again do you think this element should be included?

Education (TDF Domain 1: Knowledge, Domain 6: Belief about consequences)

1. What are your thoughts on the **education/advice** give about the benefits of exercise, pacing, muscle soreness, fatigue, and exercise intensity level? [probe its impact on self-efficacy and exercise adherence]
2. Is there a better way to deliver this?
3. When we are to run the programme again do you think this element should be included or changed?

Goal Setting (TDF Domain 9: Goals, Domain 11: Environmental context and Resources)

1. Do you think your confidence to set your own goals has changed with the programme? completing the programme? [probe its impact on exercise adherence]
4. Will you continue to set goals, why?
5. Is there a better way to deliver this?
6. When we are to run the programme again do you think this element should be included or changed?

Acceptability and feasibility

1. Which of the four BC techniques that you like the most? [Probe the reasons behind their choice, and how it made a difference].
2. Which of the four BC techniques that you like the least? [probe the reasons behind your choice and discuss why they felt it was of less value].
3. Would you recommend this programme to someone you else? [probe why]

Process of change

1. What did you learn from this programme? [probe its impact on self-efficacy and exercise adherence, overall impact on wellbeing].
2. Are there any changes in your thoughts on exercise/intensity of exercise. If yes, what are they? What brought about these changes.
3. Have you noticed any differences in your life because of taking part in the 'Parkinson's disease Exercise and Education' programme? If 'yes', what are these differences? Probe further on why they think it worked.
4. What was the reason you continued to attend the classes/sessions each week?

Barriers

1. What were the difficulties in taking part? [Probe solutions.]

Implementing change

1. Do you think you will continue to use what you have learned going forward (goal setting, barrier identification, RPE scale, exercises log (reps and sets).
2. What would help you to keep exercising now, as the programme is now finished. [probe the perceived need for support now].

Suggestions for further improvement

1. What do you think could be improved?
2. If [the research physiotherapist] was to start over again, what advice would you give them?
3. Is there anything else that you would like to mention that we have not discussed?

C5: APDM Data

Table C5: APDM Data: TUG and 2-minute walk test data

		PEEP + BC				PEEP	
		ID 6		ID 8		ID 15	
		Post-intervention	Δ	Post-intervention	Δ	Post-intervention	Δ
TUG Outcomes	TUG Duration (seconds)	8.76	-2.44	12.4	-2.04	8.85	-1.5
	Sit to Stand Duration (seconds)	0.87	-0.54	1.05	-0.29	1.12	-0.01
	Stand to Sit duration (seconds)	0.94	-0.2	0.9	-0.25	0.97	-0.09
	Turn velocity (degree/seconds)	175.3	15.4	107.1	-10.1	160.6	13.35
	Turn duration (seconds)	2.13	-0.27	3.53	0.76	2.45	-0.81
2MWT Outcomes	Cadence (steps/minute)	120.8	6.9	109	2.7	101.8	1.2
	Gait speed (metre/second)	1.1	0.1	1.1	0.2	1	-0.04
	Stride Length (metre)	1.1	0.1	1.2	0.2	1.2	-0.1
	Step duration (seconds)	0.52	-0.04	0.55	-0.01	0.6	-0.01
	Turn velocity (degree/second)	170.5	41.3	94	8.8	116.6	1.2
	Turn Duration (seconds)	2.3	-0.6	3.6	-0.1	3	-0.4

C6: Participant Information Sheet

Study Title: Behaviour Change for Parkinson's disease: A randomised controlled trial to promote physical activity and exercise adherence among People with Parkinson's disease

For permission to participate in a 12-week trial comparing a current exercise and education programme to the same programme with additional strategies to promote physical activity and exercise levels in people with Parkinson's disease.

Study Number (if applicable): Participant Name:

Name of Chief Investigator: Dr Ruth McCullagh **Contact Number:** XXX

Name of PhD Researcher: Leanne Ahern **Contact Number:** XXX

You are being asked to participate in a research study. In order to decide whether or not you want to be a part of this research study, you should understand enough about its risks and benefits to make an informed judgment. This information sheet gives detailed information about the research study. The research team will also discuss the study with you in detail.

When you are sure you understand the study and what will be expected of you, you will be asked to sign a consent form if you wish to participate. Before you decide whether you wish to take part, please read the information provided below carefully. Discuss this with your family, or friends, if you wish. Take time to ask questions – do not feel rushed or under pressure to make a quick decision.

Our aim is to promote physical activity and exercise among people with Parkinson's disease, help people with Parkinson's disease to exercise well and support them to self-manage their condition.

We are asking your permission to partake in a 12-week trial comparing a current exercise and education programme to the same programme with additional strategies to promote physical activity and exercise levels in people with Parkinson's disease.

Please take your time to read this information sheet and ask any questions.

NATURE AND DURATION OF PROCEDURE(S):

The aim of the study is to pilot behaviour strategies to encourage people with Parkinson's disease to engage in physical activity and exercise. If you are interested, we would like to invite you to participate in an exercise and education intervention to determine its benefits.

The current programme is a 12-week programme of a once-weekly supervised exercise class (led by a registered physiotherapist, consisting of 4-5 people) and multidisciplinary education sessions (delivered by a different healthcare professional each week). Education sessions include the role of a physiotherapist, occupational therapist, speech and language therapist, dietician, clinical psychologist, Parkinson's disease nurse, social prescriber and geriatrician in the management of Parkinson's disease. Classes will take place in person in XXX Primary Care Centre.

The exercise classes will include progressive and challenging strength, balance, and functional exercises. The exercise class will be tailored to your abilities and will last approximately 45 mins. The education session will be of a similar time duration. This means you are required to attend for 1.5 hours (90 mins), once a week for 12 weeks.

You are guided to complete two exercise sessions at home independently. The exercises are tailored for you, and you will be instructed carefully on how to complete them.

We would like to compare the effects of additional behaviour strategies to improve exercise adherence and confidence in exercising. These strategies are designed to help people to adhere to exercises by using strategies such as goals, diaries, and peer support.

Therefore, if you choose to take part in this trial, you consent to participate, you will be randomly allocated to the usual care group or the group with the additional strategies. The exercise and education programme will be the same, the only difference will be the behaviour strategies.

Before and after the programme, we will record details such as your age and details about your Parkinson's disease. Your confidence about exercise, levels of physical activity, and your walking and balance will be measured. Your walking activity will be measured by a small device, worn on your ankle for the first and last week of the programme (it can remain on your ankle continuously, and is fully waterproof).

Your results will be anonymised, and the group results of the study will be published. Please note, all data included will be anonymised to avoid revealing identity.

BENEFITS

By participating in this trial, you will receive the exercise and education programme being currently delivered in Cork. There is a 50% chance that you will be allocated to the group that will receive additional behaviour strategies designed to help your confidence in exercising and increase your independent exercise and physical activity.

We are running this pilot trial to see if these strategies are helpful, and if a larger trial is possible. We will examine the feasibility of the measures we take, and how you find engaging with the programme. The results of the pilot trial will help plan a large definitive trial to fully determine the effectiveness of the additional behaviour strategies.

RISKS

Injury is one of the main risks when carrying out exercise. To minimise this risk:

1. The exercise classes will be conducted by a registered physiotherapist.
2. Each participant will have a chair to provide hand support when carrying out the exercise (when required), and will have adequate space to perform their exercises, participants will be provided with adequate breaks during the classes.
3. The exercises will be tailored to your abilities.
4. Participants will be required to provide a GP clearance letter ensuring it is safe for them to exercise prior to enrolling in the study.
5. Your home exercise programme will be tailored to your ability, and you will be able to discuss any issues or concerns with your physiotherapist any day by phone, or in person at the weekly classes.

Another risk you may be exposed to is your data confidentiality. In order to minimise this risk, the information will be kept confidential.,

1. Only the researcher and supervisors at University College Cork (UCC) will have access to the information.
2. Your data will be fully anonymised, no identifiable information will be stored.
3. The anonymised data will be stored on a computer on a password protected file.
4. The data will not be given to any other party.

POSSIBLE ALTERNATIVES

Participation in this study is voluntary; you can choose to withdraw from the study at any time without question. Withdrawal from the study will not restrict your access to health care services normally available to you. You will not be penalised in any way if you refuse to participate or change your mind. All data discussed in the published work will be anonymised.

If you have any questions about this study, please contact:

Name of Chief Investigator: Dr Ruth McCullagh, Lecturer, Physiotherapy, School of Clinical Therapies, University College Cork.

Contact Number for Chief Investigator: XXX

Email: XXX

Name of PhD researcher: Ms Leanne Ahern, PhD researcher, Physiotherapy, School of Clinical Therapies, University College Cork.

Contact Number for PhD researcher: XXX

Email: XXX

Data Protection Notice

At University College Cork, we treat your privacy seriously. Any personal data which you provide to the University will be treated with the highest standards of security and confidentiality, in accordance with Irish and European Data Protection legislation. This notice sets out details of the information that we collect, how we process it and who we share it with. It also explains your rights under data protection law in relation to our processing of your data.

Who we are?

Throughout this Notice, "we", "us" and "our" refers to University College Cork, as study sponsor. For more information about us, please refer to our website: *www.ucc.ie*

How we will use your personal data

By participating in the study, information from you (also called "personal data") will be collected for the study purposes mentioned in the Patient information leaflet above.

Personal data collected at any time during the study will be kept strictly confidential.
To ensure confidentiality, the data generated during the study is **coded** with a number that will identify you in the study. A list or 'key' linking your study number to your name will also be kept securely (locked cupboard in a room with restricted access) by the investigator.

Who will access my personal data?

Your uncoded data will only be accessible to the study investigator and study staff. Results of the study will be provided to the Clinical Research Ethics Committee of the Cork Teaching Hospitals (CREC) in compliance with national and international regulations on clinical studies.

The purpose and legal basis for collecting your data

Any personal data you provide to us during the course of this study will be processed fairly and lawfully.

Signing the Informed Consent Form means that your personal data will be used for the purposes outlined in the Patient information leaflet (PIL).

Personal data collected during this study and the results of the study may be presented for scientific purposes. However, you will never be identified individually during these presentations. Your identity will not be revealed in any reports or publications.

The investigator will use your personal data within the scope defined above.

The General Data Protection Regulation allows us to process your data because you have provided your consent. You are entitled to withdraw your consent at any time.

How long we will keep your data

The personal data collected in the study will be kept for a period of at least 10 years after the end of the study. Thereafter, they may be stored for a further period of time for legal reasons (e.g. revised retention obligations), or more if required by law.

Your rights

You have various rights under data protection law, subject to certain exemptions, in connection with our processing of your personal data, including the right:

- to find out if we use your personal data, access your personal data and receive copies of your personal data;
- to have inaccurate/incomplete information corrected and updated;
- in certain circumstances, to have your details deleted from systems that we use to process your personal data or have the use of your personal data restricted in certain ways;
- to object to certain processing of your data by UCC;
- to exercise your right to data portability where applicable (i.e. obtain a copy of your personal data in a commonly used electronic form;
- to withdraw your consent to the processing of your data at any time without giving a reason by notifying your decision to the investigator. This will not affect the lawfulness of processing data about you based on your consent before the withdrawal. If you withdraw your consent for data processing, your participation in the study stops and no further data will be collected from you. Your study physician will present you the options you have concerning your personal data.
- Along with study withdrawal, you have the right to request the deletion of data about you if your data are no longer necessary for the purposes of processing or there is no other legal ground for their further processing.

If you wish to exercise any of these rights, please address your request to the study research team or the Information Compliance Manager, University College Cork (details below).

Questions or Complaints

If you have any queries in relation to this study please contact Dr Ruth McCullagh, Discipline of Physiotherapy, University College Cork. Email: XXX Telephone: XXX

If you have any complaints in connection with our processing of your personal data, you can contact UCC's Information Compliance Manager: **Information Compliance Manager, Office of Corporate & Legal Affairs, University College Cork, Western Road, Cork E: foi@ucc.ie Tel: +353 21 4903949**

You also have the right to lodge a complaint with the Data Protection Commission if you are unhappy with our processing of your personal data. Details of how to lodge a complaint can be found on the Data Protection Commission's website (www.dataprotection.ie), or by telephoning 1890 252 231.

Name of Participant_____Date _____

Signature of Participant_____Date _____

Name of Informant_____Date _____

Signature of Informant_____Date _____

C7: Participant Consent Form

Study Title: Behaviour Change for Parkinson's disease: A randomised controlled trial to promote physical activity and exercise adherence among People with Parkinson's disease

For permission to participate in a 12-week trial comparing a current exercise and education programme to the same programme with additional strategies to promote physical activity and exercise levels in people with Parkinson's disease.

Principal Researcher: Dr Ruth McCullagh, Lecturer in Physiotherapy. Contactable by email (XXX) or by phone XXX

PhD Researcher: Leanne Ahern, PhD researcher. Contactable by email (XXX) or by phone XXX

Name_____

Date_____

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

Statement of Consent

I am aware that participation is voluntary and that I may withdraw my consent at any time. I am aware that my decision not to participate or to withdraw will not restrict my access to health care services normally available to me. Confidentiality of records concerning my involvement in this project will be maintained in an appropriate manner. If required, the records of this research may be reviewed by government agencies, the research sponsors, and the clinical research ethics committee of the Cork Teaching Hospitals.

I have read the information sheet and received a copy of this consent form for my records. I have asked questions and discussed what is involved. I understand that if I have any further questions concerning this research, I can contact the Chief Investigator listed below. I understand that the study has been approved by the Clinical Research Ethics Committee of the Cork Teaching Hospitals (CREC) and if I have further queries concerning my rights in connection with the

research, I can contact CREC at Lancaster Hall, 6 Little Hanover Street, Cork, 021 4901901 or email crec@ucc.ie.

I understand that measurements will be performed before and after the intervention, and the information will be analyzed for research. By signing this consent form, I have not waived any of my legal rights.

Please answer yes or no to the following questions:

- I have read the information sheet and understand the study: Yes/No
- I agree to participate in this research Yes/No
- I understand that I can withdraw permission to use my data from the intervention in which case the material relating to me will be deleted. Yes/ No

Participant's signature_____

Participant's printed name: _____

Date _____

Researcher's signature_____

Researcher's printed name: _____

Date _____

If you have any questions, please do not hesitate to contact the chief investigator or the researcher.

Name of Chief Investigator: Dr Ruth McCullagh

Contact Number for Chief Investigator: XXX

Email: XXX

Name of PhD researcher: Ms Leanne Ahern

Contact Number for PhD researcher: XXX

Email: XXX

Appendix D

D1: Publication 1

HRB Open Research

Check for updates

STUDY PROTOCOL

REVISED Can behaviour change interventions improve selfefficacy and exercise adherence among people with Parkinson's Disease? A systematic review protocol [version 2; peer review: 2 approved]

Leanne Ahern[1], Suzanne Timmons[2], Sarah E. Lamb[3], Ruth McCullagh[1]

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v2 **First published:** 23 Feb 2022, **5**:15 https://doi.org/10.12688/hrbopenres.13474.1 **Latest published:** 22 Aug 2022, **5**:15 https://doi.org/10.12688/hrbopenres.13474.2

Abstract

Background: People with Parkinson's Disease (PwP) have a higher tendency to adopt sedentary lifestyle behaviours and have lower physical activity levels compared to their healthy peers. Previous research has indicated that personal factors including poor outcome expectation and low self-efficacy are stronger predictors of exercise adherence than disease severity.**:** The purpose of this review is to synthesize the best available evidence on interventions that encompass self management strategies to overcome barriers to exercise and improve self-efficacy and exercise adherence among PwP.

Methods: The following databases will be searched using a comprehensive search strategy: EBSCO, Medline, CINAHL, Web of Science, PubMed, Embase, Scopus, Google Scholar and Cochrane Library from database inception to 2020. Interventional studies including behavioural change interventions will be included in this review. The title, abstract and full-text screening will be conducted by two independent reviewers. The Joanne Briggs Institute Checklist will be used to assess the quality of each included study. Data will be extracted by two independent reviewers. The outcomes of interest will be self-efficacy outcomes and measures of exercise adherence. A systematic narrative synthesis will be conducted using a framework analysis, applying the Theoretical Domains Framework and Behaviour Change Wheel, producing findings focusing on practice-orientated outcomes. Presentation of data will include tables and text summarizing the characteristics and findings of the eligible studies. Data synthesis and statistical analysis will be

Open Peer Review

Approval Status ✓ ✓

	1	2
version2 (revision) 22 Aug 2022	✓ view	
version1 23 Feb 2022	? view	✓ view

1. **Katherine Baker**, Northumbria University, Newcastle upon Tyne, UK

2. **Ailish Malone**, RCSI University of Medicine and Health Sciences, Dublin, Ireland

Any reports and responses or comments on the article can be found at the end of the article.

performed in Review manager 5.3. The quality of evidence will be reviewed using the GRADE criteria.
Discussion*:* The review will comprehensively synthesize the available evidence on interventions to enhance self-efficacy, improve quality of life, physical function, ultimately improving exercise adherence among PwP and provide invaluable information for healthcare professionals. This review will make recommendations for appropriate self-management strategies for maximum effect and may have implications for policy and practice regarding enhancing self efficacy and long-term exercise adherence among PwP.

Keywords
Parkinson's Disease, exercise self-efficacy, behavioural change interventions, quality of life, exercise adherence

Corresponding author: Ruth McCullagh (r.mccullagh@ucc.ie)

Author roles: Ahern L: Conceptualization, Formal Analysis, Methodology, Writing – Original Draft Preparation; **Timmons S**: Conceptualization, Supervision, Writing – Review & Editing; **Lamb SE**: Supervision, Writing – Review & Editing; **McCullagh R**: Conceptualization, Methodology, Supervision, Writing – Review & Editing **Competing interests:** No competing interests were disclosed.

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The funders had no role in study design, data collection and analysis, decision to publish, or preparation of the manuscript.

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First published: 23 Feb 2022, **5**:15 https://doi.org/10.12688/hrbopenres.13474.1

REVISED **Amendments from Version 1**

Amendments that have been included in the new version are rephrasing and more in-depth descriptions of specific components to improve the readers understandability. For example, firstly, in the introduction, a section on "physical activity" has been added, as we felt it was important to differentiate between exercise and physical activity as both are an outcome of interest for this review.

Secondly, another section discussing the Theoretical Domains Framework (with the addition of Table 1) was also added to the introduction to provide a better understanding for readers who are not familiar with this framework.

Thirdly, we adjusted our eligibility criteria (inclusion of a comparator criteria)-this decision was made as we wanted interventions that focused on the exercise and/or physical activity component.

Fourthly, we rephrased the data analysis and synthesis section following advice from the peer-reviewers that our methods were difficult to understand as they were conflicting with our eligibility criteria.

Lastly, we added our proposed methods for conducting a meta analysis.

Any further responses from the reviewers can be found at the end of the article

Introduction

Parkinson's Disease is the second most common neurological condition globally. This neurodegenerative condition effects the basal ganglia, leading to progressive movement disorders which with time become more disabling[1]. Key motor features associated with Parkinson's Disease are tremor, rigidity (muscle stiffness), akinesia (difficulty initiating movement), bradykinesia (slow movements) and postural instability[2]. There are also many non-motor features associated with Parkinson's Disease including apathy, depression, pain, fatigue, sleep disorders, cognitive impairment, and autonomic dysfunction[3]. The combination of these motor and non-motor features can result in reduced mobility, reduction in quality of life and loss of function[4]. As a result, people with Parkinson's Disease (PwP) have a higher tendence to adopt sedentary lifestyle behaviours and have lower levels of physical activity compared to their healthy peers[4,5].

Exercise, physical activity, and Parkinson's Disease

The advantages of regular physical activity are extensive with research suggesting that PwP benefit from physical activity in multiple ways including improvements in general health, disease-specific improvements and potentially disease-modifying effects[6]

Physical activity is characterized as any bodily movement produced by skeletal muscles resulting in energy expenditure[7] including unstructured or incidental movement. The term exercise often interchangeably used with physical activity[8]. However, exercise is a subcategory of physical activity[7]. Exercise is physical activity that is planned, structured, repetitive and purposeful with the aim to improve or maintain one or more components of physical fitness (cardiorespiratory endurance, muscular strength, muscular endurance, flexibility and body composition)[7].

The role of exercise in the management of Parkinson's Disease is well-documented. The majority of exercise interventions for PwP focus of resistance training, balance, aerobic exercise, and flexibility conducted in an exercise or rehabilitative setting[9]. A meta-analysis conducted by Choi *et al.*[10] investigated the effects of exercise therapies on PwP. Exercise therapies including walking[11–13], strength and flexibility[14–17], balance[18,19], aerobic[20–23] and combined exercise[24–28] was shown to improve balance, walking speed, exercise tolerance, gait function, aerobic capacity, motor control, physical functioning, muscular strength and flexibility among PwP[10]. However, exercise therapies did not show a significant effect on the non-motor symptoms. They concluded that exercise therapy is more effective for the motor symptoms rather than the non-motor symptoms of PwP[10].

However, Tennigkeit *et al.*[29] conducted a systematic review including 24 studies which discussed the benefits of exercise and self-management education for PwP from Sweden and Germany. Self-management education interventions included interactive group sessions, educations sessions for PwP and family members, educational video clips, role playing and handouts and self-monitoring techniques (using diaries for fluctuation in symptoms). They reported positive outcomes for health-related and general quality of life (QoL)[30–40], depression[30,31,33,35–39,41,42], self-efficacy[30,35,41,43], and functional mobility[33,43,44], suggesting the benefit of behavioural change interventions for improving the non-motor symptoms of PwP.

Despite the clear benefits of exercise and physical activity for PwP, only 30% achieve recommended activity levels, some are inactive for 70% of the day and most are less active than their age-matched peers[45]. Recently, studies have shown that exercise may have protective effects associated with the basal ganglia (known as neurogenesis) which results in improvement in dopamine transmission, increased cerebral blood flow and new formation of neuronal synapses which in turn can improve motor function[46]. Neurogenesis can result in a slowed progression of Parkinson's Disease and improvements in motor control, particularly when exercise is carried out at vigorous intensities[46–48].

In addition to this, a study conducted by Sajatovic *et al.*[41] investigated the changes in depression in PwP (with depression) between a combined group exercise and self-management programme and a self-directed individual exercise and self-management program. They reported no significant changes in apathy or anxiety in both groups. However, both groups displayed modest within group improvement in cognition, while the combined group showed additional significant improvements in depression[41]. There were no significant differences between groups. This indicates that behavioural self-management strategies such as group education and peer support may improve non-motor features such as depression in PwP.

Barriers to exercise in PwP

While good compliance can be achieved with prescribed exercise programmes with supervision within a clinical trial this does not completely translate to similar compliance during everyday life. Schootemeijer *et al.*[49] conducted a comprehensive review discussing the various barriers to exercise faced by PwP. They discussed barriers including non-motor factors (anxiety, depression, fatigue, and apathy), personal factors (low self-efficacy, fear of falling, low outcome expectation and lack of

time) and environmental factors (lack of social support, lack of exercise partner, poor accessibility, bad weather, financial burden, cultural challenges, awareness of moving in a crowded environment, and discomfort of seeing advancing symptoms of peers)[49].

Although PwP experience increasing difficulties engaging in exercise as the disease progresses, previous research has indicated that personal factors including poor outcome expectation and low self-efficacy are stronger predictors of exercise adherence than disease severity[50].

In terms of exercise, self-efficacy is an individual's confidence or belief that they can successfully engage in physical activity or exercise[51,52]. Exercise self-efficacy can be categorized into performance self-efficacy (beliefs about performing exercises) or beliefs in overcoming barriers[53,54]. Exercise self-efficacy determines the type of exercise an individual partakes in, their effort level, and their long term exercise adherence when they face barriers to participation[53,55] A meta – analysis conducted by Higgins *et al.*[54] reported that short-term exercise interventions (duration between two - eight weeks) were more effective for enhancing performance efficacy. In contrast interventions that included long term strategies providing opportunities for individuals to experience and successfully conquer barriers over a longer period were more effective for enhancing confidence in overcoming barriers to exercise[54]. This indicates the potential benefits of integrating long term strategies into behavioural change interventions to promote long term adherence to physical activity and exercise among PwP. Behavioural change

Adapting health behaviour in terms of changing from a sedentary lifestyle to a more physically active lifestyle is a complex process[56]. Merely informing individuals about the benefits of physical activity has been shown as inadequate to maintaining behavioural change[56,57]. In order to assist behavioural change in PwP disease-specific counselling and coaching may be required[58]. Behavioural change interventions are complex and involved many cooperating components[59]. These psychology-focused interventions try to facilitate more constructive health behaviours[60]. Particular strategies are utilized to promote behaviour change; some interventions are tailored to enhancing physical activity engagement by identifying barriers and problem solving[61]. While others prompt individuals to track their sedentary behaviour as a method of changing behaviour[61]. These interventions utilize theories of behaviour and behaviour change to inform particular therapeutic strategies[62].

Speelman *et al.*[63] studied the long-term effect of including behavioural change interventions (coaching, goal setting, use of activity monitors) into a multi-facet exercise programme for PwP. They reported improvements in physical activity level for all subgroups of PwP[63]. While Ellis *et al.*[64] investigated the effects of short daily interactions (five minutes/day) with a virtual exercise coach to encourage walking (monitored by a pedometer) among PwP. The interactions discussed progression of short- and long-term goals, collaborative problem solving to overcome barriers and positive support[64]. They reported excellent retention rate in the walking programme and improvements in gait after one month. However, due to the short duration of the intervention the long-term effects of adherence and occurrence of behaviour change are unknown[64]. Theoretical Domains Framework (TDF)

The TDF is a combined theoretical framework which was created from 128 theoretical constructs and 33 behaviour theories[65]. The TDF has been used in implementation research[65] to perform a process evaluation of randomized trials to further understand the effect of implementing evidence[66], as guidance on identifying behaviour change techniques[62,67], to identify influences on behaviours[68–72], and systematic intervention design[73–75].

The TDF consists of 14 domains subcategorized into personal factors, social factors and environmental factors (Table 1). The TDF has previously been correlated with a simpler model of behaviour known as the COM-B[67,76]. The main principle of this model is that capability, opportunity, and motivation interact to produce behaviour. Whereas the TDF provides a more in-depth insight of psychological capability and reflective motivational processes[65].

In order to motivate individuals with Parkinson's Disease to remain physically active outside a clinical setting it is important to identify self-management strategies to overcome these barriers, improve self-efficacy and promote physical activity among PwP. To the best of our knowledge this is the only review exploring the effectiveness of behaviour change interventions on self-efficacy and long term exercise adherence among PwP. The findings of this review will make recommendations for appropriate self-management strategies and may have implications for policy and practice.

Review objectives

The purpose of this review is to comprehensively synthesize the best available evidence on behaviour change interventions that encompass self-management strategies to over barriers to exercise and improve exercise adherence among PwP.

Specifically, the objectives are to:

- Examine self-management strategies to overcome barriers to exercise among PwP.
- Determine the effectiveness of behavioural change interventions aimed to improve exercise self-efficacy, QoL and physical function and exercise adherence among PwP.
- Identify strategies to promote long term exercise adherence among PwP.

Table 1. Theoretical Domains Framework domains and definitions[65].

TDF Domain	Definition
Knowledge	Awareness of the existence of something
Skills	Ability or proficiency acquired through practice
Memory, attention, and decision processes	Ability to retain information, focus selectively on aspects of the environment and choose between two or more alternatives
Behaviour regulation	Anything aimed at managing or changing objectively observed or measured actions
Beliefs about capabilities	Acceptance of the truth, reality or validity about an ability, talent, or facility that a person can put to constructive use
Beliefs about consequences	Acceptance of the truth, reality, or validity about outcomes of a behaviour in a given situation
Social/ professional role and identity	Behaviours and displayed personal qualities of an individual in a social or work setting
Emotion	A complex reaction pattern, involving experiential, behavioural, and physiological elements, by which the individual attempts to deal with a personally significant matter or event
Intentions	Conscious decision to perform a behaviour or a resolve to act in a certain way
Reinforcement	Increasing the probability of a response by arranging a dependent relationship, or contingency, between the response and a given stimulus
Goals	Mental representations of outcomes or end states that an individual wants to achieve
Optimism	Confidence that things will happen for the best or that desired goals will be attained
Environmental context resources	Any circumstance of a person's situation or environment that discourages or encourages the development of skills and abilities, independence, social competence, and adaptive behaviour
Social Influences	Interpersonal processes that can cause individuals to change their thoughts, feelings, or behaviours

Research question

Specially, this review is aimed to answer the following questions:

1. Do behavioural change interventions improve exercise self-efficacy among PwP?

2. Do behavioural change interventions improve QoL and/or physical function among PwP?

3. Do behavioural change interventions improve exercise adherence/increase levels of physical activity among PwP?

Methods

This protocol was designed in line with the methodological framework provided by the Joanna Briggs Institute (JBI) Reviewer's Manual[77] and the Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) guidelines[78]. This review is registered with PROSPERO (ID: CRD42021293057). *Extended Data:* PRIMSA-P Checklist

Inclusion and exclusion criteria

Studies to be included in this review must satisfy the inclusion criteria outlined in Table 2.

Search strategy. Two independent reviewers (LA and RMcC) will conduct a search using the following electronic databases: *EBSCO, Medline, CINAHL, Web of science, PubMed, Embase, Scopus, Google Scholar, Cochrane Library.* Databases will be searched from inception to 2020. The search strategy was developed by the primary author (LA) and supported by a librarian with systematic review experience (VC). Two independent reviewers (LA and RMcC) will search the databases using the search terms showed in Table 3. Reference lists of related articles and relevant reviews will be checked to identify further eligible studies.

Study records. Articles identified from the literature search will be uploaded to Endnote X8, a citation manager. Duplicates will be removed using the "remove duplicates" function, and manual screening of the results will be conducted to ensure accuracy (LA). Titles and abstracts of the identified articles will then be exported to Rayyan (LA), an electronic software designed to support article screening and allows collaboration between reviewers during the study selection process.

Study selection. Two independent reviewers (LA and RMcC) will be involved in the study selection process through each phase of the review. Following the removal of duplicates, LA and RMcC will independently screen all titles and abstracts of the articles identified by the literature search. Studies not meeting the inclusion criteria will be excluded. Prior to the formal

Table 2. Inclusion and exclusion criteria.

Study Characteristics	*Inclusion Criteria*	*Exclusion Criteria*
(i) Population, or participants and conditions of interest	• Community dwelling independently mobile people with Parkinson's Disease. • No limitations will be placed on the length of time since diagnosis or age. • Studies including people with Parkinson's Disease diagnosed with other comorbidities (e.g. anxiety, depression, and diabetes) can be included. However, outcomes must focus on exercise self-efficacy and/or exercise uptake/adherence and not changes in the comorbidity. • Population will not be restricted to Ireland or the UK, articles from all countries will be examined.	If recruited participants: a) Do not have a diagnosis of Parkinson's Disease, or have a diagnosis of Atypical Parkinson's b) Are current inpatients or had a recent hospital admission within the last 3 months. c) Are immobile or wheelchair-users, c) Involve severe visual or auditory impairment, serious medical conditions in major organs (heart, lung, or kidney) or other illnesses which prevent independent ambulation. d) Involve people with Parkinson's Disease who are identified as a high falls risk (fallers)
(ii) Intervention	• Any form of behavioural change intervention (e.g. education, behavioural technology, or support groups) or support strategy to improve QoL, exercise self-efficacy or exercise uptake. For the purpose of this review *behavioural change intervention* will be defined as any psychology-focused intervention (used in conjunction with exercise or alone)[60]. While *exercise self efficacy* is defined as an individual's confidence or belief that they can successfully engage in physical activity or exercise[51,52]	• The intervention does not include self-efficacy strategies or behavioural change interventions. • The intervention focuses solely on falls prevention
(iii) Comparator	• Comparator groups must include people with a Parkinson's Disease diagnosis • A specific intervention type will not be defined for the purpose of inclusive. • Comparator groups including but not limited to exercise alone, usual care or waiting list will be included	• Comparator group including non-Parkinson's Disease individuals.
(iv) Outcomes of interest	• Outcomes reported at every time-points will be considered for this review. • Primary outcomes are self-efficacy measures (e.g. Self-efficacy for exercise scale, Physical Activity Assessment Inventory), QoL (e.g. PDQ-39. PDQ-8), physical function (e.g. 6MWT, gait velocity), and measures of exercise adherence (e.g. self-log, activity monitors).	Outcomes reported are not related to exercise adherence/uptake (i.e. medication adherence, changes in anxiety and depression)
(v) Setting	Studies conducting interventions in the following settings will be included; community gyms/halls, community outpatient facilities, acute hospitals (if the intervention is conducted with community dwelling people with Parkinson's Disease), home environment or in any geographical setting globally.	Acute hospitals (if intervention is conducted with inpatients), Long term care facilities.
(vi) Study design	Interventional studies: RCTs, quasi-experimental trials, pilot interventional studies, pre- and post-interventional studies, and feasibility studies.	Qualitative studies, observational studies, or systematic reviews
		Other: • Full-text articles are not available. • Papers are not published in English
(vii) Phenomenon of interest	The review will include studies that explore behavioural change strategies to enhance exercise self-efficacy, improve QoL, physical function and ultimately improve adherence to exercise among community dwelling individuals with Parkinson's Disease, including but not limited to behavioural interventions (motivational interviewing, goal setting and cognitive re-framing) and support strategies (peer and family education and support sessions).	

screening process, test screening questions will be developed suitable studies. Reference lists of the included articles and based on the inclusion/exclusion criteria. previously conducted reviews in the area will be checked to identify any additional studies. Both LA and RMcC will Subsequently, LA and RMcC will independently screen the independently screen any additional articles to determine their full text articles identified from the previous stage to select the suitability. Any disagreement regarding inclusion will be

Table 3. Search strategy.

Databases: - EBSCO (Academic search complete and Psychinfo) - Medline - CINAHL - Web of Science - PubMed - Embase - Scopus - Google Scholar - Cochrane Library
Search keywords:
1. ["behavioural change intervention*" OR "behavioural change intervention*" OR "behaviour change technique*" OR "behaviour change technique*" OR "cognitive behavioural therapy" OR "cognitive behavioural therapy" OR psychology OR "psychological therapy" OR "health behaviour*" OR "health behaviour*"]
2. [self-efficacy OR "self efficacy" OR *"*physical activity self-efficacy*"* OR *"*physical activity self efficacy*"* OR *"*exercise self efficacy*"* OR *"*exercise self efficacy" OR self-management]
3. 1 AND 2
*4. ["*physical activit*"* OR recreation OR sport OR exercise OR training OR fitness OR *"*physical therap*"* OR rehabilitation]
5. 3 AND 4
*6. ["*Parkinson's Disease*"* OR "Parkinsons Disease" OR "Parkinson Disease" OR Parkinson's OR Parkinson]
7. 5 AND 6

resolved by a third reviewer (ST). A Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) flow diagram will display the study selection process and summarise the inclusion and exclusion of studies at each stage of the review by providing reason for exclusion. Data collection and extraction

Two independent reviewers (LA and RMcC) will extract data from each eligible study and conduct the risk of bias assessment. Reviewers will perform practice extraction exercises prior to the formal extraction to ensure consistency. Any disagreement regarding extraction will be resolved by a third reviewer (ST) and a consensus achieved. If required, primary authors of studies will be contacted to provide further details. A data extraction template will be designed a priori. Data including study design, sample characteristics (size, sex, mean age) specific details about the intervention (type, duration and follow-up) and implementation methods, pre- and post-intervention outcome results, and theorical framework used (if applicable) will be extracted.

Methodological quality of studies

To assess the potential risk of bias The Joanne Briggs Institute Checklist[77] for the corresponding study designs will be used for each eligible study.

Two independent reviewers (LA and RMcC) will assess the potential risk of bias of each article. Any disagreements will be resolved by a third reviewer (ST). In the incidence where data is missing, or information is not clear the primary authors will be contacted for clarification. Following the assessment, studies will be classified as a high, medium, low, or unclear risk of bias.

Assessing the quality of evidence

The quality of evidence will be assessed using the Grades of Recommendation, Assessment, Development and Evaluation (GRADE) approach[79]. This involves assessing the quality of evidence using a specific points system to upgrade or downgrade the ratings for each quality characteristic. Evidence can be downgraded one level for serious limitations or two levels for very serious limitations depending on the assessment for five characteristics: limitation in study design and conduct, inconsistent results across studies, indirectness of evidence with respect to study design, populations, interventions, comparisons or outcomes, imprecision of the estimates of the effect and publication bias. Evidence can be upgraded depending on the assessment of the following three characteristics; large magnitude of effect, plausible confounding that would reduce the effect, and dose-response gradient[80–83].

Two independent reviewers will assess the quality of each eligible articles (LA and RMcC). Any disagreement will be resolved by a third reviewer (ST) and a consensus achieved. In the incidence where information is not clear the primary authors will be contacted for clarification.

Narrative synthesis and analysis of the data

Initially, a narrative analysis will be completed. If data is missing or incomplete, we will contact the author by email for the information. Data will be presented using tables and text summarizing the characteristics and findings. A narrative synthesis of the findings will be completed to investigate the association and findings between the included studies. Patterns demonstrating the effectiveness of the interventions will be discussed, including the participants, the intervention, and its

impact on the outcomes. Outcomes will include subjective measures of impact including self-efficacy and quality of life, as well as objective measures of physical / functional gains (e.g. 6MWT, gait velocity), and measures of exercise adherence (e.g. self-log, activity monitors).

The interventions will be mapped to the Theoretical Domains Framework (TDF) and Behaviour Change Wheel (BCW), producing findings focusing on practice-orientated outcomes. The TDF includes fourteen domains related to the psychology of behaviour change[84]. While the BCW focuses on the success of implementing interventions by coordinating change interventions with behavioural barriers; a person's opportunity, capability and motivation interconnects and influence their behaviour (COM-B)[85]. The effectiveness of the mapped interventions will be evaluated further in the context of the models.

The data will be assessed for eligibility for meta-analysis, exploring heterogeneity of populations, interventions, and outcome.

Meta-analytical approach. Statistical analysis will be performed by using the Cochrane Review Manager (RevMan 5.3) software. The mean difference and the 95% confidence interval (CI) will be used as an effective size for the combined analysis, with $p \leq 0.05$ considered as statistically significant.

Assessment of heterogeneity

If significant methodological, statistical, and clinical heterogeneity is detected, results will not be reported as the pooled effect estimate in a meta-analysis. Heterogeneity will be identified by visual inspection of the forest plots and by conducting a χ^2 test with a significance level of $\alpha = 0.1$. Heterogeneity will also be examined using the I^2 statistic as recommended by Higgins[86,87]. The I^2 statistic will quantify inconsistency across the included studies in order to assess the impact of heterogeneity on the meta-analysis. An I^2 statistic $\geq$ 75% signifies a substantial level of inconsistency[88]. If heterogeneity is determined, individual studies and subgroup characteristics will be examined to identify potential reasons.

Data will be summarized by means of a random-effects model with due consideration of the whole distribution of effects by presenting a prediction interval. Analyses will be conducted according to the guidelines outlined in the Cochrane Handbook for Systematic Reviews of Interventions[88].

Subgroup analysis

Subgroup analyses will be completed to determine the effectiveness of behavioural change strategies on quality of life based on the type of strategy.

Assessment of reporting biases

If ten or more of the included studies investigate the same outcome, funnel plots will be used to assess small study effects and evaluate potential publication bias using the Egger test in Stata 13.

Sensitivity analysis

A sensitivity analyses will be performed to explore the influence of the following factors (if applicable) on effect sizes.

- Restricting analysis to high-powered, larger studies
- Restricting analysis to low risk of bias studies
- Restricting analysis to studies including a control group.

To test the robustness of the results analysis will be repeated using different statistical models (random-effects and fixed effect models) and different measures of effect size (odds ratio and relative risk).

Dissemination of results

The systematic review will be disseminated in a peer-reviewed journal and the results will be presented both locally to physiotherapy clinical colleagues, and at international conferences. The dataset created during the study will be available from the corresponding author upon request.

Amendments

Any amendments to this protocol will be described in a table including the date of each amendment as well as a description of and rationale, this will be documented in a note to a later publication (section "Differences between protocol and review"). The PROSPERO register will remain updated with the protocol and any amendments made. **Ethics approval and consent to participate**

Ethical approval is not required for this study as it will not involve conducting experimental research or include identifying personal data.

Study status

The systematic review protocol was finalised in November 2021 and the database search was conducted in December 2021. Full-text screening will be completed in January 2022. It is anticipated the review will be completed in September 2022. **Discussion**

Self-efficacy and attitudes towards exercise are linked in a linear relationship[55,89]. Exercise self-efficacy increases with mastery experiences, as individual become more experienced with exercise. However, self-efficacy also plays an important role in maintaining motivation to exercise[52]. While the body of evidence supporting behavioural change interventions displays a positive effect of self-efficacy there is a need to pool evidence from trials to accurately determine the treatment effect of these different interventions.

Data availability

No data are associated with this article.

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Version 2

Reviewer Report 02 September 2022

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Katherine Baker
Department of Sport, Exercise and Rehabilitation, Northumbria University, Newcastle upon Tyne, UK

Thank you for sharing the revisions to your protocol. The additional detail and clarification have strengthened the article which is an important addition to the literature.

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Physiotherapy, Parkinson's, physical activity and exercise

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 02 Sep 2022

Leanne Ahern

Thank you very much for your comments and time to peer-review this article, it is greatly appreciated.

Competing Interests: No competing interests were disclosed.

Version 1

Reviewer Report 25 April 2022 https://doi.org/10.21956/hrbopenres.14686.r31803

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Ailish Malone

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Thank you for the invitation to review this systematic review protocol. The protocol addresses an important gap in current evidence synthesis and proposes robust methods to achieve its aims.

The Introduction clearly conveys the state of the evidence in favour of the myriad benefits of exercise in Parkinson's, and the problem of inactivity. The review refers almost exclusively to "exercise", but the interventions might have an effect on habitual physical activity, too. Does the review intend to focus exclusively on *exercise* (structured, planned, repetitive, intentional), as distinct from *physical activity* (also including unstructured / incidental movement)? (I see that "physical activity" is a search term, but the rest of the review refers to "exercise".)

The last paragraph under the subheading "Exercise in Parkinson's" presents the Sajatovic study, which compared a **group**-based exercise and self-management program with an **individual** exercise and self-management program. Participants in the **group** program showed additional improvements in depression scores, but were these differences seen within-group or betweengroup? Is the key difference, then, the mode of delivery (group v individual) rather than the components of the intervention and if so, what bearing might this have on the review?

Section "Barriers to exercise in PwP" – this section clearly communicates the problems with the translation of evidence for exercise into the real-world setting. The last paragraph could include a summary sentence. What are the implications for the review from the outcomes of short-term and long term strategies?

Methods

The methods are mostly clear and follow the expected process for a systematic review. Some clarifications:

- Inclusion and exclusion criteria

  For (i) Population, exclusion criterion b: please amend "wheelchair-bound" to "wheelchair user" ("wheelchair user" is the preferred, more inclusive term)

  (iv) Setting: The study excludes acute hospitals. I see the rationale for this for current hospital inpatients or people who had a recent admission. However, would this exclusion apply if an outpatient intervention for community-dwelling people with Parkinson's happened to be delivered at an acute hospital? The service arrangements for delivery of outpatient care to people with Parkinson's might vary among health services and interventions meeting criteria (ii) could occur at an acute, specialist neurological hospital. If a study's population, intervention, and outcome(s) meet the inclusion criteria, should it not be included, irrespective of where it took place?

- Data extraction – do the authors have a plan for identifying and handling duplicate data (for example, where the same trial produced multiple papers with secondary analyses?)

The final article needs a thorough proofread as several minor errors remain in this version.

Is the rationale for, and objectives of, the study clearly described? Yes

Is the study design appropriate for the research question? Yes

Are sufficient details of the methods provided to allow replication by others? Yes

Are the datasets clearly presented in a useable and accessible format? Not applicable

Competing Interests: No competing interests were disclosed.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Author Response 16 Jul 2022

Leanne Ahern

Thank you so much for taking the time to review our manuscript, and for your constructive comments. Responses and subsequent changes to the manuscript are detailed below.

Comment: The Introduction clearly conveys the state of the evidence in favour of the myriad benefits of exercise in Parkinson's and the problem of inactivity. The review refers almost exclusively to "exercise" but the interventions might have an effect on habitual physical activity, too. Does the review intend to focus exclusively on exercise (structured, planned, repetitive, intentional), as distinct from physical activity (also including unstructured/incidental movement)? (I see that "physical activity" is a search term, but the rest of the review refers to "exercise".)

Response: Thank you for this comment, with was a factor in which we overlooked

Action: Paragraph added to the introduction regarding physical activity. This review intends to focus on both exercise and physical activity

Comment: The last paragraph under the subheading "Exercise in Parkinson's" presents the Sajatovic study, which compared a group-based exercise and self-management program with an individual exercise and self-management program. Participants in the group program showed additional improvements in depression scores, but were these differences seen within-group or between-group? Is the key difference, then, the mode of delivery (group v individual) rather than the components of the intervention and if so, what bearing might this have on the review?

Response: Thank you for this comment as it is important that the information is clear for the readers. Upon further review of the paper, the differences that were reported in this review were within-group, therefore, highlighting that the differences are not solely related to mode of delivery.

Action: Rephrasing and more information provided to ensure clear message is conveyed regarding the results of this study

Comment: Section "Barriers to exercise in PwP" – this section clearly communicates the problems with the translation of evidence for exercise into the real-world setting. The last paragraph could

include a summary sentence. What are the implications for the review from the outcomes of short-term and long-term strategies?

Response: Thank you for this comment

Action: Included summary sentence at end of paragraph

Comment: The methods are mostly clear and follow the expected process for a systematic review. Some clarifications: Inclusion and exclusion criteria

For (i) Population, exclusion criterion b: please amend “wheelchair-bound” to “wheelchair user” (“wheelchair user” is the preferred, more inclusive term)

(iv) Setting: The study excludes acute hospitals. I see the rationale for this for current hospital inpatients or people who had a recent admission. However, would this exclusion apply if an outpatient intervention for community-dwelling people with Parkinson’s happened to be delivered at an acute hospital? The service arrangements for delivery of outpatient care to people with Parkinson’s might vary among health services and interventions meeting criteria (ii) could occur at an acute, specialist neurological hospital. If a study’s population, intervention, and outcome(s) meet the inclusion criteria, should it not be included, irrespective of where it took place?

Response: Thank you for this comment, we agree that clarification is needed.

Action: The suggestions have been considered and amendments have been made regarding the inclusion criteria for the population and the setting. ***Competing Interests:*** None

Reviewer Report 11 March 2022

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Katherine Baker

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Thank you for the opportunity to review this manuscript. The proposed review will make an important contribution to the evidence base.

Abstract: Provides a useful summary and rationale for the review. Methods could include study designs that will be included.

Introduction: includes relevant and contemporary work in the area. This section clearly outlines the need to better understand ways of influencing behaviour change. As the Theoretical Domains Framework and Behaviour Change Wheel are proposed as the theoretical frameworks for the review, it would be appropriate to acknowledge them here.

Review objectives: exercise adherence is not identified as an outcome in the second objective, consider including this given the third objective which talks about the strategies but not adherence as an outcome.

Methodology: it is interesting that you propose a qualitative synthesis when the review inclusion criteria allow only quantitative study designs. Further explanation is needed on how this will be done.

There are typographical mistakes throughout, please review carefully.

Is the rationale for, and objectives of, the study clearly described? Yes

Is the study design appropriate for the research question? Yes

Are sufficient details of the methods provided to allow replication by others?
Partly

Are the datasets clearly presented in a useable and accessible format? Not applicable

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Physiotherapy, Parkinson's, physical activity and exercise
I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard, however I have significant reservations, as outlined above.

Author Response 16 Jul 2022

Leanne Ahern

Thank you so much for taking the time to review our manuscript, and for your constructive comments. Responses and subsequent changes to the manuscript are detailed below.

Comment: Abstract: Provides a useful summary and rationale for the review. Methods could include study designs that will be included.

Response: We agree with this comment and believe it would provide important information to the readers

Action: Sentence “Interventional studies including behavioural change interventions will be included in this review” was included in the abstract

Comment: Introduction: includes relevant and contemporary work in the area. This section clearly outlines the need to better understand ways of influencing behaviour change. As the Theoretical Domains Framework and Behaviour Change Wheel are proposed as the theoretical frameworks for the review, it would be appropriate to acknowledge them here.

Response: We agree with this comment and admit it was an element which we overlooked. Thank you for this comment.

Action: Paragraphs regarding the Theoretical Domains Framework and Behaviour Change Wheel have been included in the introduction

Comment: Review objectives: exercise adherence is not identified as an outcome in the second objective, consider including this in the third objective which talks about the strategies but not adherence as an outcome.

Response: We agree with this comment as exercise adherence is referred to many times in the article.

Action: Exercise adherence included as an outcome in the second objective

Comment: Methodology: it is interesting that you propose a qualitative synthesis when the review inclusion criteria allow only quantitative study designs. Further explanation is needed on how this will be done.

Response: Thank you for this comment, we were not aware of the lack of transparency with regards to this.

Action: Methods section has been amended to a narrative synthesis with the addition of assessment for eligibility for meta-analysis

Competing Interests: No competing interests were disclosed.

Journal of Frailty, Sarcopenia and Falls

Review Article

A systematic review of Behaviour Change Interventions to improve exercise self-efficacy and adherence in people with Parkinson's disease using the Theoretical Domains Framework

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Abstract

Physical activity and exercise can limit the development of sarcopenia in Parkinson's Disease. This review aims to evaluate the potential effects of behavioural change (BC) interventions on exercise self-efficacy and adherence in people with Parkinson's Disease. We searched nine databases and included randomised and non-randomised studies reporting exercise self-efficacy, quality of life (QoL), physical function and/or exercise adherence. Two reviewers independently screened, data extracted and assessed risk of bias and certainty of evidence. The interventions were mapped to the Theoretical Domains Framework. Eleven studies (n=901) were included. Four were randomised trials and risk of bias was mixed. Most interventions were multi-component, including education, behavioural techniques, and support groups. The most effective domains appear to be *Behavioural regulation, Belief about Capabilities, Social influences, Reinforcement and Goals*. Future research should examine multi-component BC interventions encompassing the five most effective TDF domains.

Keywords: Behavioural Change Interventions, Parkinson's Disease, Physical Function, Quality of Life, Theoretical Domains Framework

Introduction

Parkinson's Disease is a progressive neurodegenerative condition with motor and non-motor symptoms[1,2]. Disease progression leads to muscle atrophy, reduced physical capacity, and impacts vitality. People with Parkinson's Disease (PwP) are three times more likely to develop sarcopenia and fall twice as often compared to age-

matched healthy controls[2-5]. PwP have an annual falls incidence of 60%[6], highlighting falls are a serious concern.

Maintaining an active lifestyle is essential to reduce sarcopenia and fall risk in PwP[7]. However, PwP are 30% less active than healthy age-matched controls[8,9], keeping active for only 30% of the day[9]. Only 30% of PwP meet the World Health Organisation's recommended activity guidelines[9]. "Physical activity" is described as any bodily movement produced by skeletal muscles resulting in energy expenditure[10], including unstructured or incidental

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movement while "exercise" is planned, structured, and purposeful, with the aim to improve or maintain one or more components of physical fitness[10].

Exercises can improve muscle strength, aerobic fitness, and balance in PwP[11]. A recent pilot study[12] (n=30) showed that a 24-week high intensity interval training

The authors have no conflict of interest.

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Inclusion Criteria	Exclusion Criteria
Population, or participants and conditions of interest: Community dwelling independently mobile people with Parkinson's Disease (Hoehn and Yahr stage 1-4; i.e. mobile without assistance of another person when "on").	a) Diagnosis of Atypical Parkinson's (e.g. Progressive supranuclear palsy) b) Current inpatients or had a recent hospital admission (< 6 weeks ago) c) Immobile or a wheelchair-user d) Severe visual or auditory impairment, serious medical conditions in major organs (heart, lung, or kidney) or other illnesses which prevented independent ambulation. e) Identified as a high falls risk (fallers)
Intervention: Any form of behavioural change intervention (e.g. education, behavioural technology) or support strategy used in conjunction with exercise	The intervention; a) did not include self- efficacy strategies or behavioural change strategies. b) did not include an exercise component c) focused solely on falls prevention
Comparator: Comparator groups must include people with a Parkinson's Disease diagnosis. A specific intervention type was not defined for the purpose of inclusion (comparator groups including but not limited to exercise alone, usual care or waiting list were included)	Comparator group including non-Parkinson's Disease individuals.
Outcomes of interest: a) Exercise self-efficacy measures (e.g. Self-efficacy for exercise scale, Physical Activity Assessment Inventory) b) Quality of life (e.g. PDQ-39. PDQ-8, EQ5D) c) Physical function (e.g. 6MWT, gait velocity) d) Exercise adherence (e.g. self-log, activity monitors).	Other outcomes (e.g. medication adherence, changes in anxiety and depression) Self-efficacy outcomes related to the management of a chronic condition rather than exercise self-efficacy
Setting: Community gyms/halls, community outpatient facilities, acute hospitals (if the intervention was conducted with community dwelling PwP in hospital-based gyms or clinics), or the home environment	Study interventions carried out in acute hospitals with inpatients, or in long term care facilities
Study design: Interventional studies: Randomized control trials, quasi-experimental trials, pilot interventional studies, pre- and post- interventional studies, and feasibility studies.	Qualitative studies, observational studies, or systematic reviews

Table 1. Inclusion and exclusion criteria.

significantly increased leg lean mass, appendicular muscle mass, walking endurance and physical performance[12]. While a systematic review conducted Chung et al.[13] (7 studies, n=401 participants) demonstrates that intensive progressive resistance training, 2-3 times per week over 8-10 weeks can result in significant strength, balance and motor symptoms improvements in people with early to moderate Parkinson's disease[13]. Further to this, a large scale randomized controlled trial (n=231)[14] compared PwP who exercised 40 to 60 minutes, 3 times weekly to usual care for 6 months[14]. They found that an exercise programme targeting balance, leg strength, and freezing of gait improved physical and psychological health[14]. Falls were reduced in people with milder disease but not in those with more severe Parkinson disease[14]. These studies show that exercise can improve muscle strength and physical function and in turn reduce the risk of developing sarcopenia and falls in those with early to moderate Parkinson's Disease.

From these studies, we can see that interventions require adherence to intensive exercise lasting over three months. It is established that non-motor features are a considerable barrier to exercise among PwP. Apathy may be defined simply as a loss of motivation, appearing as though the person is lazy or uncaring[15]. A recent meta-analysis (18 studies; n=1,144 participants)[16] would suggest that exercise alone fails to improve non-motor

symptoms. However, Tennigkeit et al.[16] found when exercise is combined with behavioural strategies to help disease management, the results were more promising.

Strategies including videos, role-playing, education sessions, and self-monitoring (symptom diaries) led not only to improved mobility and QoL, but also improved selfefficacy and depression, suggesting behavioural change (BC) approaches may help non-motor symptoms. However, it remains unknown whether these techniques further led to better exercise adherence and more physical activity, suggesting that a comprehensive review of exercise behavioural strategies is indicated.

Exercise self-efficacy is positively correlated to more exercise behaviour and adherence[17,18]. Speelman et al.[19] has shown that BC approaches (coaching, goal setting, activity monitors) are widely accepted by participants, and perceived as effective[19], with the activity monitor being identified as the most useful tool[19]. Ellis et al.[20] has shown that short daily interactions (five minutes/day) with a virtual coach is also well accepted among participants[20]. However, their effects on adherence and physical activity remains unclear.

Behavioural change interventions aim to overcome barriers to behaviour. Atkins et al's[21]. Theoretical Domains Framework (TDF) provides a structure to understanding the barriers and motivators to behaviour (in this case, exercise among PwP), and can be used to classify BC interventions and their components. This may, in turn, explain the how interventions facilitate exercise adherence and help identify the effective core components across interventions.

In short, to motivate PwP to remain active to help reduce the risks of sarcopenia, falls, and frailty, it is important to identify BC interventions that overcome barriers to exercise, to improve exercise self-efficacy and adherence, which in turn, lead to less falls, greater strength, fitness, and better quality of life (QoL). To the best of our knowledge, no previous review has explored the effects of BC interventions on exercise self-efficacy and adherence among PwP. This review aims to address this evidence by providing recommendations for self-management approaches.

Review objectives

This review aimed to synthesise the available evidence on BC interventions to improve exercise adherence among PwP. Specifically, this review aimed to:

1. Describe the most common behaviour change interventions to improve exercise adherence
2. Map the identified intervention components to the Theoretical Domains Framework.
3. To determine the effects of the BC intervention on exercise self-efficacy, QoL, physical function, and exercise adherence.

Methods

This review was conducted guided by the Joanna Briggs Institute (JBI) Reviewer's Manual[22] and reported using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses guidelines[23]. The protocol was registered with PROSPERO (ID: CRD42021293057) and is published online (https://doi.org/10.12688/hrbopenres.13474.2). We included randomised and non-randomised studies to provide evidence of effect, recognising that non-randomised studies provide less robust evidence.

Eligibility Criteria

We included full-text studies reporting exercise selfefficacy, exercise uptake and adherence in PwP's and published in English. PwP diagnosed with other comorbidities (e.g. anxiety, depression, and diabetes) were included. See Table 1 for eligibility criteria.

BC interventions are defined as complex coordinated sets of activities devised to change specified

behaviour patterns[24]. *BC techniques* are defined as complex, observable, and reproducible components of an intervention designed to alter behaviour[25], such as goal- setting, decision-making or problem solving. Finally, *exercise self-efficacy* was defined as an individual's confidence or belief that they can successfully engage in physical activity or exercise[26,27].

The primary outcomes of interest were exercising selfefficacy, QoL, physical function and exercise adherence and every timepoint was considered.

Database searching

The search strategy was developed by the primary author (LA) and supported by an experienced librarian (VC). A search of nine databases (Table S1) from inception to 10th September 2023 was performed (LA).

Study selection and article screening

Identified articles were uploaded to Endnote X8. Following de-duplication, titles, abstracts, and full texts were independently screened by two reviewers (LA, RMcC), using the search terms displayed in Table S1. The reference lists of the included articles and topical reviews were hand-searched. Any disagreement regarding inclusion was discussed with a third reviewer (ST).

Data extraction

One reviewer (LA) extracted the data. A second reviewer (RMcC) randomly selected four studies to verify data extraction methods. Data extracted included author, year, country, study design and size, participant characteristics, disease severity, details of the exercise and BC interventions, results, and theoretical framework used.

Risk of bias assessment

Three independent reviewers (LA, RMcC and ST) assessed the risk of bias using the Cochrane Risk of Bias Tool (Version 2)[28] for randomised controlled trials (RCTs) and the ROBINS-I tool[29] for non-randomised trials, as recommended[30]. Any ambiguity was reviewed, and a consensus was achieved.

Mapping to the Theoretical Domains Framework (TDF)

The extracted intervention components were mapped to the Theoretical Domains Framework (TDF), using Atkins

et al.[21] for guidance. Using the coding described by Atkins et al.[21], two researchers (LA, RMC) extracted the suitable codes, and assigned them to the TDF domains. Codes were re-reviewed by three researchers (LA, RMcC and ST) to confirm final allocation.

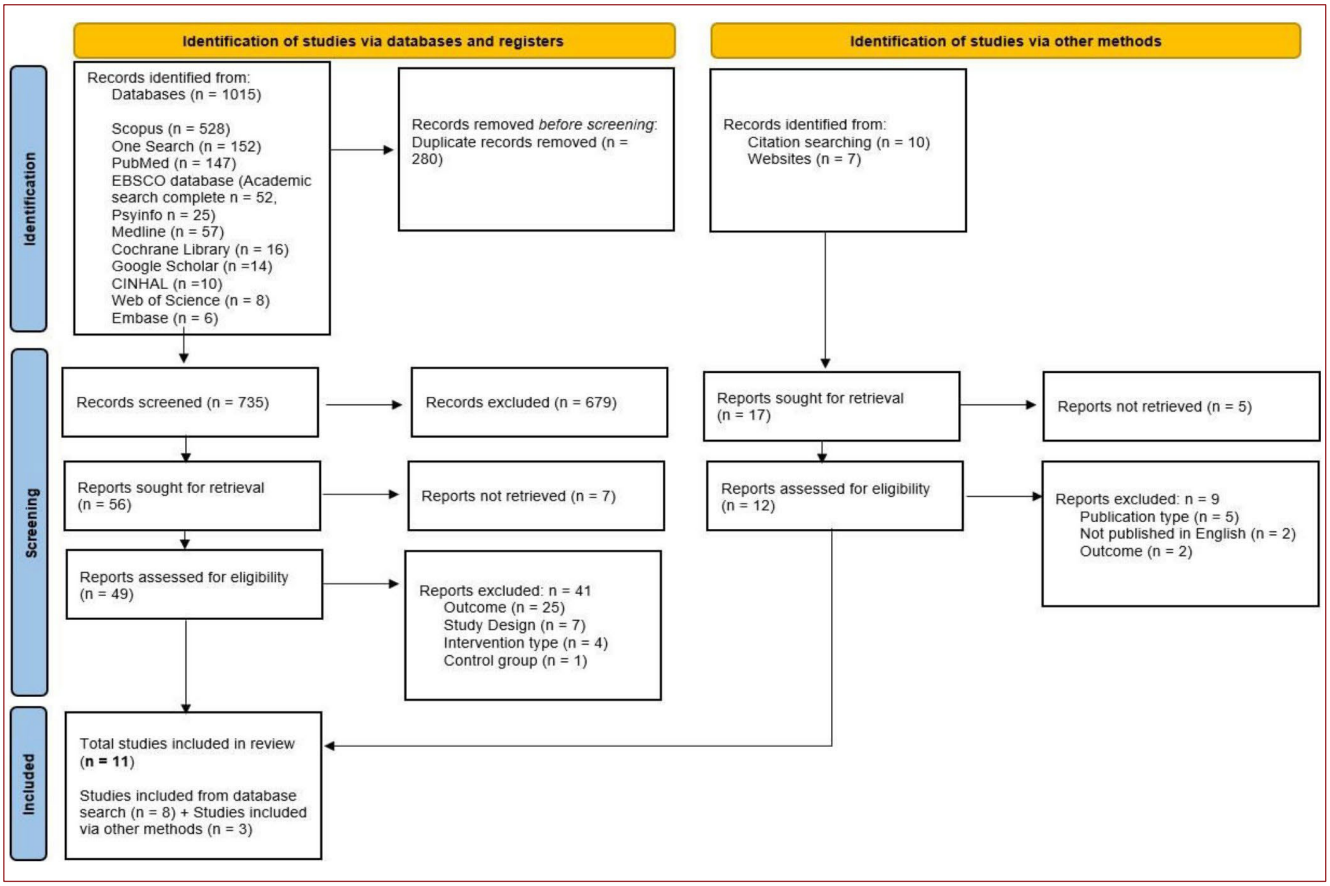


Figure 1. PRISMA flowchart.

Data synthesis

We completed a narrative synthesis to examine the effects of BC interventions. Components of the effective BC interventions were mapped to the TDF, to identify which barriers and facilitators were addressed in the effective interventions. Negative effects were also recorded. We attempted a meta-analysis, but the heterogeneity between studies led to a very small number of studies being included in each model, with low/very low certainty in the evidence.

Results

Study selection

After completing the searches, 1032 articles were identified, 61 full-text articles were reviewed and finally eleven articles (2002-2020) (n=901) were included (Figure 1). Table 2 describes the characteristics of the included studies.

Description of studies

Study Characteristics

Study quality was mixed. Included were four randomized controlled trials (Tickle-Degnen et al.[31], n=107; van Nimwegen et al.[32], n=586; Ellis et al.[33], n=51; Peteet[34], n=19), two n-RCTs (Lee et al.[35], n=42; Lai et al.[36], n=20) and five single-arm feasibility studies (Landers and Ellis[37], n=28; Long[38], n=13; Hermanns et al.[39], n=5; Ellis et al.[20], n=20; Colon- Semenza et al.[44], n=10).

Control group interventions were described as no rehabilitation[31], standard exercise intervention[32-34,36] and usual pharmacological care only[35]. Most studies were conducted in the United States of America[20,31,33,34,36-40], one in South Korea[35] and one in the Netherlands[32].

Risk of bias within studies

The outcome of the risk of bias assessment of the RCTs was mixed. Only Ellis et al.[33] was considered to have a low

Table 2. Study characteristics and description of interventions of included trials.

First Author, Publication year, Country, Study design, Participants, Sample Size	Aim	Programme Facilitator/s	Behavioural Change		Exercise Intervention	Comparator intervention	Outcome Measures
			Behavioural change framework	Mode of delivery	Intervention type, FITT, Setting		
Colón-Semenza et al.(2018)[40] USA **Feasibility study** (Mixed methods) Idiopathic Parkinson's Disease (H&Y stage 1- 3) **Total: n=10** (5 coaches; 5 mentees) Peer coaches: Age: 64.6 ± 4.04 Sex: 3/2 (M/F) Peer mentees: Age: 63.4 ± 2.06 Sex: 3/2 (M/F)	To develop a PD-specific peer coach training programme and a remote peer-mentored walking programme using mHealth technology with the goal of increasing physical activity in persons with PD.	Peer coaches *Training Programme* 1) Peer coaches were asked to review printed and Web- based educational materials independently over a 1- to 2-week period. 2) Peer coaches participated in two,4-hour, in-person training sessions	1) Self-determination theory. 2) Social Cognitive Theory	***Multi-component Behavioural Change Components: Technology + Support Groups*** *Peer-mentored walking program:* 1) The peer coaches and mentees were given a wireless activity tracker (FitBit Zip). 2) Coaches were instructed on how to become friends on the Fitbit mobile app, so as to instruct mentees during their initial interaction. 3) Within 1 week after training, peer coach scheduled initial conversation focusing on establishing rapport, jointly determining the 8-week walking goal for the mentee, and developing the initial action plan. 4) Peer coach and mentee did not walk together, but in their own self-selected environment. 5) Peer pairs viewed the steps they accumulated over the week using the FitBit friends' option. This feature allows remote interaction between the peer coach and peer mentee, allowing regular feedback (ie, cheering with an emoji or instant messaging) on progress toward goals. 6) Mentees could see the coach's step counts, providing a social comparison and vicarious experiences to improve self-efficacy. *Weekly Phone Calls:* 1) The peer coach and mentee engaged in phone conversations weekly. 2) Peer coaches had checklists to guide peer discussions to ensure that they were adhering to the recommended techniques for peer mentoring. 3) These were: assessing the walking activity goal, progress made, problems encountered, strategies to overcome barriers, and resources available. **Frequency**: Self-selected. **Duration**: 8 weeks. **Setting**: Self-selected environment	Self-regulated exercise in self-selected environment. **Duration**: 8 weeks	No control group	1) Activity tracker. 2) Self-efficacy for Walking Duration. 3) LLFDI

Ellis et al. (2013)[20] USA **Single group prepost study** Idiopathic Parkinson's Disease (H&Y stage 1.5-3) **Total: n=20** Age: 65.5 ± 5.6 Sex: 9/11 (M/F)	To explore the feasibility, acceptability, and preliminary evidence of the effectiveness of a virtual exercise coach to promote daily walking in community-dwelling persons with Parkinson disease	N/A	None	***Multi-component Behavioural Change Components: Technology + Support Groups*** *Activity monitor in conjunction with Virtual Coach (focused on promoting walking):* 1) Participants instructed to wear a pedometer and walk daily for 1 month and to interact with the virtual exercise coach for 5 mins per day. 2) Conversations with the virtual exercise coach were dialogue and other media designed to promote health behaviour change and conversational nonverbal behaviour designed to build a relationship and a therapeutic alliance. 3) A daily 5-min conversation typically was: a greeting, social chat, and well-being check-in to see whether the participant needed to progress or suspend their walking programme and to provide empathic opportunities.	Participants were instructed to walk daily for 1 month (No specified exercise intervention)	No control group	1) Useability and Acceptability (Activity monitor steps). 2) Safety. 3) Efficacy (6MWT; Gait speed; Self-selected walking speed)

First Author, Publication year, Country, Study design, Participants, Sample Size	Aim	Programme Facilitator/s	Behavioural Change		Exercise Intervention	Comparator intervention	Outcome Measures
			Behavioural change framework	Mode of delivery	Intervention type, FITT, Setting		
				4) After this, participants plugged their pedometer into the system to upload their steps. 5) The virtual coach reviewed their progress relative to short-term and long-term goals, provided positive reinforcement if warranted, identified barriers to walking, and engaged the participant in a problem-solving discussion for any barriers identified, then negotiated a new short-term goal, if warranted. 6) The session closed with an exercise tip of the day. Each day's dialogue varied in content and structure and was augmented with additional media for participant engagement and retention. **Frequency**: Self-selected. **Duration**: 1 month. **Setting**: Self-selected environment.			

Ellis et al. (2019)[33] USA RCT Idiopathic Parkinson's Disease (H&Y stage 1-3) Total: n=51 Age: 64.1 ± 9.5 Sex: 28/23 (M/F) Intervention: 26 Age: 64.8 ± 8.5 Sex:15/11 (M/F) Control: 25 Age: 63.3 ± 10.6 Sex: 13/12 (M/F)	To explore the preliminary effectiveness, safety, and acceptability of a mobile health (mHealth)-mediated exercise programme designed to promote sustained physical activity in people with PD.	A licensed physical therapist with expertise in PD to develop an individualized exercise and walking program. Exercises were adapted remotely over time by the physical therapist in response to improvements or setbacks experienced by participants	None	***Behavioural Change Component: Technology*** *mHealth App* The mHealth condition was used in conjunction with the individualized exercise and walking programmes. It included: 1) Remote monitoring, 2) More accessible communication, 3) More frequent programme adaptation by a physical therapist. 4) Incremental walking and exercise goals were entered into the mHealth app. 5) Action plans included what (which exercises, duration of walking), how (appropriate technique), when (time of day, days per week), and where (community, mall) for exercise. 6) Notifications (ie, automated prompts and reminders) were used to motivate participants 7) Exercises were adapted remotely over time by the therapist in response to improvements or setbacks. 8) Adherence and progress toward goals was graphically displayed to allow participants to track their own performance. 9) Triggered contact between the physical therapist and participants during a change in the pattern of exercise adherence (i.e., unexplained lack of engagement > 1 week), a participant-reported acute health condition or a participant-initiated question about the program. **Frequency**: Daily interaction with mHealth app. **Duration**: 12 months. **Setting**: Self-selected environment. Both exercise and control interventions of the programme included standard elements designed to promote behavioural change. These included: 1) Participant goal setting, 2) Tailoring the programme to participants' preferences, and 3) The provision of feedback via activity trackers.	The programme was developed from a predetermined set of exercises based on the American Parkinson Disease. Association "Be Active and Beyond" programme (included strengthening and stretching exercises).Walking Component: Consisted of an individualized recommended range of steps per day (e.g., 5000-7500 or 7500-10,000) that was determined from each participant's baseline activity level. **Frequency:** Exercise component 5 to 7 exercises for ≥3d/wk. Walking component Individualized recommended range of steps per day (e.g.,5000-7500 or 7500- 10,000). **Duration:** 12 months. **Setting:** Self-selected environment.	Stretching and strengthening exercises provided using printed photographs; walk daily using a pedometer; interact with a physical therapist at the beginning of the study only; **no use of mobile technology**	1) StepWatch Activity Monitor. 2) PDQ-39. 3) 6MWT

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First Author, Publication year, Country, Study design, Participants, Sample Size	Aim	Programme Facilitator/s	Behavioural Change		Exercise Intervention	Comparator intervention	Outcome Measures
			Behavioural change framework	Mode of delivery	Intervention type, FITT, Setting		
Hermanns et al. (2019)[39] USA **Feasibility** pre-post- study Idiopathic Parkinson's Disease (H&Y stage 1-4) **Total: n=5** Age: 73 ± 4.95 Sex: 3/2 (M/F)	1) To assess the feasibility of an intervention that requires wearing a physical activity tracker and participating in an online support group, and 2) To examine the effect of this intervention on the self-efficacy for physical activity and QOL of older adults with PD.	Physical Therapist	Social Cognitive Theory	***Multi-component Behavioural Change Component: Technology + Support Groups*** *Activity Tracker:* 1) Participants were given physical activity tracker. *Online Support:* 1) Participants were instructed to engage in a private online support group where they would engage in education session, share what exercises or other physical activity they performed, their overall perceived health, and other PD resources with the other study participants. **Frequency**: Minimum three times per week. **Duration**: 12 weeks. **Setting**: Self-selected environment.	1) Participants were provided with an iPad. 2) Three videos were preloaded and available for viewing: warm-up and two additional videos of specific exercises for balance, rigidity, and gait. 3) Beginning with the seated warm-up video performed by therapist- included stretching. 4) Instructed to select one of the two remaining videos for large muscle exercise. **Frequency**: Three times per week. **Duration**: 12 weeks. **Setting**: Self-selected environment.	No control group	1) Physical Activity Assessment Inventory. 2) Functional Assessment of Cancer Therapy-General. 3) Physical activity tracker

Lai et al.(2020)[36] USA **Preliminary Quasi-experimental (Mixed methods)** Idiopathic Parkinson's Disease (H&Y stage 1-3) **Total: n=20** Intervention: 10 Age: 63.4 ± 10.4 Sex: 7/3 (M/F) Control: 10 Age: 70.8 ± 7.1 Sex: 7/3 (M/F)	To inform future, large-scale trials that aim to implement Internet-exercise interventions in Parkinson's disease	Physical Therapist	Social Cognitive Theory	***Behavioural Change Component: Technology*** *Telecoach TAE group to* 1) Participants received oneto-one exercise training through the telehealth system. 2) The system allowed telecoaches to monitor vital signs remotely in real-time during the exercise sessions and communicate with participants through videoconferencing. 3) A telecoach accompanied and observed the participant for all of each exercise session. 4) In addition to ongoing verbal support during exercise training, participants received behavioural coaching at the initial home visit (20 min). 5) Behavioural coaching aimed to instruct participants on proper exercise technique to increase mastery; discuss barriers or issues with the participant's ability to attend the exercise sessions; help participants set achievable goals to complete the exercise prescription; provide verbal encouragement to achieve the desired exercise workload; answer questions related to exercise and discuss the benefits of exercise. **Frequency**: 3 sessions per week. **Duration**: 8 weeks (Total: 24 sessions). **Setting**: Self-selected environment.	1) Both the TAE and SRE group received a home visit prior to starting the intervention and the same exercise prescription of combined aerobic and strength exercises. 2) Participants were told to perform moderate aerobic exercise within 40-60% of their heart rate reserve, using telehealth system & stationary recumbent cycle. 3) For strength exercises, participants used adjustable ankle weights (1-5 lb) to perform 2-3 sets of 10-20 repetitions for major lower-extremity muscle groups. 4) Participants were informed that they could independently perform 'more or less exercise' than prescribed, as long as they were connected to the telehealth system. **Frequency**: 165 minutes per week. **Duration**: 8 weeks (Total: 24 sessions). **Setting**: Self-selected environment.	*SRE group (No telecoach):* 1) Participants independently managed their exercise training using the telehealth system. 2) The journal was used to record their progress and included written instructions on exercise techniques. 3) Participants were told that exercise data during sessions were recorded for later inspection by a telecoach, on weekly basis. 4) Participants were given the contact information of a telecoach to discuss exercise-related questions or technical issues with equipment. 5) Similar to the TAE group, SRE participants received a behaviour coaching session at initial home visit.	1) Measures of adherence: (a) the total number of exercise sessions performed, (b) time in minutes exercising per week, (c) time exercising at a moderate aerobic intensity per week, and (d) attendance. 2) Walking Capacity (walking capacity (6MWT, and comfortable and fast walking speed)

First Author, Publication year, Country, Study design, Participants, Sample Size	Aim	Programme Facilitator/s	Behavioural Change		Exercise Intervention	Comparator intervention	Outcome Measures
			Behavioural change framework	Mode of delivery	Intervention type, FITT, Setting		
						Frequency: 3 sessions per week. **Duration**: 8 weeks (Total: 24 sessions). **Setting**: Self-selected environment.	
Landers and Ellis (2020)[37] USA **Single-arm pilot study** People with Parkinson's disease (self-reported) who had downloaded the commercially available app **Total: n=28** Age: 62.1 ± 9.6 Sex: 6/14 (M/F) (8 unspecified)	To test the feasibility, safety, and signal of efficacy of a mobile app that facilitates exercise for people with Parkinson disease	The customized exercise regimen was constructed and developed by physical therapists	None	***Behavioural Change Component: Technology:*** *Online Mobile Exercise App:* 1) After registering on app and completing several self- report Likert scale questions and performance-based assessments, exercise regimen was made for participant's level of function. 2) The customized exercise regimen was constructed and developed by physical therapists. 3) The app chose the exercise programme based on the primary goal (ie, mobility) and then used the responses from self-report questions and the data from performance-based tests to determine the severity of the PD. 4) From this information, the app selected exercises consistent with the primary goal and at the appropriate level of function based on one's severity of Parkinson disease. 5) At preset intervals (generally after 2 weeks), the app reassessed functional capacity (same self-report questions and performance-based measures). Type, duration, and intensity of each exercise was adjusted in the exercise regimen. **Frequency**: 150 mins per week. **Duration**: 12 weeks. **Setting**: Self-selected environment.	Aerobic, strengthening, balance, yoga based, range of motion/stretching, meditation based, and speech therapy exercises. **Frequency**: At least 150 minutes per week. **Duration**: 12 weeks. **Setting**: Self-selected environment.	No control group.	1) Feasibility. 2) Safety. 3) Efficacy (30- second STS; Timed Up and Go; PDQ-8.

Lee et al. (2019)[35] South Korea **Quasi-experimental study (With a non-equivalent control group)** Idiopathic Parkinson's Disease (H&Y stage 1-3) **Total: n=42** Intervention group: 22 Age: 62.73 ± 8.50 Sex: 13/9 (M/F) Comparison group: 20 Age: 62.20 ± 5.27 Sex: 12/8 (M/F)	To test the effects of group exercise and telephone counselling on physical and psychosocial health in people with Parkinson's disease.	Classes were supervised by three experts who were doctoral students majoring in geriatric nursing or sports medicine and who had previously participated in exercise programmes for participants with chronic disease. Counselling-NR.	Social Cognitive Theory	***Behavioural Change Component: Support Groups:*** *Motivational Telephone Counselling:* 1) Telephone counselling was delivered to motivate continuation of exercise and obtain feedback on the group exercise program. 2) Counselling content included: (a) Have you lately experienced any health problems such as a fall or unpleasant symptoms? (b) Has any positive or pleasing change occurred since you began participating in the group exercise program? If so, what is it? (c) Has any negative or unpleasant change occurred since you began participating in the group exercise program? If so, what is it? Let's think about what we could do to solve the problem. (d) Are you willing to participate in the group exercise programme consistently? If not, what is the reason for your decision? (e) Is there anything more that you want to talk about or suggest? **Frequency**: Once every 2 weeks. **Duration**: 12 weeks. **Setting**: Sporting facility.	The group programme consisted of 10 minutes of warm- up (range of motion exercise and stretching were conducted for relaxation of muscles and joints), 15 minutes of aerobic exercise (line dancing), 15 minutes of resistance exercise (upper limb theraband exercises; lower limb body weight exercises), and 10 minutes of cool down (stretching). **Frequency**: Twice a week. **Duration**: 12 weeks. **Setting**: Group classes in sporting facility.	Usual Care-Pharmacological treatment from outpatient clinic.	1) The International Physical Activity Questionnaire-Short Form. 2) The Schwab and England Activities of Daily Living Scale. 3) Short Form Geriatric Depression Scale-Korean Version. 4) 30-second STS. 5) TUG. 6) Berg Balance Scale. 7) 6MWT. 8) PDQ39.

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First Author, Publication year, Country, Study design, Participants, Sample Size	Aim	Programme Facilitator/s	Behavioural Change		Exercise Intervention	Comparator intervention	Outcome Measures
			Behavioural change framework	Mode of delivery	Intervention type, FITT, Setting		
Long (2020)[38] USA **Single arm feasibility study** Idiopathic Parkinson's Disease (H&Y stage 1-2) **Total: n=13** Age: 61.69 ± 9.14 Sex: 9/4 (M/F)	To evaluate feasibility, acceptability and preliminary efficacy for PA levels, self-efficacy, motivation, and self-perception of performance	Occupational Therapist	1) Bandura's Self-Efficacy Theory. 2) Self-Determination Theory Further supported by The Transtheoretical Model of Behaviour Change and 3) The Transformative Exercise Framework.	***Multi-component Behavioural Change Components: Technology + Support Groups + Education + Behavioural Techniques:*** *Activity monitor (tracking and feedback):* a Fitbit PA monitor with online monitoring platform. *Therapist support (emphasizing stages of change):* 1) Participant/therapist interaction (included discussing the stages of change, motivational interviewing: positive reinforcement, goal setting). 2) Sessions that occurred over the following 14 weeks (week 1, 2, 3, 6, 10, and 14). The therapist checked-in with the participant via phone or email to provide additional support and feedback on the weeks when the participant did not have one-to-one sessions (week 4,5, 7, 8, 9, 11, 12, and 13). *Educational workbook (emphasizing self-management strategies and self-efficacy):* a PD-specific PA workbook (included information of physical activity and PD-specific exercise benefits, overcoming challenges, developing a physical activity plan, goals and targets, safety and monitoring and recording physical activity and progress). **Frequency**: Six one-to-one sessions. **Duration**: 14 weeks. **Setting**: Self-selected environment	No specific exercise component- Participants engaged in self-regulated exercise in self-selected environment.	No control group	1) Activity tracker. 2) Brunel lifestyle inventory Physical Activity Questionnaire. 3) The Exercise Self-Efficacy scale. The Behavioural Regulation in Exercise Questionnaire. 4) Modified Canadian Occupational Performance Measure.

Peteet (2002)[34] USA **Pilot RCT** Idiopathic Parkinson's Disease (H&Y stage 2-3) **Total: n=19** Age: 60.89 ± SD NR Sex: 12/7 (M/F) Intervention: 8 Age: 58 ± 6.59 Sex: 5/3 (M/F) Control: 11 Age: 63 ± 9.52 Sex: 7/4(M/F)	NR	Physical Therapist (exercise) Instructor (self-management program).	1) The Health Belief Model. 2) The Transtheoretical model (stages of change). 3) Social Learning theory.	***Multi-component Behavioural Change Components: Behavioural Techniques + Education:*** *Self-management educational program:* 1) Instructor-led group discussion of topics including exercise barriers, fall prevention, strategies for relaxation, physical activity action planning and feedback, modelling of behaviour by participants for one another, reinterpretation of symptoms by giving many possible causes for each symptom, management strategies for symptoms, and individual decision making. 2) Informal group problem solving, 3) Individualized self-management exercise plans for participants. **Frequency**: 45 mins per session, once per week. **Duration**: 6 weeks. **Setting**: Group session (setting NR).	1) Warm-up (bicycle, upper-extremity ergometer, stretching exercises to the legs and arms, and mobility exercises to the neck, trunk, aims and legs. 2) Aerobic component using theraband and/or weights for strengthening. Treadmill and overground walking with varying speeds and frequencies was used along with external visual (e.g., stripes on the floor) and auditory (e.g.,metronome or music). 3) Functional activities like turning in bed, transferring to sitting & standing, and stairs. 4) Introduction of recreational activities, such as ball games and aerobics. 5) Relaxation exercises. 6) Cool down. **Frequency**: 45 mins session, once/ week. **Duration**: 6 weeks. **Setting**: Group session (setting NR).	Control group engaged in exercise component only. Both groups participated in the same standard exercises.	1) The Physical Activity Scale for the Elderly. 2) The Self-Efficacy for Exercise scale. 3) the Geriatric Depression Scale. 4) Functional Reach Test. 5) Timed Up and Go Test. 6) Berg Balance Scale.

First Author, Publication year, Country, Study design, Participants, Sample Size	Aim	Programme Facilitator/s	Behavioural Change		Exercise Intervention	Comparator intervention	Outcome Measures
			Behavioural change framework	Mode of delivery	Intervention type, FITT, Setting		
Tickle-Degnen et al.(2010)[31] US **RCT** Idiopathic Parkinson's Disease (H&Y stage 2-3) **Total: n=107** Age: 66.3 ± 9.0 Sex: 72/35 (M/F) Intervention: 27 hours rehabilitation:37 Age: 67.6 ± 10.3 Sex: 26/11 (M/F) 18 hours rehabilitation:33 Age: 65.8 ± 8.3 Sex: 22/11 (M/F) Control 0 hours rehabilitation:37 Age: 65.6 ± 8.3 Sex: 24/13 (M/F)	1) To determine whether self-management rehabilitation promoted HRQOL beyond best medical therapy. 2) To determine whether rehabilitation outcomes persisted at 2 and 6 months of follow-up. 3) To determine whether rehabilitation-targeted domains of mobility, communication, and activities of daily living were more responsive to the intervention than were nontargeted areas such as emotions, stigma, social support, and cognitive ability.	A physical therapist led all sessions and an occupational therapist and speech and language therapist each participated in half of the sessions, assisted by therapy students.	1) Theory of planned behaviour. 2) Social Cognitive Theory.	**Behavioural Change Component: Education:** *Interdisciplinary Self-management Rehabilitation: 27 hours of rehabilitation, with 18 in clinic group rehabilitation and 9 hours of rehabilitation:* 1) Participants assigned to the 27-hour condition engaged in 4.5 hours of self-management rehabilitation per week in two 1.5hour group clinic sessions and one 1.5-hour individual home or community session to transfer self- management skills to the locations of daily living. 2) A physical therapist led all sessions and an occupational therapist and speech and language therapist each participated in half of the sessions, assisted by therapy students. 3) Participants received manuals with detailed photographs of exercise routines. Each group clinic session involved physical exercises, speech exercises, functional training, and a discussion about self- management strategies (Barriers to exercise, communication, mobility, benefits of exercise, enhancing social communication, strategies to improve walking, mastering moving in bed, rising from chairs, coping with tremor, stiffness, self-management for life: moving forward, preventing falls, talking on the phone. strategies to improve dressing, relaxation, stress management, self- management for life: staying on track). *18 hours of clinic group rehabilitation plus 9 hours of attention control social sessions:* 1) Participants assigned to the 18-hour condition had 3 hours of self-management rehabilitation per week in two 1.5-hour group clinic sessions. 2) They did not receive weekly 1.5 hour of transfer-of- training session in the home or community. 3) Instead, they received weekly 1.5-hour student-facilitated social group session in the clinic, which was intended to control for the extra attention. **Duration**: 6 weeks. **Setting**: in clinic (group session), home environment (transfer training).	Motion, flexibility, and strength exercises (25 min) Active ranging/stretching to increase trunk extension/rotation. Stretching hip flexors, hamstrings and gastrocnemius, Strengthening trunk/hip postural muscles, knee and ankle extensors. Daily function training examples (15 min) Moving in bed. Rising from chair. Up and down from floor social communication Dressing. Handwriting Swallowing. Social Communication. Gait training (10 min). Walking with external auditory cues to optimize gait pattern and Speed. **Frequency**: One a week (part of the group self-management rehabilitation sessions). **Duration**: 6 weeks. **Setting**: In clinic.	0 hours rehabilitation	PDQ-39

Van Nimwegen et al. (2013)[32] Netherlands **Multicentre RCT** Idiopathic Parkinson's Disease (H&Y stage 1- 3) **Total: n=586.** Intervention: 299 Age: 65.1 ± 7.9 Sex: 194/105 (M/F) Control: 287 Age: 65.9 ± 7.2 Sex: 188/99 (M/F	To evaluate Physiotherapists whether a multifaceted behavioural change programme increases physical activities in participants with Parkinson's disease.	1) Social Cognitive Theory. 2) The transtheoretical model of health behaviour change.	***Multi-component Behavioural Change Components: Support Groups + Education+ Behavioural Techniques + Technology:*** *ParkFit Activity Coach:* 1) Physiotherapists served as personal activity coaches who guided participants towards more active lifestyle during monthly coaching sessions. 2) Physiotherapists educated participants about the beneficial effects of physical activity and about suitable activities. 3) Additionally, participants were stimulated to participate in group exercise to experience beneficial effects of physical activity and to receive social support from fellow participants. *Education Brochure and Health Contract:* 1) Participants received an educational workbook covering specific elements to promote a behavioural change. 2) The workbook gave information about the benefits of physical activity, the risks of a sedentary lifestyle, suitable activities for PD participants, strategies to identify and overcome barriers to engage in physical activity, setting goals and recruiting social support. 3) The workbook included a health contract (written agreement between participant and physiotherapist) to support initiating and maintaining physical activities by formulating long term activity goals. 4) A logbook was included to monitor short term goals. Participants received a bi-annual newsletter accentuating the benefits of physical activity. *Goal setting:* 1) During the coaching sessions participants and physiotherapists formulated activity goals. 2) These were created in order to obtain the long-term goals a formulated in the health contract. 3) During the coaching sessions participant and therapists evaluated these goals as well as the experienced barriers. 4) The formulated activity goals had to be realistic, concrete, and individualized and had to be formulated in a systematic way. *Activity Monitor:* 1) All participants got a personal ambulatory monitor. 2) The accelerometer showed the amount of actually delivered daily physical activity using light-emitting diodes. 3) At a personalized website, participant and coach could formulate a personal goal based on kilocalories; feedback of the monitor was directly related to this personal goal. 4) Since data of the monitor were uploaded to this website, participant and coach could monitor the individual progress. **Frequency**: NR. **Duration**: 24 weeks. **Setting**: Community Hospital.	*Physiotherapy:* 1) The ParkFit programme also included regular physiotherapy sessions. 2) Based on individual disabilities, the therapist and participant jointly formulated individually tailored treatment aims, according to the evidence-based guideline of physiotherapy for PD. **Frequency**: NR. **Duration**: 24 weeks. **Setting**: Community Hospital.	*ParkSafe:* Regular physiotherapy aimed at promoting safety of movement. Received an education brochure (similar to ParkFit group) but provided information about benefits on physiotherapy and safety movements. **Frequency**: NR. **Duration**: 24 weeks. **Setting**: Community Hospital.	*Primary Outcome*: LAPAQ. *Secondary Outcomes*: 1) 6MWT. 2) PDQ-39. 3) 7-day activity diary. 4) Ambulatory activity monitor.

FITT=Frequency, Intensity, Time , Type; H & Y=Hoehn and Yahr; M=Male; F=Female; RCT=Randomized control trial; PD=Parkinson's Disease; IPD=Idiopathic Parkinson's Disease; LLFDI=Late life function and Disability Instrument; mHealth=mobile health d/wk=Days per week; ; 6MWT=6-minute walk test; PDQ-39=Parkinson's Disease Questionnaire-39; Min=Minute; N/A=Not Applicable; TAE=Telecoach-assisted exercise; SRE=Self- regulated exercise; STS=sit to stand; PDQ-8=Parkinson's Disease Questionnaire-8; TUG=Timed Up and Go; NR=Not reported; LAPAQ=LASA physical activity questionnaire.

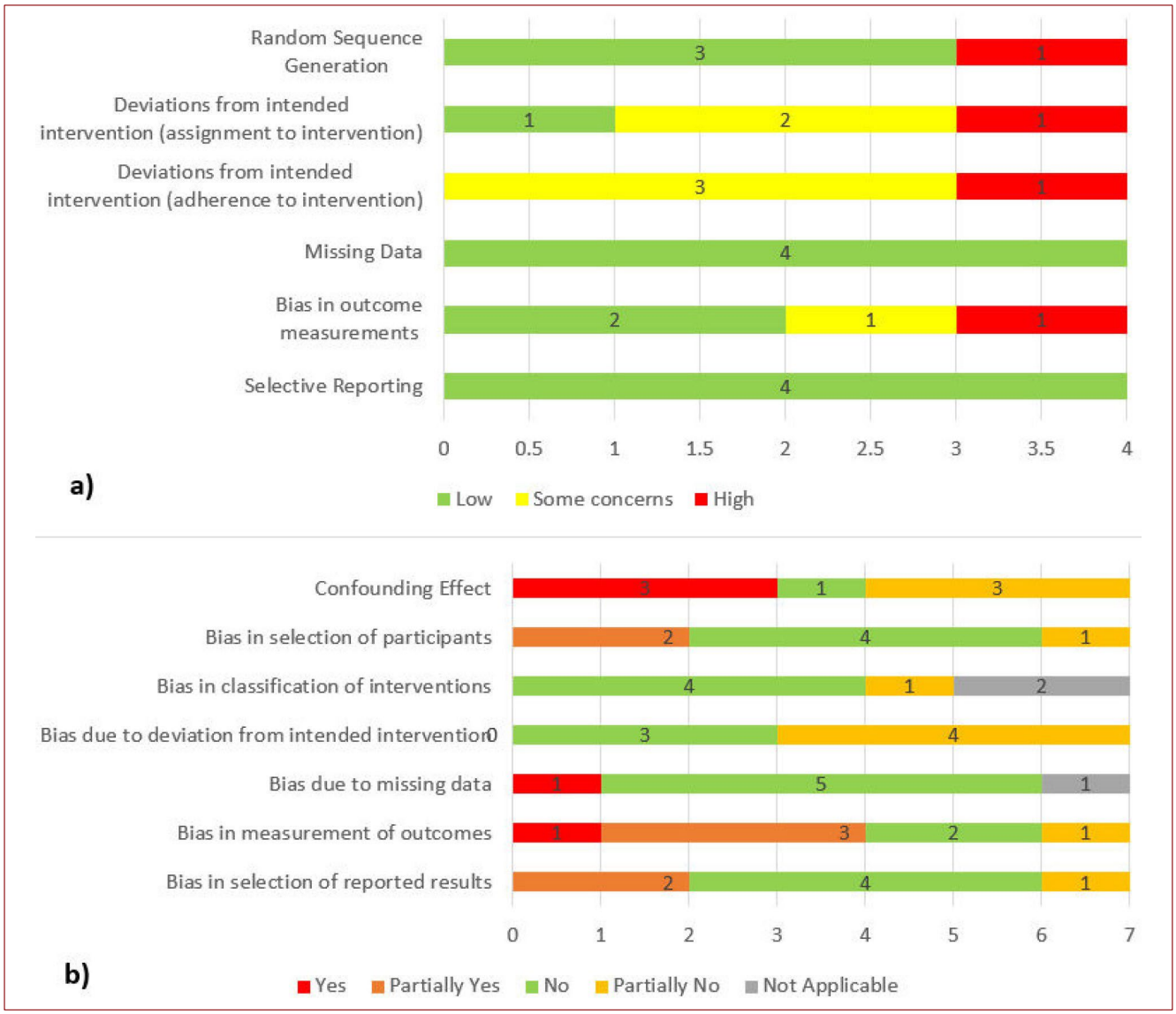


Figure 2. a) risk of bias across randomized controlled trials b) risk of bias across non- randomized studies.

risk, with the others considered moderate[31,32] or high[34], due to potential bias from deviations from the intended intervention[31,34], poor randomization[34], and lack of allocation concealment[34].

Most of the seven non-RCTS were deemed at a moderate risk of bias using the ROBINS-I tool. Potential sources included the selection criteria[39], lack of blinding[20,35,38], inability to adjust, or control for confounding variables[35,38,40] and failure to report participant withdrawal[35] (Figure 2, Table S2, Table S3).

Participants

In total, 901 participants were included (570 males, 331 females; mean weighted age 65.17 years). Sample sizes ranged from five[39] to 586 participants[32]. Nearly all used the original or modified Hoehn and Yahr (H&Y) scale to determine disease severity. Three studies[36,37,39] did not provide individual H&Y stages (n=179 participants). Most participants were Stage 2/2.5 (n=623) and only one study included participants at Stage 4[43].

Theory/Models underpinning BC interventions

Eight studies using a theory/model to underpin the BC intervention[31,32,34-36,38-40]; the Social

Cognitive Theory[31,32,35,36,39,40], Transtheoretical Model of Behaviour Change[32,34,38], Self- determination Theory[38,40], and Self-Efficacy Theory[38].

Behavioural techniques such as goal setting[32,38], barrier identification[32,34], cognitive restructuring[34], problemsolving[34], decision-making[34], action planning[34,38] and relaxation[34] were explored through informal group-work or workbooks[32,34].

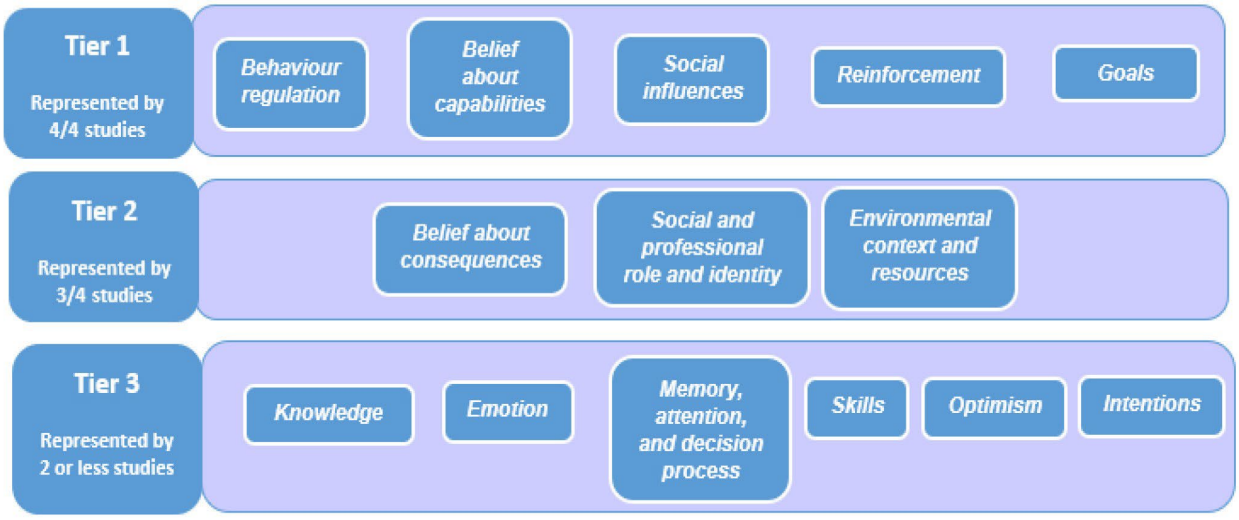


Figure 3. TDF domains used in studies detecting significant improvements.

The BC interventions mapped to the Theoretical Domains Framework (TDF)

The BC interventions consisted of education[31,32,34,38], behavioural techniques[32,34,38], technology[20,32,33,36-40] and peer/support groups[20,32,35,38-40]. Intervention duration varied greatly from 4 weeks to 12 months.

A total of 47 items from the interventions were extracted, coded, and mapped to the TDF (Table 3). Of interest, over half (57%) of the items aimed to improve intrinsic motivation (personal factors; barrier identification, goal setting, action planning), while fewer than 20% related to external motivators (social factors, activity monitors, incentives, support groups) (Table S4 and S5).

Education programmes consisted of either workbooks/ brochures[32,38], or weekly lectures[31,34]. Topics included the condition and symptom management, importance of physical activity, suitable exercises including relaxation, overcoming barriers, and fall prevention[31,34] (Table 3). As anticipated, *knowledge* and *skills* domains of the TDF were addressed in all the studies utilizing education.

(Table 3). Behavioural techniques mostly aimed to enhance *knowledge, beliefs about capabilities*, and promote *behaviour regulation, control environmental contexts and social influences* (Table 3 and Table S5).

Technology included activity trackers[32,38-40], pedometers[20], virtual coaches[20,36] and online exercise

apps[33,37] which provided prompts and feedback to participants regarding exercise (Table 3). Technology was mainly used as an extrinsic motivator (*behaviour regulation*), with some studies incorporating intrinsic motivation strategies (*knowledge about their condition, action planning, decision making, and awareness of negative consequences*). Of note, technology addressed the same issues as the other behaviour change interventions (education, behavioural techniques, and support groups), and while it may not provide *more* than other interventions, it may be *efficient* and can be tailored to the person's needs and intrinsic motivation. Of note, technology was always managed by a trained professional or trained peer (training prior to the intervention).

Support groups were delivered either individually, through telephone peer coaching[40] or motivational

	Education	Technology			Support groups	Multi-component					
						Behavioural Techniques +Education	Technology + support groups			Technology + Behavioural Techniques + Support groups + Education	
TDF Domain	**Tickle -Degnen et al.[31]**	**Ellis et al.[33]**	Lai et al.36	Landers and Ellis[37]	**Lee et al.[35]**	Petee[34]	Colon -Semenza et al.[40]	Ellis et al.[20]	Hermanns et al.[39]	Long[38]	**Van Nimwegen et al.[32]**
Knowledge											
Skills											
Memory, attention and decision processes											
Behaviour regulation											
Beliefs about capabilities											
Beliefs about consequences											
Social/ professional role and identity											
Emotion											
Intentions											
Reinforcement											
Goals											
Optimism											
Environmental context resources											
Social Influences											
Total	**12/14**	**5/14**	8/14	5/14	**10/14**	11/14	7/14	11/14	6/14	11/14	**11/14**

***Bold**=Significantly positive findings for what outcomes.*

counselling[35], or, through peer-group online sessions[39], or therapist-led support[32,38 and] aimed to address most of the TDF domains (9/14 domains). Participants were encouraged to identify their progress, problems encountered, strategies to overcome barriers, and resources were made available (Table 3). Only Lee et al.[35] used it as a single intervention to support behaviour change (*action planning, awareness of negative consequences, barrier identification and recruitment of social supports*).

From the mapping exercise, we can see that each intervention provided elements to address most of the TDF domains. Education addressed *knowledge* and self-management skills. Behavioural techniques addressed the *intentions* of the individual, *environment context and resources and decision-making processes*. Technology addressed beliefs *about capabilities, goal setting* and *social comparisons*. Finally, support groups addressed *action planning and social influences* through peer/group support and address individual's *beliefs about consequences*.

Table 3. Intervention type mapped across TDF domains.

Outcomes of the interventions

Summary of overall findings

Only four of the 11 studies detected significant changes in one or more outcomes (Ellis et al.[33], n=51; Lee et al.[35], n=42; Tickle-Degnen et al.[31], n=107; and van Nimwegen et al.[32], n=586). Improvements in QoL[31,33,35], physical function[32], and exercise adherence[32] were found. No improvements in exercise self-efficacy were detected, however only the smaller/feasibility studies measured self-efficacy, hence the effects remain unclear[34,38-40]. Finally, no negative effects were reported.

Interventions included education only (Tickle-Degnen et al.[31] (n=107)); technology only (Ellis et

al.[33] (n=51)); multi-component intervention (van Nimwegen et al.[32] (n=586) and support groups only (Lee et al.[35] (n- RCT, n=42)). Only Van Nimwegen et al.[32] detected improvements in more than one outcome (physical function and exercise adherence), suggesting that a multi-component intervention encompassing education, behavioural techniques, technology and support groups could be more effective (improved QoL, physical function, and exercise adherence).

Quality of life

Using various BC interventions, three RCTs[31-33], and one n-RCT[35] reported QoL changes, using the Parkinson's disease questionnaire (PDQ-39)[31-33,35] (Table S6).

With 18-hours/27-hours of interdisciplinary self-management education (n=107), Tickle- Degnen et al.[31] detected improved QoL (54%), with some benefits persisting six months after the programme. Similarly, using a health app, Ellis et al.[33] detected better mobility-related QoL in the less-active participants, (n=51, 12-month intervention). Finally, Lee et al.[35] found 12- week telephone counselling (*support groups*, n=42) improved QoL (+15%), which further improved at 16 weeks (+21%) however this study was non-randomised. Conversely, van Nimwegen et al.[32] (RCT, n=586, 24-week multi-component intervention) reported no changes in QoL. This robust large study suggests no additional impact on QoL with a comprehensive BC intervention, however, more large-scale studies need to re-confirm this finding.

Mapping to the TDF revealed no clear pattern. Common domains included *belief about capabilities, social influences, and behaviour regulation*, while most of the other domains were addressed by two or less studies (Table 3).

Physical function

Only two RCTs (Ellis et al.[33], n=51; van Nimwegen et al.[32], n=586) measured physical function, both using the 6MWT (Table S6). Van Nimwegen et al.[32] (24-week multicomponent) found improved physical function and Ellis et al.[33] (12-month mHealth intervention) detected only within group improvements.

Again, mapping to the TDF revealed no clear pattern. Key common domains included *belief about capabilities, goals, and social influences* (Table 3).

Exercise activity/adherence

Of three RCTs[32-34] measuring exercise uptake/ adherence using activity trackers or various questionnaires, only van Nimwegen et al.[32] detected more physical activity compared to conventional physiotherapy[32] (11/14 TDF domains, Table 3).

Which TDF domains are most effective?

The TDF domains addressed in the larger adequately powered studies were grouped to identify the most effective TDF domains. To recap, Tickle-Degnen et al.[31] implemented an education intervention (12/14 TDF domains), Ellis et al.[33] utilized technology (5/14 TDF domains), van Nimwegen et al.[32] used a multi-component intervention encompassing education, behavioural techniques, technology and support groups (11/14 TDF domains) and Lee et al.[35] conducted support groups (9/14 TDF domains). Only five TDF domains were addressed by all four studies (*behaviour regulation, belief about capabilities, goals, reinforcement, and social influences*). Three further domains were addressed by only three studies[31,32,33] (*belief about consequences, social and professional role* and *identity,* and *environmental context resources*). From this, the TDF domains were categorized into three tiers (of effectiveness) based on the domains represented by these studies (Figure 3).

Therefore, the findings would suggest that Tier 1 displays the more commonly addressed TDF domains, with Tier 3 displaying the domains addressed least. While there is no strong evidence for one approach over another, the most effective studies employed an intervention addressing many TDF domains.

Discussion

People with Parkinson's Disease have trouble sustaining exercise and reaching the recommended physical activity guidelines, increasing their risk of frailty and falls. The aims of this review were to

firstly, identify BC interventions aimed to improve exercise self-efficacy and adherence, secondly, to map them to the TDF, and finally, to examine their effect on health outcomes. We identified education, behavioural techniques, technology, and support groups, either as a single or multicomponent intervention, were used to address most domains of the TDF. However, the most effective interventions addressed *behaviour regulation, belief about capabilities, goals, reinforcement, and social influences*. The quality of the included studies was poor. Therefore, we can assume that the evidence of BC interventions to improve self- exercise adherence and self-efficacy is limited and of low quality, further demonstrating that the topic is relatively new and unknown.

We found the TDF gave us a good understanding of the BC interventions. The framework helped to tease apart the issues/barriers addressed by each intervention and structure our analysis accordingly. It helped to identify the importance of intrinsic factors, and which domains appeared most effective. Of note the TDF was originally aimed at healthcare providers, hence it was unclear whether PwP were aware of their "*intentions*" and "*social and professional role and identity*" (domains listed in the TDF)[21].

From the literature, multi-component interventions appear to be used commonly, and our review suggested that the multi-component intervention (van Nimwegen et al.[32] (n=586)) appears to be the most effective. In a recent review (n=24 studies), Tennigkeit et al.[16] found that uni-dimensional BC interventions often failed to address the complex cognitive- behavioural challenges with Parkinson's Disease, while multi-component self-management programmes improved health, mobility, QoL, as well as self-efficacy and depression, demonstrating effects on non-motor features. The authors did not examine exercise adherence or physical activity. It is difficult to draw conclusions from our review, we found some encouraging evidence of improved exercise adherence, but no definitive study measured exercise self-efficacy. Therefore, we conclude that effective interventions to enhance exercise self-efficacy remain unknown, a fundamental requirement for long term exercise adherence.

Behavioural change interventions targeting intrinsic motivation

Many intrinsic methods improved outcomes, including goal setting[31-33,35], social supports[32,33,35], coping strategies31 and barrier identification[31,32,35] (Table S5). These findings concur with findings of Room et al.[41] (n=11 studies), who found that intrinsic behavioural techniques improved exercise adherence in older adults. Techniques were categorised as

(1) comparison of behaviour, (2) social support, (3) identity of goals and planning, (4) natural consequences and (5) feedback and monitoring. While the evidence was insufficient to recommend intrinsic behavioural techniques, the results are similar to ours (goal setting, social support, feedback and monitoring, identification of barriers and action planning), further strengthening the concept that intrinsic motivation is an essential aim of BC interventions.

Recognising the importance of intrinsic motivation in physical activity maintenance, Krishnamurthi et al.[42] is currently examining the differences between the ReadySteady intervention (motivational sessions, mobile app, pole striding and education), versus a pole striding and education intervention, versus education alone[42]. Some evidence exists in the older adult population. In a nonrandomised trial, Azizan et al.[43] found a twofold increase in exercise self-efficacy and threefold increase in physical activity with a BC intervention (based on the Transtheoretical model of Behaviour Change) with a 24-week exercise programme (n=63).

To the best of our knowledge, this is the only review exploring the effects of BC interventions on exercise selfefficacy and adherence to exercise and physical activity among PwP.

Limitations

The synthesis combined both randomised and nonrandomised evidence, which come from different levels of hierarchical evidence and must be interpreted with caution. Many studies had inadequate sample sizes ($n \leq 20$ were common), or poor study design (2 n-RCT, 4 feasibility studies).

Most studies recruited only highly educated Caucasian individuals, and all failed to control (or failed to report control of) participants' additional exercise beyond of the intervention. Some studies identified selection bias in their recruitment process[20,33,37,39,40]. Finally, inadequate methodology reporting prevented a comprehensive assessment of the methodological quality, or when reported well, most were deemed to be a moderate risk of bias.

Conclusion

We conclude that there is insufficient high-quality evidence to recommend the most effective BC intervention to promote exercise adherence among PwP. Our analysis using the TDF has helped highlight the most effective domains to bring about change.

Future research should explore multi-component BC interventions encompassing the five most effective TDF domains (*Behavioural regulation, Belief about Capabilities, Social influences, Reinforcement* and *Goals*). Future trials should be sufficiently powered, with diverse populations recruited, and sufficient follow-up periods to indicate sustained exercise adherence.

Clinical Messages

- There is insufficient high-quality evidence to recommend the most effective BC intervention to promote exercise adherence among PwP.
- Future research should examine multi-component BC interventions encompassing the five most effective TDF domains (*Behavioural regulation, Belief about Capabilities, Social influences, Reinforcement* and *Goals*).
- We recommend that trials are sufficiently powered, diverse populations are recruited, with sufficient follow-up periods to indicated sustainable exercise adherence.

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Authors' Contributions

LA: Conceptualization, Formal Analysis, Methodology, Writing – Original Draft Preparation. ST: Conceptualization, Supervision, Writing – Review & Editing. SL: Supervision, Writing – Review & Editing. RMcC: Conceptualization, Methodology, Supervision, Writing – Review & Editing. All authors read and approved the final version of the manuscript.

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Supplementary Data

Difference between protocol and review

The following amendments were made after the publication of the review protocol.

Date: 10/09/2023

As per the protocol the database was from inception to 1st of September 2021. This is subsequently updated and searched to 10th September 2023.

Date: 15/11/2021

Amendment: The inclusion criteria outlined in the protocol stated that interventions would be included if they implemented "any form of behaviour change intervention, used in conjunction with exercise or alone". However, prior to conducting the database search this was amended to only include studies that implemented a behaviour change intervention used in conjunction with exercise.

Rationale: This amendment ensured that the search was clearly focused to answer the specific research question

Date: 20/01/2022

Amendment: The protocol stated that the findings would be mapped to the Behaviour Change Wheel (BCW) and the Theoretical Domains Framework (TDF). However, during data synthesis it was determined that the findings would only be mapped to the TDF.

Rationale: The components of the BCW are embedded within the TDF and mapping to both would not provide any additional information.

Date: 06/04/2022

Amendment: The protocol outlined that the JBI Risk of Bias tool would be used to assess the risk of bias in the included studies. However, we used the Cochrane Risk of Bias Tool (Version 2) for randomised control trials and the ROBINS-I tool for non-randomised trials.

Rationale: These tools are the preferred method of assessing risk of bias.

Date: 25/05/2022

Amendment: The protocol outlined that the proposed sensitivity analysis would include "restricting analysis to studies including a control group"; this was further refined to "restricting analysis to studies including a control group with an exercise component."

Rationale: To ensure the specific research question was answered.

Table S1. Search strategy.

Databases:
- EBSCO (Academic search complete and Psychinfo) - Medline - Cinahl - Web of Science - PubMed - Embase - Scopus - Google Scholar - Cochrane Library
Search keywords:
1. ["behavioural change intervention*" OR "behavioural change intervention*" OR "behaviour change technique*" OR "behaviour change technique*" OR "cognitive behavioural therapy" OR "cognitive behavioural therapy" OR psychology OR "psychological therapy" OR "health behaviour*" OR "Health behaviour*"] 2. [self-efficacy OR "self efficacy" OR "physical activity self-efficacy" OR "physical activity self efficacy" OR "exercise self-efficacy" OR "exercise self efficacy" OR self-management] 3. 1 AND 2 4. ["physical activit*" OR recreation OR sport OR exercise OR training OR fitness OR "physical therap*" OR rehabilitation] 5. 3 AND 4 6. ["Parkinson's Disease" OR "Parkinsons Disease" OR "Parkinson Disease" OR Parkinson's OR Parkinson] 7. 5 AND 6

Table S2. Results of the RoB 2 tool[28].

Author(s) (yr)	Random Sequence Generation	Deviations from intended intervention (Assignment to intervention)	Deviations from intended intervention (adherence to intervention)	Missing Data	Bias in outcome measurements	Selective Reporting	High/ Moderate/ Low Risk
Ellis et al. (2019)[33]	Low	Low	Some concerns	Low	Low	Low	Low
Peteet (2002)[34]	High	High	High	Low	Low	Low	High
Tickle-Degnen et al. (2010)[31]	Low	Some concerns	Some concerns	Low	Some concerns	Low	Moderate
van Nimwegen et al. (2013)[32]	Low	Some concerns	Some concerns	Low	High	Low	Moderate

Table S3. Results of ROBINS-I scale[29].

Author (year)	Confounding Effect	Bias in selection of participants	Bias in classification of interventions	Bias due to deviation from intended intervention	Bias due to missing data	Bias in measurement of outcomes	Bias in selection of reported results	Overall bias High/ Moderate/ Low Risk
ColónSemenza et al. (2018)[40]	Y	N	NA	N	N	PN	PN	Moderate
Ellis et al. (2013)[20]	PN	PY	N	PN	N	PY	PY	Moderate
Hermanns et al. (2019)[39]	PN	PN	N	PN	NA	N	N	Low
Lai et al. (2020)[36]	PN	N	PN	N	N	N	N	Low
Landers and Ellis (2020)[37]	N	N	N	PN	N	Y	N	Moderate
Lee et al. (2019)35	Y	N	N	PN	Y	PY	PY	High
Long (2020)[38]	Y	PY	NA	N	N	PY	N	Moderate

Y=Yes; PY=Partially yes; N=No; PN=Partially No; NA=Not applicable; NI=No information.

Table S4. TDF domains mapped for included studies.

Author (year)	Knowledge	Skills	Memory, attention and decision processes	Behaviour regulation	Beliefs about capabilities	Beliefs about consequences	Social/ professional role and identity	Emotion	Intentions	Reinforcement	Goals	Optimism	Environmental context resources	Social Influences
Colón-Semenza et al.(2018)[40] USA														
Ellis et al.(2013)[20] USA														
Ellis et al.(2019)[33] USA														
Hermanns et al.(2019)[39] USA														
Lai et al.(2020)[36] USA														
Landers and Ellis (2020)[37] USA														
Lee et al.(2019)[35] South Korea														
Long (2020)[38] USA														
Peteet (2002)[34] USA														
Tickle-Degnen et al.(2010)[31] USA														
van Nimwegen et al.(2013)[32] Netherlands														
Total	6/11	8/11	3/11	11/11	11/11	7/11	5/11	3/11	6/11	10/11	8/11	0/11	8/11	11/11

***Bold** =studies with significantly positive findings.*

Table S5. TDF domains and component constructs identified in the included studies.

TDF Domain	COMPONENT CONSTRUCTS
Knowledge	Education of: condition[34,38,39], communication[31], mobility[31], exercise and physical activity[31,32,38.]
Skills	Skill development[20,31,32,38,39], self-management skills[20,31,32,38,39], coping strategies[31,34,39], competence[36-38], transfer training[32]
Memory, attention, and decision processes	Decision making[34,35], problem solving[20,34]
Behaviour regulation habit32,35, feedback32,33,38,40	Action planning[31,34-38], activity tracking[20,32,38-40], self-monitoring[32,33,37,38], breaking
Beliefs about capabilities	Perceived competence[20,32-34,36-4-], empowerment[20,33,34,37,38,40], identification of prompts/cues for successes[35], self-confidence[20,33,34,36-38,40], self-efficacy[35,40], beliefs[31,32,36,38] pleasant change[35]
Beliefs about consequences	awareness of actions[20,31,38,40], negative consequences[31,32,35,38,] unpleasant change[35]
Social/ professional role and identity	Leadership[31,34,39], Group Identity[31], Organizational commitment[31,32,35,39], Professional role[31,34,35,38,39]
Emotion	Stress management[34], relaxation[34,37]
Intentions	Promote health behaviour change[20], transtheoretical model of change[31,34,38], stages of change[38], theory of planned behaviour[31]
Reinforcement	incentives[33,40], reinforcement[20,32,33,36-39], rewards[35]
Goals	Long[20,31] and short-term goal setting[20,31,33,35,36,48,40], goal-setting[31]
Optimism	
Environmental context resources	Barrier identification[20,31,32,34-36,38,40]
Social Influences	Recruiting social supports[31], social support[20,31,32,35,37,38,40], social comparisons[31,34,40], online support group[39], online verbal support[36], feedback[34,35,38]

Table S6. Results for studies investigating quality of life and physical function outcomes.

Article	Outcomes	Conclusions
Author (year)	Outcome(s) of interest	Results
Ellis et al. (2013)[20] *Multicomponent Behavioural Change Components: Technology + Support Groups*	6MWT; Gait speed; Self-selected walking speed	Walking distance improved significantly in the 6-MWT, from a mean (SD) distance of 459.5 (91.9) m at baseline to 484.1 (85.3) m after the intervention (P=0.02). Self-selected walking speed improved from a mean (SD) of 1.19 (0.2) m/sec at baseline to 1.26 (0.18) m/sec after the intervention (P=0.02). In addition, the baseline maximum walking speed improved from 1.66 (0.32) m/sec to 1.77 (0.32) m/sec after the intervention (P=0.02). On the basis of minimal clinically important differences of 50 m for the 6-MWT and 0.1 m/sec for the 10-m walk test derived from the geriatric population, the results in this study reveal a clinically meaningful change of 0.11 m/sec in the maximum walking speed. Changes of 24 m in the 6-MWT and 0.07 m/sec in the 10-m self-selected condition did not exceed the minimal clinically important difference.
Ellis et al. (2019)[33] *Behavioural Change Component: Technology*	PDQ-39 6MWT	*Quality of Life* PDQ-39 mobility domain scores for the mHealth group declined from baseline to 12 months, which reflected improved mobility (-1.7 points, 95% CI=-4.4 to 1.1). While the active control group scores increased by 2.1 points (95% CI=0.76 to 5.0). The between-group difference did not cross the threshold level of .05 α (estimated mean change: -3.8 points, 95% CI=-7.8 to 0.2; p=0.06); however, the magnitude of the difference was clinically meaningful. Participants with lower activity at baseline reported better mobility-related quality of life in the mHealth condition compared with the active control condition, with a statistically significant and clinically meaningful difference in the change in PDQ-39 mobility over 12 months between groups (-8.2 points, 95% CI=-15.4 to -0.9; p=0.03). *Physical Function* The change in 6MWT from baseline to 12 months (3.8 m 95% CI=5.1-62.5) was statistically significant (p =0.02) and could be considered clinically meaningful for the mHealth group but not the Active control group (5.3 m, 95% CI=-25.6 to 36.2) However, the difference in the change scores between groups was not statistically significant (28.5 m, 95% CI=-14.4 to 71.5; p =0 .19). *Less active participants* There was a nonsignificant between-group difference in improved distance walked (23.4 m, 95% CI=-49.4 to 96.3; P=.51); however, within-group changes in the mHealth group were similar to those in the whole sample (29.1 m, 95% CI=-16.8 to 75.0; P=.20) although this improvement was not significant.

Table S6. *(Cont. from previous page).*

Article	Outcomes	Conclusions
Author (year)	Outcome(s) of interest	Results
Hermanns et al. (2019)[39] *Multicomponent Behavioural Change Components: Technology + Support Groups*	Functional Assessment of Cancer Therapy-General	Percentage of change findings suggested that the physical activity tracker and electronic tablet intervention did not have a significant effect on participants' QoL (percentage change: -3.18).
Lai et al. (2020)[36] *Behavioural Change Component: Technology*	Walking Capacity	All TAE participants exhibited a small to moderate increase (range: 2-101 m) in distance achieved on the 6MWT, with a mean increase of 35 m from baseline. TAE participants also displayed improvements in comfortable walking speed and fastest walking speed with a mean change of 0.31 (0.77) m/sec and 0.16 (0.63) m/sec from baseline respectively. Whereas SRE participants appeared to have a more variable response (changes in walking distance ranged from -67 to 83 m), with a mean increase of 1.35 m from baseline. SRE displayed decreases in comfortable walking speed and fastest walking speed with a mean change of -0.11 (0.67) m/sec and -0.002 (0.41) m/sec from baseline respectively.

Landers and Ellis (2020)[37] *Behavioural Change Component: Technology*	PDQ-8 30-second STS Timed Up and Go	*Quality of Life* The PDQ-8 improved from the baseline, mean 6.8 (SD 5.0), to the 8-week measurement, mean 4.1 (SD 5.0; P= 0.01; Hedges g=0.53; 95% CI 0.14-0.94). At the 8-week point, 6/28 (21%) improved beyond the MDC on the PDQ- 8. The results of the ANOVAs (baseline, 8-week, and 12-week measurements) suggest that there were no additional improvements from the 8-week to the 12-week measurement points for the PDQ-8 (P=0.94). There were no statistically significant interactions for the factorial ANOVAs to test dosing effect: STS (P=0.39), TUG (P=0.41), and PDQ-8 (P=0.86). Likewise, there were no statistically significant correlations for the average time of app exercise usage and change scores on the STS (r=-0.148, P=0.45), TUG (r=0.113, p=0.57), and PDQ-8 (r=-0.017, P=0.93). *Physical Function* There was a statistically significant improvement at both 8 and 12 weeks. The STS improved from the baseline, mean 11.6 (SD 4.0), to the 8-week measurement, mean 14.3 (SD 4.7; p=0.01; Hedges g= 0.59; 95% CI 0.16-1.04). At the 8-week point, 15/28 (54%) improved beyond the MDC on the STS. The TUG improved from the baseline, mean 11.2 (SD 3.9), to the 8-week measurement, mean 8.5 (SD 2.6; P<0.001; Hedges g=.80; 95% CI 0.46-1.18). At the 8-week point, 8/28 (29%) improved beyond the MDC on the TUG. The results of the ANOVAs (baseline, 8-week, and 12-week measurements) suggest that there were no additional improvements from the 8-week to the 12-week measurement points for the STS (P > 0.99), TUG (P > 0.99),
Lee et al. (2019)[35] *Behavioural Change Component: Support Groups*	PDQ-39 30-second STS TUG Berg Balance Scale 6MWT	*Quality of Life* The intervention group displayed overall improvements health-related QoL from baseline (38.75 (20.28)) to postintervention (32.63 (17.99)) to 16-week follow-up (30.45 (14.52)). While the control group displayed poorer QoL from baseline (26.72 (13.47)) to postintervention (32.55 (19.84)) to 16-week follow-up (30.11 (16.47)). There was a significant difference found between the groups for overall health related QoL (p=0.012) and the subscales of stigma (p=0.023), cognition (p=0.028), communication (p=0.014) and social support (p=0.003) *Activities of Daily Living* The intervention group displayed improvement in ADLs from baseline (76.36 (23.21)) to postintervention (81.58 (13.02)) to 16-week follow-up (82.63 (14.85)). The control group displayed a smaller improvement from baseline (80.00 (14.91)) to postintervention (84.67 (15.52)) with a small decline from postintervention to 16-week follow-up (82.94 (10.47)). There were no significant differences found between the groups (p=0.406) *Functional Fitness* The intervention group displayed improvements in leg strength (baseline: 12.48 (2.98); postintervention 13.67 (2.57); 16-week follow-up 13.28 (2.95)), mobility (baseline: 9.44 (1.52); postintervention 8.08 (1.66); 16-week follow-up 8.27 (1.85)), balance (baseline: 52.32(2.77); post intervention 53.63 (3.00); 16-week follow up 53.63 (2.69)) and cardiopulmonary endurance (baseline: 398.04 (75.81); postintervention 427.05 (82.98); 16-week follow-up 434.34 (82.52)) from baseline to 16-week follow-up. While the control group also displayed improvements in leg strength (baseline: 11.28 (3.30); postintervention 12.27 (3.65); 16-week follow-up 15.44 (2.56)), mobility (baseline: 9.41 (2.83); postintervention 8.75 (2.02); 16-week follow-up 6.95 (1.56)), balance (baseline: 51.89 (3.40); postintervention 52.87 (4.42); 16-week follow-up 54.12 (2.26)) and cardiopulmonary endurance (baseline: 401.69 (72.24); postintervention 433.89 (82.12); 16-week follow-up 460.15 (72.55)) from baseline to 16-week follow-up. There were no significant differences found between the groups for any of these variables (Leg strength p=0.874, mobility p=0.541, balance p=0.699 and cardiopulmonary fitness p= 0.258)
Peteet (2002)[34] *Behavioural Change Components: Behavioural Techniques and Education*	Functional Reach Test Timed Up and Go Test Berg Balance Scale	*Physical Function* Both experimental and control groups did not demonstrate a statistically significant change between the two groups in either the Timed Up and Go test (p=0. 126) or the Functional Reach test (p= 0.135).

Table S6. *(Cont. from previous page).*

Article	Outcomes	Conclusions
Author (year)	Outcome(s) of interest	Results
Tickle-Degnen et al. (2010)[31] Behavioural Change Component: Education	PDQ-39	*Quality of Life* Those who overall HRQOL scores improved when receiving rehabilitation (18 or 27 hours) were compared with those whose scores improved when receiving no intervention (0 hours). A decrease of at least 5.39 points on the summery index (a reduction in problems) was used as the criterion for clinically relevant improvement. Rates of improvement were greater for rehabilitation versus no rehabilitation at post and 6 months follow-up in particular, with a smaller difference at 2 months. At immediately post-test, 54% of participants in rehabilitation were improved versus 18% receiving no rehabilitation. The difference of these two rates is 36%, the absolute benefit increases due to rehabilitation (95% CI 5 20- 53%; p<0.0001)). At 2 months follow-up, 34% of participants in rehabilitation were improved versus 20% of those who did not receive rehabilitation

		(p=0.11). At 6 months, 38% who received rehabilitation were improved versus 10% of those who received no rehabilitation (p<0.001).
van Nimwegen et al. (2013)[32] *Multicomponent Behavioural Change Components: Technology + Behavioural Techniques + Education + Support Groups*	PDQ-39 6MWT	*Quality of Life* Quality of life did not differ between the groups (adjusted group difference -0.9 points, 95% CI -2.1 to 0.3; p =0.14) *Physical Function* ParkFit patients increased their physical function compared with controls (6MWT adjusted group difference 4.8 m, 95% CI 0.1 to 9.6; p=0.05).

*SD=standard deviation; PD=Parkinson's Disease; 6MWT=6-minute walk test; PDQ-39=Parkinson's Disease Questionnaire-39; PDQ-8=Parkinson's Disease Questionnaire-8; 95% CI=95% Confidence Interval; NR=Not reported; STS=sit to stand; QoL=Quality of life; HRQoL=Health-related quality of life; EQ-5D= European Quality of Life Five Dimension; TAE=Telecoach-assisted exercise; SRE=Self- regulated exercise; MDC=Minimal Detectable Change; TUG=Timed Up and Go; ADLs =Activities of Daily Living; M=Mean; m/sec=metre per second; s=seconds; ns=Non-significant, **Bold**=studies with significantly positive findings.*

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Article

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

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Abstract: The benefits of exercise have been widely explored among people with Parkinson's Disease (PwP). Exercise can improve non-motor (fatigue, pain, sleep, etc.) and motor features (balance, muscle strength, gait speed, etc.), maintain function, as well as prevent disease progression. Although the benefits are well known, PwP continue to show difficulty adhering to physical activity and exercise. This study aims to explore motivation to exercise, support, and self-management needs among people with Parkinson's Disease, their family members, and physiotherapists. Purposeful and maximum-variation sampling methods (age, sex, geographical setting, and disease severity) were employed. PwP and family members were recruited through physiotherapy services and local support groups. Twelve semi-structured interviews with PwP and two group interviews, one with family members (n = 4) and one with physiotherapists (n = 5), were conducted. Interview guides were informed by patient–public input and a recent systematic review. Interviews were recorded, transcribed, and analysed using thematic analysis informed by the Grounded Theory methodology. Four common themes emerged: (1) The value of an intrinsic connection with exercise, for which there are

[1]. Impact Statement

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

[2]. Implications for Rehabilitation

- Differences in exercise patterns and preferences between sexes should be considered when designing exercise programmes (targeting individual's intrinsic motivators and perceived needs);

challenges. A greater connection to exercise led to long-term adherence. (2) Adapting exercise to the needs and preferences of a person is essential. Preferred exercises and environments were mixed, with differences emerging between sexes. (3) Physiotherapists' aim to only maintain physical function led to frustration. Limited self-management opportunities, stigma, and dehumanisation were discussed. (4) Non-motor symptoms, stigma, fear, and determination as well as apathy, pain, and low mood were discussed. Exercise provided physical, emotional, and social rewards. Supports are necessary; however, challenges arise when PwP's motivations are mismatched to family members' and physiotherapists' goals. Co-created goals, tailored to their preferences, and exercise plans with supported self-management are recommended.

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

- Family members are crucial in supporting exercise, and physiotherapists rely on them, especially in cognitive decline. However, frustration can arise when they "push" exercise rather than supporting exercise;
- Explaining the rationale for tailored exercises is important, but people value having ownership and independent self-management of their exercise programmes;
- Exercise intensity is often under prescribed, missing the opportunity to guide people to high-intensity exercise, which may have a neuroprotective effect, slowing disease progression;
- Highly functioning, motivated people feel excluded from challenging exercise. They are signposted to community-based classes or neurological gyms, where they feel underchallenged.

3. Introduction

Alongside pharmacological management, exercise is important in the management of Parkinson's Disease. Exercise has been shown to attenuate motor and non-motor symptoms [1] and improve sleep [2], mood [3], and memory [3]. There are some indications that exercise can subsequently slow disease progression, especially in the early stages [4,5]. The positive effects are detected across a wide spectrum of exercise types and intensities; high-intensity aerobic exercise, high-intensity balance training, and unstructured physical activity have all shown attenuated motor symptoms and improved function [6], irrespective of nigrostriatal degeneration [7].

However, adherence to exercise is challenging. Despite the growing evidence of its value, as few as 30% of people with Parkinson's Disease (PwP) with mild disability achieve the World Health Organisation recommended activity levels [8,9], with some inactive for 70% of the day, which is considerably less active than age-matched peers [10]. Ellis et al. [11] identified self-efficacy and outcome expectations as strong predictors of exercise adherence in PwP. Similarly, Dobkin [12] recommended self-management strategies in all neurological rehabilitation to improve exercise adherence, optimise motor learning, and improve long-term outcomes. A recent systematic review examined the effects of behavioural change (BC) interventions to improve exercise self-efficacy and adherence in PwP [13]. The BC interventions were mapped to the Theoretical Domains Framework [14], which helped identify effective core components across the interventions [14]. Most were small exploratory studies [15–21], and interventions were multicomponent [15–19,22], including education, behavioural techniques, and support groups. While exercise selfefficacy or adherence remained unchanged, it appears that QoL and physical function improved [11]. The most effective TDF domains were behavioural regulation, belief about capabilities, social influences, reinforcement, and goals [13]. Heterogeneity between studies prevented a meta-analysis, highlighting the novelty of the topic and need for further exploration [13].

While self-efficacy and exercise adherence seem to be difficult to change, qualitative evidence suggests that the social and physical environment [23,24] and family support [23–25] are important in sustaining physical activity. In light of this, we need to explore family support and physiotherapy support in sustaining physical activity. Early physiotherapy involvement, daily exercise, and support from both clinicians and family empower PwP to stay motivated and involved in activities [26]. Many PwP look forward to engaging with their therapists, exercise instructors, and fellow classes

members [27]. While many studies have explored barriers and enablers of PwP, they have not provided insight into their support systems, i.e., their physiotherapists' and family members' experience of supporting exercise and activity to PwP.

Therefore, this study aims to explore motivation, support, and self-management to keep physically active among PwP and to discuss these further with family members and physiotherapists. Interviewing PwP, family members, and physiotherapists provides us with an understanding of PwP's motivation to exercise and the challenges to supporting meaningful, enjoyable exercise for all involved. To gain insight into the relationship between their experiences, this is a sequential qualitative interview study with the first phase informing the subsequent phases. In Phase 1, through semi-structured one-on-one interviews with PwP, the main supports and motivational needs of the PwP were identified. These topics were brought to the subsequent Phase 2 group interview with their family members and Phase 3 group interview with their physiotherapists.

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

4. Methods

4.1. Design and Ethical Considerations

The study was conducted between November 2022 and January 2023 and is reported following the consolidated criteria for reporting qualitative research (COREQ) [28]. Local ethical approval was received (ECM 4 (d) 11/1/2022).

4.2. Recruitment and Study Sample

Purposeful and maximum-variation sampling methods were employed to recruit PwP of varying age, sex, geographical setting, and disease severity. Posters were used in urban primary care centres and local support groups to recruit participants and their family members. Interviews were offered in person, by phone, and online. People with cognitive and mood disorders were not excluded from the study; it was suggested that a family member attended (dyad interview) to validate the data. A convenience sample of local community/hospital (public healthcare) physiotherapists with a minimum of three years' experience of working with PwP was recruited by email.

4.3. Data Collection

The topic guides were informed by a recent systematic review [13], clinical experience, and patient and public involvement group (PPI) (see Supplemental Data). In line with this systematic review, the Theoretical Domains Framework was used to structure the topic guide to explore barriers to exercise [14], focusing on the five key domains of behavioural regulation, belief about capabilities, social influences, reinforcement, and goals [12].

The interviews were conducted by a registered physiotherapist (with qualitative research training. All interviews lasted up to one hour and were conducted in a quiet, private room at the physiotherapy department. At the end of the interviews, all participants briefly reviewed the interview for verification. Between interviews, the data were checked for emerging themes and to allow self-reflection. Phase 1 was terminated when data saturation based on code meaning [29] (no new themes emerging and data beginning to repeat), was reached. All interviews were audio-recorded, transcribed, and checked for verification. The transcripts were used for analysis.

4.4. Data Analysis

The data were analysed using a Grounded Theory approach, using Braun and Clarke's reflexive thematic analysis [30]: (1) The data were reviewed with reflexivity, highlighting the key notes. (2) The text was coded, and highlighted data were extracted. Codes were reviewed by a second experienced qualitative researcher. An integrated code and corresponding list of quotations was completed. (3) Subthemes and themes were developed. (4) The themes were independently reviewed for overlap and sense-making. (5) Refinements were made, similar topics were merged, and large topics were split repeatedly until all authors reached a consensus, with no new themes. (6) Finally, all authors examined the relationship between the themes and finalised the report with supporting illustrations.

5. Results

5.1. Participants

Forty-two people were contacted (n = 20 PwP, n = 12 family members, and n = 10 physiotherapists); twenty-one were interviewed, (n = 12 PwP (6 women), n = 4 family members (1 woman), and n = 5 physiotherapists (5 women)) (see Table 1). Two PwP completed a dyad interview: One was online, and one interview was completed by telephone. Neither dyad-interviewed family member participated in the family member group interview. All physiotherapists were at senior grade (Table 1). One person with Parkinson's Disease engaged in advanced therapies (deep brain stimulation). Eleven PwP self-reported that they engaged in regular physical activity; the twelfth self-reported that they exercised infrequently. Eight were urban dwellers, while four were rural dwellers.

Table 1. Clinical characteristics of participants.

Phase 1 Participants: People with Parkinson's Disease									
Code	Interview performance method	Age (years)	Sex (M/F)	Hoehn and Yahr Stage	Years Since Diagnosis	Geographical setting	Mobility	Activities of Daily Living	Main Caregiver
P1	In person	57	F	1	4	Rural	Independent (no aid)	Independent	Oneself
P2	Phone interview	-	F	3	12	Urban	Independent (no aid)	Minimum assistance	Oneself
P3	In person	57	M	1	17	Urban	Independent (no aid)	Independent	Oneself
P4	In person	62	F	1	2	Urban	Independent (no aid)	Independent	Oneself
P5	Online dyad interview (spouse present)	68	M	2	6	Rural	Independent (with walking aid)	Moderate assistance	Spouse
P6	In person	52	F	1	2	Urban	Independent (no aid)	Independent	Oneself
P7	In person	84	M	2	8	Urban	Independent (no aid)	Independent	Daughter
P8	In person	82	M	2	11	Urban	Independent (with walking aid)	Minimum assistance	Spouse
P9	In person	76	F	3	6	Rural	Independent (no aid)	Moderate assistance	Spouse
P10	In person	73	F	2	8	Urban	Independent (no aid)	Minimum assistance	Oneself
P11	In person	73	M	1	1	Rural	Independent (no aid)	Independent	Spouse
P12	In person dyad interview (spouse present)	76	M	3	6	Urban	Independent (no aid)	Independent	Spouse

Phase 2 Participants: Group interview with family members (of participants from phase 1)			
Code	Sex	Relationship with phase 1 participant	Phase 1 participant code
FM1	F	Spouse	P8 (11 years diagnosed)
FM2	M	Spouse	P4 (2 years diagnosed)
FM3	M	Spouse	P10 (8 years diagnosed)
FM4	M	Spouse	P9 (6 years diagnosed)

Phase 3 Participants: Group interview with physiotherapists			
Code	Sex	Years working years with PwP	Work Location

PT1	F	14	Residential care
PT2	F	7	Urban primary care
PT3	F	5	Urban primary care
PT4	F	15	Outpatient department
PT5	F	12	Rural primary care

5.2. Theme 1: The Value of an Intrinsic Connection with Exercise: But There Are Challenges

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

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

The analysis of the transcripts was underpinned by Grounded Theory methodology to better understand the meanings of participants' subjective experiences with engaging in exercise and physical activity, their supports, and social actions. Data analysis led to four themes across, family members, and physiotherapists. Each theme is presented as PwP's perspectives, then family members' perspectives, and finally physiotherapists' insights.

The subthemes and representing quotes are displayed in Table A1 (see Appendix A).

5.3. Theme 2: Adapting Exercise to the Needs and Preferences of a Person Is Essential

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

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

make this a more normal part of their lives") and adapting the exercises to the person's ability and environment.

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

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

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

5.4. Theme 3: Physiotherapists' Aim to Only Maintain Physical Function Led to Frustration (This Theme Was Not Expressed by Family Members)

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

Those with fewer motor symptoms felt particularly excluded by physiotherapy services. They were rarely offered physiotherapy but rather were signposted to other community-based exercise classes, which did not seem to be a good fit for their needs.

At most, they were offered physiotherapy-led exercise classes, where they felt that their condition of Parkinson's Disease was seen rather than them as individuals and their broader needs. They perceived that the exercises' dosage and intensity were too low to be effective. A community-based gym (providing accessible equipment, physiotherapy prescribed programmes, and supervision) was offered frequently where they again felt underchallenged, or exercises did not progress sufficiently to be challenging (*P3:* "But why can't exercise help me get better; why did it have to be at best a flat liner?"). A common assumption was that physiotherapists were overly concerned about potential adverse events with exercise progression.

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

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

These findings revealed that people were motivated to exercise to improve and to be more responsible for their own exercise programmes. Conversely, physiotherapists felt their primary

obligation was to keep people active rather than to progress exercises and were frustrated with resources.

5.5. Theme 4: Non-Motor Symptoms, Stigma, Fear, and Determination

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

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

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

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

6. Discussion

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

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

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

This research identified three key considerations for exercise services for PwP. These include careful tailoring in exercise prescription, including sex considerations; the importance of creating shared responsibility for exercise progression; and preventing the exclusion of higher-functioning PwP in exercise classes. Although data saturation was achieved in this high-functioning cohort, there is a need to explore whether these findings/issues are similar in people with limited function.

6.1. Considering Sex in Tailoring Exercise Prescription

Sex-specific exercise preferences in this study included types of motivation, the ideal exercise environment, and mindfulness. Women with Parkinson's Disease appeared to be motivated to exercise with peer support and company, while men with Parkinson's Disease engaged in exercise

for the physical and/or mental benefits. Family members also valued the social aspect of exercise for the PwP. van Uffelen et al. [31] similarly found that older women were more motivated by spending time with others, meeting friends, or improving appearance, while older men were motivated by managing stress, preventing health problems, and the "feel good" factor associated with exercise [31].

Women consistently reported enjoying exercising outdoors, while men did not express a preference. However, this does not seem to be universal. Older men were found to prefer outdoor activities more compared to older women [31,32] and described it as a "spirit lifter" [33] (p. 9). Generally, outdoor activity was preferred among both men and women Swedish and Irish seniors [34,35]. The importance of being outdoors with nature was highlighted in this study.

Other "spirit lifters" mentioned were music, enjoyment, fun, and mindfulness. Mindfulness motivated some women to self-manage and adhere to exercise; this was not the case among men. Blair Kennedy et al. reported improved exercise adherence and selfefficacy when mindfulness is integrated with exercise [36]. As an emerging area of research, Nymberg et al. [37] in Sweden are currently examining the impact of mindfulness on motivation and adherence to physical activity in middle-aged to older adults [37].

6.2. Shared Responsibility to Tailor Exercise Type, Dosage, and Intensity

Importantly, PwP want to share responsibility for their exercise progression. Patient centred care is at the forefront of good practice [38]; however, when prescribing exercises, this principle can be inadvertently de-prioritized. PwP felt unheard and frustrated with little shared ownership of their exercise programmes.

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

Exercise can improve balance, strength, gait, and physical function [39] and non-motor features including quality of life and depression [40]. Emerging evidence suggests that high-intensity exercise (65–85% max. heartrate) is associated with neuroprotective effects, slowing disease progression, and appears to be feasible and safe [6], but more research is required. Thus, healthcare professionals should consider higher-intensity exercise initially for PwP and keep informed of emerging evidence.

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

6.3. Strengths and Limitations

A few factors hinder the transferability of the findings. Firstly, the study mostly represents high-functioning PwP. Although the recommendations provided by Mutrie et al. [41] were followed, and every attempt was made to recruit people with varying exercise adherence, the sample included participants who were more interested/already engaged in exercising only. Secondly, the sample size of PwP is small [42]; however, guided by information power versus data saturation [43], rich data from twelve high-functioning PwP with varying sex, years since diagnosis,

and living circumstances were gathered. Data saturation was achieved with no new emerging themes in the final interviews. Furthermore, the small sample size of both interview groups limits the transferability of this study. For future studies, we would like to include a larger sample of family members and physiotherapists. Finally, the findings only represent physiotherapists who worked in the Irish National Public Health system. All were women; recruiting male physiotherapists was challenging, as 74% of physiotherapists in Ireland are women [44].

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

7. Summary and Key Messages for PwP, Clinicians, and Family Members

The interviews highlighted an interest from all parties to willingly partake in health and activity. However, a discordance emerged at times between the person with Parkinson's Disease and their supportive network, leading to frustration and challenges. It was evident that family members were frustrated if PwP were not active "enough". Physiotherapists were frustrated with resource issues, and PwP were frustrated with the lack of support and focus on maintaining function from physiotherapy services. Ultimately, the interviews highlighted the need for a patient-centred, patient-led approach to support, beginning at a level they feel comfortable with.

The data showed the importance for PwP to express their motivation and preferences for exercise. Factors such as social engagement and mindfulness were important, especially among the women interviewed, while men expressed frustration with exercise prescription being "a flat liner". Rather than encouraging more exercise, family members could explore motivation and personal preferences to identify meaningful ways to exercise or stay active, such as the stationary bike being "the greatest thing [they] ever bought" or "being out with other people". Importantly, physiotherapists need to hear the PwP's preferences and their challenges and guide family members to be supportive in the home rather than being "coaches". Through hearing PwP motivation and preferences, a meaningful and engaging programme can be co-created. Opportunities to exercise beyond physiotherapy can be explored. It is important for the individual to be safe and enjoy the activity.

Opportunities to self-manage were often overlooked. It was evident that PwP were well informed; however, the service demanded a crutch-like dependency on physiotherapy guidance, with limited resources. Parkinson's Disease is a lifelong condition and providing all PwP with the skills and knowledge to self-manage their condition is important, empowering, and respectful. Education, signposting to services, safe exercise guidance, highlighting issues that may need medical attention, and ease of access to services when required will facilitate self-management.

It is important to change and adapt exercise routines. As guided by the evidence, including strength, balance, aerobic, and stretching in all exercise routines is recommended. The intensity must be adequate to ensure effectiveness. More specific exercises should be included to target individual challenges, i.e., hip or knee strengthening for pain. As noted, exercise intensity is often under prescribed. To prevent this, exercise intensity should be monitored, for example, by the Rate of Perceived Exertion Scale [45].

Suitable outcome measures can include validated physical or functional performance measures in Parkinson's Disease (six-minute walk test; 30 s sit to stand) and a self-reported QoL measure (PDQ-39). Qualitative indicators of effectiveness can include self-reported motivation and adherence and family members' perceptions.

8. Conclusions

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

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/geriatrics9040092/s1. Section S1A: Interview Questions—Semi structured interviews: People with Parkinson's. Section S1B: Interview Questions—Group Interview 1: Family-Member/Carers. Section S1C: Interview Questions—Group Interview 2: Physiotherapists.

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Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki and approved by the Clinical Research Ethics Committee of University College Cork (ECM 4 (d) 11/1/2022).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study. Written informed consent has been obtained from the patient(s) to publish this paper.

Data Availability Statement: The datasets presented in this article are not readily available to protect participant confidentiality. Requests to access anonymised partial datasets should be directed to r.mccullagh@ucc.ie.

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Appendix A

Table A1. Themes, Subthemes, and Quotations.

Theme 1: The value of an intrinsic connection with exercise: but there are challenges.	
People with Parkinson's Disease	
Subtheme	Quotation

Meaning of exercise	P3: Exercise is anything and everything you know, it can literally be a walk to the shops, getting up and walking up and down the stairs.
	P9: . . . as long as you are moving its exercise.
Physical and mental benefits of exercise	P11: I believe a good workout sorts a lot of other problems. It flushes out the system, it rejuvenates it. If I don't get out for three or four days with three or four weeks, my mental health and everything starts and slide.
Exercise is essential to Parkinson's Disease	P3: I would try to combat it [Parkinson's Disease] through exercise. Doing the exercises isn't necessarily for fitness, it's about not letting it take control over you. You're both there under sparing of each **"fighting"** other, who's going to win? Who's gonna last the longest?
	P2: I'm still able to do the things I want to do, and I believe it's just because I exercise regularly.
Intrinsic motivation leads to long-term adherence	P11 (male): . . . I always like to exercise; I think it is just a gene you are born with.
	P4 (female): I always prided myself on having the insight to know that we need to keep fit.
	Family members
Subtheme	Quotation
Reluctance to suggest exercise	FM3: It depends. She's always saying, I'm tired and I have something else to do. And she'll always find an excuse.
	FM4: I had it out with Julie three weeks ago, four weeks ago. . . Because I felt that, I was taking over all that and I suppose, you see, if [she is] the recipient of that, [she] can say "I'll sit back for a session, he is going to remind me to do those things".
	FM1: Tom gets irritated with me; he gets mad says I'm nagging him.
	Physiotherapists
Subtheme	Quotation
Emotional burden on family members	PT1: Yeah, I agree. I guess over the years I felt sometimes not like a referee. . . and then the wife's like 'I'm always telling him that.' And they like 'he gets cross when I remind him' you know.

Theme 2: Adapting exercise is essential.

People with Parkinson's Disease	
Subtheme	Quotation
Exercise should be personalised and adapted to each individual	P11: Well, what works for me doesn't work for a lot of people. But there is a lot more to it than that you have to check the individual and design a programme that suits him.
. . **Exercise preferences varied per individual**	P4: I would have always been a very outdoorsy person. . . So, like, if the sun is shining. natural vitamins that are out there.
	P1: People with Parkinson's should be outside; they should be outside and getting the natural vitamins from the sunlight rather than kept indoors and dark places.
Group exercise created a sense of belonging	P11: camaraderie is a great thing if, if you can inject, you can inject that into your group. They, they help each other then and it's, it's comforting.
Exercise preferences varied among sex	P2 (female): Even though the exercise may not be enjoyable, that social event is very important to keeping people going. . . These social events should allow for a social discussion. Don't make it medical.
	P4 (female): I find I like to exercise in the group setting like a, so I don't really fancy the walking. I walk with anybody. But I don't like doing it on my own. And it just being part of a group.
	P10 (female): There's good camaraderie. . . In the group. That are in there with me and.. . The craic, as they say (giggles). It's the social aspect of it that's it.
	P3 (male): It's not the kind of thing that I would enjoy (group classes), and I think there's a degree that you can put yourself under too much pressure to participate you know? I prefer to do it myself.
	P12 (male): [For] someone who needs it to be fun, I think group exercise would work. But I am happy exercising just me.
Mindfulness	P6: My joints were sore. Every part of me. Do you know? I know my body and I just knew, like, this is my Parkinson's. So just take a break this week.
	P4: And, I started looking into mindfulness, and I then realized it's so important to have a plan, to be able to know, I didn't even know my body.
Family members	
Subtheme	Quotation
Benefit of social element	FM4: She is very happy about that, and I think it's as well the meeting other people.
	FM4: She needs to be mixing. She used to get into the car and visit her sister's every Thursday night and a couple of jazz get a taxi home and that kind of thing, so I think when she is exercising the socialising in a group is good for her.
Physiotherapists	

Subtheme	Quotation
	PT3: We have to look at what we're actually giving the patient, taking time to go
Adapting exercise to the person	PT2: The other thing then would be, I, when they can't access it, 'well then what exercise can you access?' And saying that anything is better than nothing.

through that with them and I suppose finding out what works for them what doesn't work for them

.

Theme 3: Physiotherapists' aim to only maintain physical function led to frustration.

Under prescribing—intensity too low, lack of exercise progression	P3: Being told what you can do and can't do. People telling me that I shouldn't do this then I shouldn't do that or I need to slow down or I need to stop. . . . if I can cycle nine kilometres there and I'm going to cycle nine kilometres back, but my chart says I'm only supposed to do so many minutes so I can't do any more than that. . . . like I find it frustrating.
	P1: I have asked and asked and asked and I'm not being assessed. I shouldn't have to ask to be assessed I should be assessed naturally; my exercises should be progressed as I get better.
	P12: The classes aren't hard enough for me. I'm not saying it is beneath me, don't get me wrong, but I just need harder to be beneficial
PwP want more responsibility,	P3: Being told what you can do and what you can't do. And I'm constantly trying to break the system you know. People telling me that I shouldn't do this then I shouldn't do that, or I need to slow down, or I need to stop.

People with Parkinson's Disease	
Subtheme	Quotation
Physiotherapists should be encouraging not authoritative	P1: Just say "you know what you're doing brilliant now, come back in a month time I know better you'll be after improving, we'll see now, I bet you will be better", not "you must do this, and you must do that."
	P3: But I jump on it, and I hop straight up to level 18 because I'm capable of this, and then he (physiotherapist) has a hernia.

Family members	
Subtheme	Quotation
Mismatch between need and the service provided	FM4: She has [Parkinson's Disease] for about 7 years, and slowly but surely the deterioration, even though [the doctor] don't notice it (speaking to interviewer), because [they are] not living with the person. Her strength is quite good, but a dexterity is awful, she can't open the tops of bottles. She can't put on her bra. Like you said (speaks to FM1) [I'm] actually caring for the person. . . . if I leave the house, I have to leave something for her to eat. And I wouldn't want to be going out too much like (laughs), because again it's the dexterity issue. . . . but every time I mention it to a doctor, I'm told she is doing well. . . . all because she can walk perfectly.

Physiotherapists	
Subtheme	Quotation
independence to progress	

	PT1: But I think it's taken the time to actually teach them the right way to exercise, teach them what this is and like, try and get them started on that and look into the barriers that might be there.
Education is the first step	PT2: It's a cultural thing. And a health literacy thing as well. They might have never exercised a day in their lives. Now they are being told they have a engage in regular exercise—that's difficult for anyone. PT4: If the GP hasn't accessed the service, people could have never accessed the services nor seen a neurologist, and they haven't been educated so they don't actually know that exercise is good.
Focus is to maintain function	PT2: Introducing them to exercise and showing them and how they're going to maintain themselves. PT4: I suppose we see a lot of them when in with early (stages). You know, they've just been diagnosed with Parkinson's. And I suppose the, your education component would be huge in that. They might be functioning at a very high level but just to educate on the progression of Parkinson's and the importance of exercising at every stage and you know, the problems associated with progression.
	PT5: It's really hard to give patients the amount of time they need and maybe the number of sessions they need to set them up.
Lack of resources and expertise, poor awareness	PT1: Not every therapist will have expertise in the area. PT2: GPs not thinking I should get them into physio now, because they're not bad, they are relatively high functioning. . . And I think it often boils down to resources as well because. . . if somebody's functioning well, there's no resource there to look at that prevention piece.

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

People with Parkinson's Disease

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

	Family members
Subtheme	Quotation
Non-motor barriers	FM1: He can do it (exercise). He can do it. But he's suffering very badly from mood swings, and he did before and then it got a bit better, and he exercised a little bit more. Mood swings and mood swings are a terrible thing because you don't know when you have them.
	FM4: She knows what to do but she finds it very frustrating that she can't do those things.

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Article

‘I Knew Nothing About Parkinson’s’: Insights into Receiving a Diagnosis of Parkinson’s Disease and the Impact of Self-Management, Self-Care, and Exercise Engagement, from People with Parkinson’s and Family Members’ Perspectives: Qualitative Study

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Abstract: This paper draws on stories of receiving the diagnosis of Parkinson’s disease, which emerged from a broader narrative study exploring beliefs about exercise and challenges facing people with Parkinson’s disease. Background/Objectives: By interviewing people with Parkinson’s disease (PwPD) and their family members, this paper aimed to gain insights into PwPD’s experiences with diagnosis, its influence on exercise engagement, and access to

services in Ireland. Methods: This study employed a qualitative research design, using purposeful and maximum variation sampling. PwPD (varying in age, sex, geographical setting, and disease severity) were recruited from urban physiotherapy services. Semi-structured interviews with 12 PwPD and a group interview with four family members were conducted between November 2022 and January 2023. The interviews were recorded, transcribed, and analysed using thematic analysis. Results: Four themes emerged: (1) firstly, there was disempowerment and emotional shock at diagnosis: PwPD expressed frustration with delays in diagnosis and with how language and empathy affected their ability to cope initially. (2) There was a lack of signposting and services access: a strong need exists for clear information on services and resources to prevent social disengagement. (3) In terms of exercise education and self-management support, PwPD lacked early exercise education and guidance, relying on self-education. (4) With regard to the emotional burden on family caregivers, family members manage care logistics and face emotional burdens, which they try to conceal. Conclusions: The delivery of a Parkinson's diagnosis could be improved by recognising its psychosocial impact on PwPD and families. Providing clear information on services within weeks of diagnosis was considered crucial. Limited exercise education affected PwPD's ability to self-manage. Early physiotherapy access is strongly recommended to help delay functional decline and encourage an active lifestyle.

Keywords: Parkinson's disease; diagnosis; self-care; physical activity; physiotherapy; health services; caregiver burden; qualitative study

Introduction

Parkinson's disease (PD), is a progressive neurodegenerative disorder, affecting millions of people worldwide [1]. For PwPD and their families, the moment of receiving a diagnosis of PD is the beginning of a life-altering journey. It may evoke an array of emotions, from fear and uncertainty to relief or even a sense of validation regarding symptoms long endured. Receiving a PD diagnosis can substantially impact PwPD's quality of life for many years [2]. This, in turn, possibly influences self-care and engagement in beneficial behaviours, such as exercise. Therefore, understanding the subtleties of this critical moment and its emotional impact is vital not only for healthcare professionals tasked with delivering these diagnoses but also for shaping interventions and support systems that are tailored to the unique needs of people with PD (PwPD).

Advances in medicine have made it possible to manage symptoms and enhance quality of life, but the psychosocial impact of receiving a PD diagnosis remains profound and, at times, overlooked. The time it takes to reach a diagnosis, the referral procedure, how the decision was reached, how it is communicated, the information given and explained, the planned follow-up actions, and the initiation of treatment, are all likely to be factors that impact a person's experience of diagnosis [3]. Each person's journey is immensely unique and multifaceted, including adjusting to physical and mental challenges to overcoming the shock of a diagnosis which may impact every aspect of their lives.

Person-centred care has been increasingly important in the treatment of chronic illnesses like PD in recent years [4]. Understanding patients' needs, preferences, and personal experiences is fundamental to this approach, and serves as the foundation for personalised treatments and support services [4]. By giving voice to the lived experiences of people diagnosed with PD, we can gain invaluable insights into the diverse ways in which the diagnosis shapes their perceptions, priorities, coping mechanisms, and, particularly, their early engagement with self-management, including exercise.

The authors are aware of only four studies that have explored patients' experiences with receiving a PD diagnosis [5–8]. Schrag et al. [5], in 2016, surveyed patients' experiences through the European Parkinson's Disease Association in eleven European countries (n = 1775 patients). Peek [6] (n = 37) and Warren et al. [7] (n = 6) conducted qualitative interviews with PwPD living in the UK in 2017 and 2016, respectively. Although dated, their findings clearly highlight the shortcomings of the diagnosis experience that need to be addressed and highlight the importance of support systems. More recently, Krieger et al. [8] conducted focus groups and semi-structured interviews with PwPD and family members in Germany (n = 52 PwPD, n = 29 family members). They identified several issues, including the persistent lack of support for people with Parkinson's disease in accessing self-management strategies, as well as the inadequate and unstructured provision of information, system orientation, and social awareness [8]. These studies show that, regardless of time or national health provision, people are still finding self-management challenging and need more support.

The initial aim of our qualitative study was to explore PwPD's relationship with exercise, their motivations, needs, and supports. These first results have already been published in a report [9]. However, the impact of receiving the diagnosis on people's ability and motivation to manage their Parkinson's disease emerged as a significantly concerning topic in the initial interviews.

This led to an iterative expansion of the topic in later interviews, with these data presented in this current paper.

This paper thus seeks to describe the multifaceted experiences of people receiving a diagnosis of Parkinson's disease in terms of its impact on the emotional, social, and practical dimensions of their journey but also with respect to their early management of their condition through exercise. Through qualitative analysis of patient narratives and experiences, we aim to uncover common themes, challenges, and resilience factors encountered during and after the diagnosis process. This knowledge may inform a more compassionate and holistic approach that respects the lived experiences of PwPD and their families, ultimately enabling people to face PD with dignity and resilience, and to empower them to self-manage their condition.

Therefore, the aim of this paper is to report the impact of the diagnosis on PwPDs' ability to self-manage and practise self-care through exercise and to discuss these issues further with family members.

2. Materials and Methods

The methodology for this study is described in detail in our previous publication, Ahern et al. [9]. A brief description is as follows.

2.1. Design

This study employed a qualitative research design. The study was reported following the consolidated criteria for reporting qualitative research (COREQ) [10] (Supplementary Material S1).

To explore PwPD's relationship with exercise [9], we conducted qualitative interviews sequentially over three stages, with the first stage informing the enquiry of the subsequent stage. Stage One comprised semi-structured one-to-one interviews with PwPD; Stage Two was an interview group with family members/caregivers of a person with PwPD in the study, and Stage Three was an interview group with physiotherapists with experience of working with PwPD. The impact of receiving a diagnosis on a person's readiness to self-manage their Parkinson's disease, emerged prominently in the initial interviews with PwPD, and this topic was supported and corroborated during the group interview with family members. The discussions with family members gave a broader understanding of the diagnostic experience, as they are key in supporting the individual through the diagnostic process, and interpreting information received from healthcare professionals. The inclusion of family members provided valuable perspectives on the shared nature of the diagnostic journey, recognising that the impact of a Parkinson's diagnosis extends beyond the individual to their close relationships and support network. The data from the interviews with physiotherapists did not discuss this topic and, therefore, are not included in this report.

This study was conducted in Ireland, and participants were recruited from the city of Cork and surrounding areas.

2.2. Recruitment and Study Sample

Purposeful sampling and maximum difference sampling methods were employed to recruit participants. Inclusion criteria for PwPD were the following: Hoehn and Yahr disease stage 1–3; being able to communicate in English; both males and females; and of varying ages (>50 years) and geographical settings (living in both urban and rural sites). Inclusion criteria for their family members/caregivers were the following: self-reported as a caregiver (without a minimum number of hours of assistance per week), aged > 18 years, and being able to communicate in English. Participants were recruited through physiotherapy primary-care services in urban areas and local support groups, where they expressed an interest in taking part in the study by responding to recruitment posters (either via phone or through their local physiotherapists, who subsequently informed the researcher). To accommodate participants and their ability to attend in person, interviews were offered in person, by phone, and online. Participants were excluded from the study if they could not provide consent, could not communicate in English, or did not have a diagnosis of PD. If eligible, the study was explained to them, and a copy of the participant information leaflet was sent to them by post.

2.3. Data Collection

Based on the findings of our systematic review [11], the author's clinical experience, and feedback from our patient–public involvement (PPI) group, we developed a separate topic guide for the semi-structured 1:1 interviews (PwPD) and for the group interview (families) (Supplementary Material S2 and S3).

The interviews were conducted by a registered physiotherapist (LA, PhD scholar) who received qualitative research-skills training. The interviews were conducted in a private room in a primary-care centre if held in person and via Microsoft Teams for online interviews. The interviews lasted for a maximum of 60 min (including the group interview). PwPD were offered the option of dyadic interviews for support and prompting if required. The interviewer recorded field notes during the interviews. All interviews were videoed or audio recorded and then transcribed. At the end of the interview, the interviewer completed member checking by reviewing the topics discussed and ensured that the information was interpreted correctly.

The data were analysed on a rolling basis, including self-reflection by the interviewer between interviews. We terminated the recruitment of each stage when data saturation was reached (based on criteria code meaning [12] [no new themes were emerging and the data was beginning to repeat]), and progressed onto the next stage, using the data obtained to inform the next stage's interview topic guide. The interview process was designed to be interactive and iterative, allowing participants to reflect deeply on their experiences while shaping the direction of the conversation. The use of semi-structured interviews allowed for the emergence of rich, contextually grounded narratives, while reflexivity and participant validation ensured alignment with the lived experiences being explored.

2.4. Ethical Considerations

The study received ethical approval from the Clinical Research Ethics Committee of the Cork Teaching Hospitals (ECM 3 (gg) 22 February 2022). The research was conducted between November 2022 and January 2023. All participants provided written informed consent before the interviews. If the interviews were conducted via phone or online, a participant information

leaflet and consent form were posted to the participants. Prior to the interview, the participants were given the opportunity to ask further questions, and, if happy to proceed, gave fully informed written consent (return via post prior to the interview) and gave verbal consent on the recorded call. This study was conducted according to the European General Data Protection Regulations (GDPR) No.679 of 27 April 2016. Personal data collected at any time during the study were kept strictly confidential. To ensure confidentiality, the data generated during the study were coded with a participant number. All recordings were stored securely on encrypted, password-protected servers in line with institutional data-governance policies. The participants were informed they had the freedom to address only aspects considered as appropriate. The participants were also informed they were free to withdraw from the study at any point without explanation. Quotes used to illustrate findings were carefully chosen to reflect the participants' viewpoints, and identifiable information was removed or adapted.

2.5. Data Analysis

The data analysis was guided by a constructivist phenomenological methodology, which recognises that individuals construct meaning from their experiences through interaction with their social and cultural environments [13,14]. This perspective aligns with the findings of the study, exploring how PwPD interpret and make sense of their diagnostic journey within their personal, social, and cultural contexts. Constructivist phenomenology emphasises the co-construction of meaning between participant and researcher, acknowledging that the researcher plays an active interpretive role in the analytic process [15] and values participants' subjective accounts as central to understanding lived experience. This lens was chosen to allow for a rich and situated understanding of the lived experience of diagnosis, where multiple realities and meanings are possible.

To analyse the data, we applied Braun and Clarke's reflexive thematic analysis framework, which offers a flexible and rigorous method for identifying patterns of meaning within qualitative data. While thematic analysis is not inherently tied to any single theoretical position, it can be used within a constructivist paradigm when the analysis is oriented toward understanding how participants make sense of their experiences [16,17]. The data were manually analysed in Excel (Microsoft Corporation) using Braun and Clarke's framework [18] for reflexive thematic analysis to allow for the identification of emerging themes. An inductive approach was taken, allowing themes to emerge from the data rather than being imposed by pre-existing theoretical constructs. (1) One member of the research team transcribed each interview, highlighting the key notes in the text, and they reviewed the data with reflexivity. (2) A research team member coded the transcripts line by line and highlighted the text to extract data. The codes were reviewed by a second experienced qualitative researcher and relevant adjustments were made. Finally, an integrated code and corresponding list of quotations were completed. (3) The first researcher developed subthemes and themes from the code list. (4) A second and third member of the research team independently reviewed the extracted themes for overlap and sense-making. (5) The first researcher made any required changes, merging similar topics and splitting large topics where required. This method was repeated until all authors reached a consensus and no new themes appeared. (6) Finally, all three researchers examined the relationship between the themes. This approach was considered appropriate for capturing the nuanced and individual nature of participants' experiences of receiving a Parkinson's diagnosis.

The analysis of the results was integrated by verbatim statements which emerged in the transcription of the interviews. Some editing of original verbatim statements was provided to

facilitate the comprehension, and pseudonyms were used to replace possible names of persons mentioned. Additionally, words were added in square brackets to improve comprehension, and round brackets were used to indicate nonverbal communication. Text was also highlighted in bold to improve its emphasis.

3. Results

3.1. Participants

We contacted 32 people (*n* = 20 PwPD, *n* = 12 family members). Sixteen were interviewed, *n* = 12 PwPDs (six females and six males, aged 52–84 years), and *n* = 4 family members/caregivers (three males and one female; none were related) (Table 1). The group interview with the family members was held face to face at their request. One PwPD requested a telephone interview, while two requested a dyad interview (one online and one face-to-face). All dyad interviews were conducted with the spouse. For the dyad interviews, the family members declined to partake in the subsequent group interview with other family members. Of the twelve PwPD, eleven self-reported as being keen exercisers, engaging in regular physical activity (self-reported as achieving the World Health Organisation physical activity guidelines weekly), and one self-reported being an infrequent exerciser (P8). All twelve PwPD were independently mobile, and two used walking aids (P5 and P8). Although all twelve participants were recruited through urban-based primary care services, four lived in rural areas. Baseline characteristics (e.g., mobility, ADLs and main caregiver) were self-reported by the participant. The interviewer had no previous physiotherapist–patient relationship with any of the participants.

Table 1. Clinical characteristics of participants.

Stage One Participants: People with Parkinson's Disease									
Code	**Interview Performance Method**	**Age (Years)**	**Sex (M/F)**	**Hoehn and Yahr Stage**	**Years Since Diagnosis**	**Geographical Setting**	**Walking Aid (Yes/No)**	**Activities of Daily Living (Independent/Moderate/Minimum Assistance)**	**Main Caregiver**
P1	In person	57	F	1	4	Rural	No	Independent	Self-care
P2	Phone interview	-	F	3	12	Urban	No	Minimum	Self-care
P3	In person	57	M	1	17	Urban	No	Independent	Self-care
P4	In person	62	F	1	2	Urban	No	Independent	Self-care
P5	Online dyad interview	68	M	2	6	Rural	Yes	Moderate	Spouse
P6	In person	52	F	1	2	Urban	No	Independent	Self-care
P7	In person	84	M	2	8	Urban	No	Independent	Daughter
P8	In person	82	M	2	11	Urban	Yes	Minimum	Spouse
P9	In person	76	F	3	6	Rural	No	Moderate	Spouse
P10	In person	73	F	2	8	Urban	No	Minimum	Self-care
P11	In person	73	M	1	1	Rural	No	Independent	Spouse
P12	In person dyad interview	76	M	3	6	Urban	No	Independent	Spouse
Stage Two Participants: Group Interview with Family Members (of Participants from Stage One)									

Code	Sex	Relationship with Stage One Participant	Stage One Participant Code
FM1	F	Spouse	P8 (11 years diagnosed)
FM2	M	Spouse	P4 (2 years diagnosed)
FM3	M	Spouse	P10 (8 years diagnosed)
FM4	M	Spouse	P9 (6 years diagnosed)

Appendix D

The analysis of the data led to four overarching themes demonstrating PwPD's and family members' experiences and impact of receiving the diagnosis, education about their condition, knowledge of available services, and the emotional burden on the family members. Each theme is presented from PwPD's perspectives first, then family member/carers' perspectives (if applicable). Figure 1 presents the themes and subthemes which emerged from the data. The subthemes and representing quotes are displayed in Table 2.

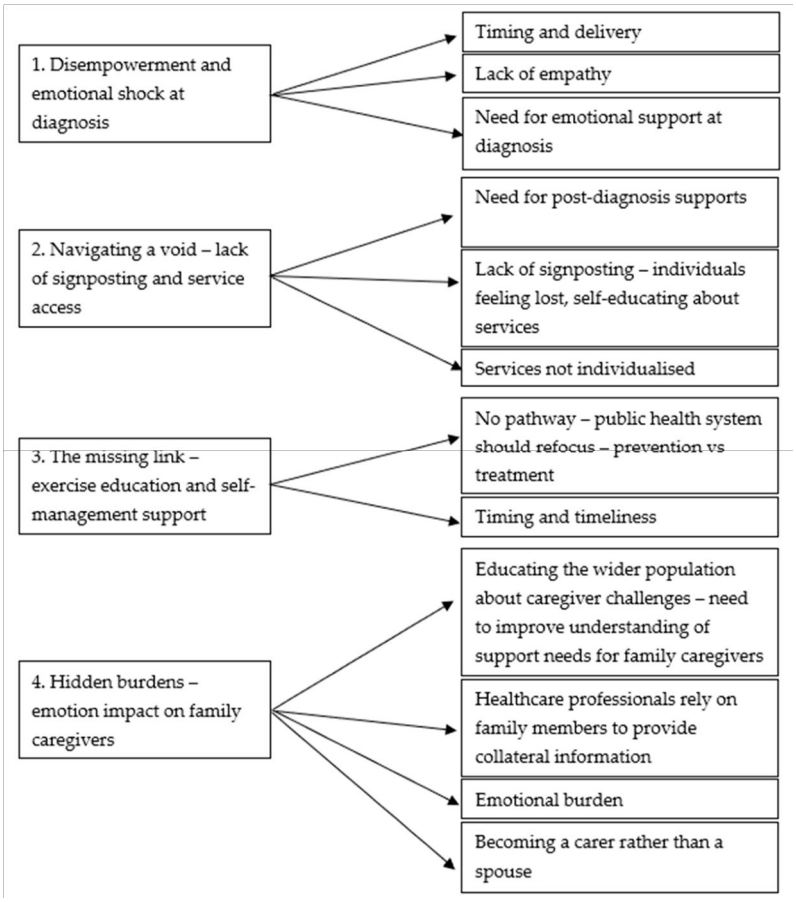


Figure 1. Themes and subthemes.

Table 2. Themes, subthemes, and quotations.

Theme 1: Disempowerment and emotional shock at diagnosis	
People with Parkinson's	
Subtheme	Quotation
The dehumanizing impact of clinical encounters	P1: I went to see three consultants, and I told my GP, and none of them listened… and that was infuriating.
	P4: [The consultant] just didn't realize that they had just taken my world and pulled the rug from under me.
	P5: They didn't tell me anything properly, just "you have Parkinson's." It felt like being handed a bomb.
The critical Role of compassionate communication	P10: I just wanted someone to [put] an arm around me and let me ball [cry]. Because nobody dealt with the shock.
	P6: It was very much like… 'well this is where we are now.' No offer of help or what I could do.
Family Members	
Subtheme	Quotation

Lack of emotional support for PwPD at diagnosis	FM2: When delivering news like that, you need empathy, and you need to give them time.
	FM1: I felt totally dismissed when I questioned the process. Nobody sat us down and explained anything.
Theme 2: Navigating a Void — Lack of Signposting and Service Access	
People with Parkinson's	
Subtheme	Quotation
Absence of structured information pathways	P1: Nobody told me about anything, nobody has ever told me about anything.
	P7: If you don't know where to go, you just sit at home, and that makes things worse.
	P8: In my own opinion, I think there is a lack of communication.
Risk of social isolation	P4: There needs to be a step in between, everyone should be able to find their village.
	P9: You have to figure it out yourself. It can feel very lonely.
Family Members	
Subtheme	Quotation
Lack of involvement in care planning	FM2: You need to be included in the plan… not just assume that we know what's ahead.
	FM3: We're not just drivers and carers. We need to know the plan too.
Theme 3: The Missing Link — Exercise Education and Self-management Support	
People with Parkinson's	
Subtheme	Quotation
Early exercise misinformation and missed opportunities	P3: At the time I was told to take it easy. Don't get wound up and relax for myself and not to get exercise or not to be overly strenuous.
	P2: Exercise was never encouraged.
	P11: Nobody explained how critical exercise would be; I lost a year just sitting at home.
Self-initiated learning as resistance	P5: I had to look everything up myself — nobody pointed me in the right direction.
	P7: The only [exercise-related] knowledge of Parkinson's that I got was from a physio and that was about five or six years after I was diagnosed.
Family Members	
Subtheme	Quotation
Self-education necessity	FM1: You almost have to become a mini doctor yourself.
	FM2: I have researched it online; no one sat me down and told me what to expect.
Theme 4: Hidden Burdens — Emotional Labor of Family Caregivers	
Family Members	
Subtheme	Quotation
Concealed grief and fear for the future	FM2: I'm looking down the line and saying the road is going to reverse.
	FM3: Who will care for her when I'm gone?
	FM4: You worry all the time, but you try not to show it.
Shifting roles from spouse to caregiver	FM1: I'm very much a carer now, where I wasn't a carer.
	FM4: "Her strength is quite good, but her dexterity is awful… like you said, you're actually caring for the person.

	FM3: We married as equals. Now it feels different; more responsibility, less partnership.

3.2. Theme One: Disempowerment and Emotional Shock at Diagnosis

Receiving a diagnosis of Parkinson's disease (PD) was described by participants as profoundly disempowering, deeply emotional, and life-altering. Participants vividly recalled moments where empathy was lacking and where the manner of diagnosis delivery had long-lasting effects. Two subthemes were identified: the dehumanising impact of clinical encounters and the critical role of compassionate communication.

3.2.1. Subtheme One: The Dehumanising Impact of Clinical Encounters

People with PD consistently described feeling unheard during early consultations, where healthcare professionals missed opportunities to engage meaningfully. PwPD felt frustrated when a delay in their diagnosis occurred and felt that healthcare professionals were not actively listening to them at the time. P1 powerfully stated, "I went to see three consultants, and I told my general practitioner (GP), and none of them listened. . . and that was infuriating". This created a sense of invisibility and loss of agency among PwPD. For some, the clinical delivery felt mechanical, and this resulted in disappointment among PwPD at the lack of empathy portrayed by healthcare professionals. Regarding the experience during the delivery of their diagnosis, they emphasised the importance of supportive language and phrasing, as P4 explained, "[The consultant] is probably so used to it, [the consultant] just [did not] realize that they had just taking my world and pulled the rug from under me. I [could not] speak… Because I had aged. I went in with a [musculoskeletal complaint] and came out with Parkinson's".

This impersonal mode of delivery also led to feelings of profound disorientation and psychological shock. As P6 reported, "It was very much like. . . 'Well, this is where we are now. And you have Parkinson's. And you got a good ten years before you really have to worry'".

This often resulted in the PwPD feeling dehumanised and lacking hope. These moments often marked the beginning of emotional isolation and despair.

PwPD discussed the need for support at the time of diagnosis disclosure. They explained having a family member or friend with them when receiving the diagnosis was important; P4 compared the experience to "quicksand", and P6 reported that once "you hear whether it's good news or bad news. . . you switch off. . . that's the advantage of having somebody with you. . . they're listening and taking in".

3.2.2. Subtheme Two: The Critical Role of Compassionate Communication

PwPD expressed a strong desire for emotional acknowledgment during diagnosis disclosure, which was rarely met. P10 poignantly stated, "[The consultant] [did not] have the words to console me, because they are a step above (gestures hand over head to show above) the personal side of it. Like, I just wanted someone to (gestures putting a hand around someone) [put] an arm around me and let me ball [cry]. Because nobody dealt with the shock. It's a frightening place to be".

Similarly, family members felt marginalised. One family member (FM2) echoed the experiences of the PwPD with regards to the lack of empathy during the diagnosis. FM2 observed, "When delivering news like that, you need empathy, and you need to give them time, because when it

hits them, they are sitting there on their own. I can own imagine what goes through their head (shrugs shoulders)". Family members like FM1 felt dismissed: "I felt totally dismissed coming out" after questioning the diagnostic process, highlighting gaps in communication and respect.

Others echoed the need for empathy and understanding during diagnosis. P12 reported, "[The consultant] [did not] give me much hope you know. And [the consultant] is finished with me, [the consultant] said "there [is not] much more I can do for you"'.

While all PwPD emphasised the importance of a personalised rapport, P4 reported, ". . . when you get those words, and the doctor is a highly professional person. But they [the consultant] understands practices, but they [do not] understand me".

FM1 reported that visits with the consultant are "just business", explaining the absence of a personalised experience. FM4 further added, "They're [consultant] writing (demonstrates writing), writing, answering questions, but they are never looking at the person who's asking those questions". Family members expressed the importance of including them in the care plan and for healthcare professionals not to assume the family member's knowledge. FM1 stated, "I think as a carer, you need to be sat down, and you need to have a discussion, you need to be included in the plan, as we are the person looking after them". Adding to this, FM2 reported, "And I think it's probably important that they [do not] assume that you know, as the years go on, things change and that you kept up to date [with research] with everything that's changing. You know, [do not] assume that we already know something".

These conversations revealed how shocking the diagnosis disclosure was for PwPD and their family members and offered little hope. People felt unsupported as they processed the news. Overall, the diagnosis was perceived not simply as a transfer of medical information but as a deeply emotional and relational event that required more compassionate, person-centred communication strategies. Active listening, self-care, and positive self-management strategies may have fostered hope and empowerment.

3.3. Theme Two: Navigating a Void—Lack of Signposting and Service Access

PwPD described a vacuum following diagnosis where clear information, direction to services, and emotional support were largely absent. The participants shared a sense of being left to navigate an unfamiliar path alone, with little help from the healthcare system. This lack of early support not only delayed engagement with important services like physiotherapy or support groups but also heightened anxiety, confusion, and a sense of vulnerability. Two subthemes emerged: the absence of structured information pathways, and the risk of isolation and self-navigation.

3.3.1. Subtheme One: Absence of Structure Information Pathways

People with PD reported receiving little-to-no guidance on available resources, physiotherapy, or support groups. P1 stated simply, "Nobody told me about anything, nobody has ever told me about anything", while P8 added, "In my own opinion, I think there is a lack of communication". This led to a lack of knowledge regarding their condition and the services. PwPD found themselves isolated in managing their condition, with P5 explaining, "I can see why people would be freaked out, you know? People are afraid of it [PD]. Because they [do not] know". The health system was perceived as reactive rather than proactive, with P6 noting, "If you're not in the [health] system or your GP is not good, you're forgotten about". P5 further added to this by

stating, “The biggest hurdle is getting the GP’s and consultants to recommend services. The challenge is how to get referred to anything”.

Some believed the health system should redirect its focus from treatment to prevention. P3 reported, “Throughout the early stages when someone is diagnosed why [are they not] redirected towards exercising, towards classes? The Health Service Executive (HSE) [public health service in Ireland] is going to capture them at some point, but when they do it will be too late, they need to start exercising early”. P7 also highlighted the need for immediate signposting to exercise, “Straight away I would say, go on an exercise program, now! [Do not] wait for 12 months”.

The lack of signposting led to some PwPD independently educating themselves about their condition and the available services. They felt unsupported by the health service as they felt “it [should not] be the individual’s responsibility to go and see what’s out there”.

3.3.2. Subtheme Two: The Risk of Isolation and Self-Navigation

In the absence of structured support, many PwPD were forced to self-educate. P4 reflected on the social consequences: “There needs to be a step in between, everyone should be able to find their village. That’s where it’s lacking; you either go straight to the Parkinson’s society or you’re staying here on your own”. Of the available services, PwPD felt they are not tailored and personalised, with some not suitable for young people. PwPD felt alone, with a lack of peer support. As a result, PwPD are frustrated with the lack of clear care pathways and referrals to health professionals or services.

Family members also echoed the frustrations regarding the lack of signposting. FM2 stated, “You need to be included in the plan. . . not just assume that we know what’s ahead”. This absence of coordinated care exacerbated feelings of vulnerability and abandonment.

Together, these subthemes highlight a systemic gap in post-diagnostic care that leaves PwPD and their families without the tools, information, or emotional support necessary to engage confidently with disease management. The absence of structured pathways fosters disempowerment, delays proactive care, and compounds feelings of abandonment. Strengthening signposting and personalising support from the point of diagnosis could play a vital role in mitigating early-stage distress and promoting long-term self-management and engagement.

3.4. Theme Three: The Missing Link—Exercise Education and Self-Management Support

People with PD consistently identified a critical gap in early care: the lack of timely education on the role of exercise in disease management. While participants recognised the benefits of physical activity later in their disease journey, they described how early misinformation or the complete absence of guidance left them uncertain and hesitant. Many only came to understand the therapeutic value of exercise through self-initiated efforts or informal sources, often years after diagnosis. This gap in professional guidance not only delayed engagement in physical activity but also contributed to unnecessary fear, confusion, and social withdrawal. Two subthemes emerged: early exercise misinformation and missed opportunities, and self-initiated learning as a form of resistance.

3.4.1. Subtheme One: Early Exercise Misinformation and Missed Opportunities

With time, all the PwPD reported awareness of the importance of exercise in the management of PD but, at the time of diagnosis, there was not a focus on its importance with many receiving no information or being encouraged to rest. Several PwPD recalled being discouraged from pursuing physical activity at diagnosis, reflecting outdated medical advice. P3 (diagnosed seven years ago) noted, “At the time I was told to take it easy. [Do not] get wound up and relax for myself and not to get exercise or not to be overly strenuous”. P2 (diagnosed three years ago) similarly reported, “Exercise was never encouraged”.

With that lack of education linked with the risk of social disengagement, P7 reflected, “At the start, I was afraid of moving my body, but I’m not afraid now because I know better”. These early messages contributed to fear around movement, delaying engagement in beneficial activities. P4 stated, “I had worked myself into such a state. I [did not] want to go out”. Only two PwPD reported receiving immediate advice promoting exercise, notably P5, who said, “The consultant was adamant about [exercise] the first day”.

3.4.2. Subtheme Two: Self-Initiated Learning as a Form of Resistance

In response to the lack of guidance, many PwPD pursued their own education. P7 emphasised, “The only [exercise-related] knowledge of Parkinson’s that I got was from a physio and that was about five or six years after I was diagnosed”.

Family members also reported relying on independent research. FM2 said, “I have researched it online; no one sat me down and told me what to expect”. This demonstrates a proactive but burdensome form of self-advocacy to bridge systemic gaps.

The lack of timely early education led to many resorting to self-education to improve their knowledge. All PwPD reported that they would prefer early education, provided within a few months of diagnosis, and, although it was not specified which healthcare professional should provide the information, the PwPD strongly highlighted that the information should be provided rather than them resorting to self-education.

Family members also reported a lack of education regarding the progression and management of the condition, again relying on self-education. They echoed the need for education provision for family members. These conversations highlight the lack of guidance about exercise and physical activity in the early stages of the disease.

This theme highlights a significant disconnect between emerging evidence on the benefits of exercise in Parkinson’s and the early-stage clinical guidance provided to PwPD and families. The absence of timely, structured education on exercise and self-management represents a missed opportunity for early intervention and empowerment. Promoting consistent, early-stage information provision could prevent misinformation, reduce fear, and foster proactive engagement in self-management practices from the outset.

3.5. Theme Four: Hidden Burdens—Emotional Impact on Family Caregivers

People with PD acknowledged the emotional burden that is oftentimes placed on their family members, reporting that it is not just the person with PD whose life is affected but also their families. Family members assumed much of the emotional and logistical burden post-diagnosis, often without adequate support. All family members expressed fear for the future. Two subthemes were identified: concealed grief and fear for the future and shifting roles from spouse to caregiver.

3.5.1. Subtheme One: Concealed Grief and Fear for the Future

Family members expressed deep fears about the future and grief for lost aspects of their loved ones' identity. FM2 noted, "She has always cared for everyone, and in my head, I'm looking down the line and saying the road is going to reverse". FM3 shared fears regarding long-term caregiving: "I worry what's down the road, you know? She's only 72 and I'm 83, who will care for her when I'm gone?"

FM1 articulated the emotional struggle: "I find it incredibly hard. . .sometimes, I want to scream because I still want to be doing things with him and he stopped talking, little things like that". FM1 also expressed the need to conceal and hide their emotions from their spouse, "I'm losing the man I'm married to; I'm married 53 years. So, I [do not] have the man that I married. I, like, you could get sad about it, but you [cannot] give up, for them, they need us to the strong".

3.5.2. Subtheme Two: Shifting Roles from Spouse to Caregiver

Many family members described an identity shift, moving from partner to caregiver. FM1 stated, "I'm very much a carer now, where I [was not] a carer". FM4 described the increasing dependency: "Her strength is quite good, but her dexterity is awful. . . like you said, you're actually caring for the person".

All family members agreed there is a need for social supports for family members. These conversations highlight the challenge family members face in coping with the changes and associated sense of loss, while trying to support and, at times, care for their family member with PD, to enable them to practise self-care and manage PD. This redefinition of roles added emotional strain and highlighted a critical gap in healthcare support for family caregivers.

These insights highlight the often-invisible toll Parkinson's disease takes on family caregivers, particularly in the early and mid-stages of disease progression. Emotional burdens, fears for the future, and changing relational roles contribute to a sense of grief and strain that remains largely unacknowledged in current healthcare provision. The findings underscore an urgent need for structured emotional and practical support for caregivers, recognising them not only as informal helpers but as individuals experiencing a parallel journey of adaptation and loss.

4. Discussion

This paper aimed to explore the experiences of PwPD in Ireland regarding their diagnosis, its impact on exercise engagement, and their access to relevant services. Through in-depth interviews with PwPD and their family members, the study revealed four key themes: the emotional and disempowering nature of receiving a Parkinson's diagnosis; a lack of clear signposting to available services; insufficient early education on exercise and self-management; and the emotional and logistical burdens placed on family caregivers. These findings highlight significant gaps in the current care pathway and underscore the need for more empathetic diagnostic communication, timely information provision, and early access to physiotherapy and support services. Acknowledging the emotional impact of receiving a Parkinson's disease diagnosis is essential, and healthcare professionals are encouraged to adopt a supportive, empathetic, and positive approach during diagnosis disclosure. Providing PwPD with adequate time and support to process this life-changing information is recommended. Following the diagnosis, a prompt follow-up appointment is an important opportunity to share relevant information and signpost available services.

Early referral to physiotherapy at the point of diagnosis, rather than waiting for functional deterioration, can empower people with Parkinson's to engage in self-management strategies, particularly exercise. In addition, healthcare professionals should be mindful of the burden often placed on family caregivers. By building rapport with caregivers, clinicians can offer timely support and refer them to appropriate services to help them in their caregiving role.

4.1. Disempowerment and Emotional Shock at Diagnosis

Experience of receiving their diagnosis was mixed. Most PwPD reporting a negative experience, with many being able to directly recall the consultant's diagnosing words, highlighting the emotional impact of their experience. This experience impacts their ability to self-manage and may delay their motivation to engage in exercise services.

Peek [6] highlighted the importance of creating open dialogue and the need for consultants to modify their consultation style in response to individuals [6]. Even though PD is often not regarded as the "worst" neurological condition [19], receiving a PD diagnosis should not be treated as a routine that ignores the psychosocial implications of this diagnosis. People respond differently to the same news, but regardless of these differences, everyone requires time to process the diagnosis, process their reactions, and express their worries and fears [6]. The participants' narratives revealed a desire to feel secure at this uncertain time, empowered again during a period of disempowerment, and comforted knowing that a plan was in place for the future when they left the diagnostic appointment.

Krieger et al. [8] conducted a qualitative study in Germany exploring the lived experiences, care provision, self-management, and future support needs of people with Parkinson's disease (n = 52 PwPD, n = 29 caregivers/relatives) and their relatives. Through interviews and focus groups, including those newly diagnosed (de novo), they identified major gaps in diagnosis communication, emotional support, and access to structured services. Participants frequently reported feeling abandoned, overwhelmed, and underinformed, with both PwPD and families struggling to navigate care and manage the condition [8]. These findings strongly support the results of our study, highlighting shared experiences of poor diagnostic communication, lack of signposting, and the emotional burden on families. Krieger et al.'s [8] work reinforces the need for empathetic, person-centred care and timely access to self-management resources, particularly exercise education. It validates the call for structured, early-stage interventions to support both de novo PwPD and their families in adjusting post diagnosis. Healthcare professionals should be mindful of the emotional impact that this moment can have on PwPD, acknowledging the need for time to process the information and offering psychological support.

Subramanian et al. [20] highlights the critical importance of delivering a Parkinson's disease diagnosis with compassion, hope, and clear communication, emphasising that the way a diagnosis is shared can have long-lasting emotional and psychological effects on people [20]. Their findings reinforce the need for clinicians to be mindful of the initial emotional shock, to challenge stereotypical representation of the disease, and to encourage early engagement in self-management strategies [20]. Their findings support the need for clinicians to modify their approach based on the individual's emotional state and to foster early engagement in self-management strategies. Following a diagnosis, it is crucial to offer the person a space to ask questions and process their emotions, providing tailored information relevant to their condition [20]. This aligns closely with this findings in the current study, where participants described how the delivery of their diagnosis profoundly shaped their early coping mechanism, sense of

empowerment, and willingness to engage in exercise and self-care. Embedding these principles into clinical practice could help address the gaps identified in early support and information provision, ultimately promoting better long-term outcomes for PwPD.

Guidelines on breaking bad news (reviewed by Fallowfield et al. [21]) place a strong focus on evaluating the patient's knowledge and emotional wellbeing, providing information and treatment alternatives, and a contact point soon after their receipt of the diagnosis. Most of these guidelines are centered on terminal illnesses, but more emphasis is being placed on the delivery of bad news in neurology [22–24]. How a PD diagnosis is explained to patients still needs to be improved, particularly with regard to remaining sensitive and aware of patient's understanding, feelings, and expectations. Giving time to ask questions at the time of the diagnosis and providing information that is relevant to each person (e.g., signposting to physiotherapy and/or exercise services) increases patient satisfaction with the diagnostic process [5].

4.2. Lack of Signposting and Service Access

All individuals reported receiving little or no information at the time of diagnosis, and many resorted to self-education, but others were at the risk of becoming social disengaged, particularly the younger PwPD (aged < 65 years) as they felt there was no supports that suited their age profile. At the time of diagnosis, they required guided and staged information instead of depending on themselves to learn about their condition. PwPD would welcome early information and signposting to community services for self-management and exercise engagement.

In 2023, O' Shea et al. conducted a national survey [25] (n = 1402) and an independent qualitative interview study [26] (n = 22) of PwPD's experiences of accessing the health service in Ireland, which supports our findings. Experiences included not being advised to bring a family member at the time of diagnosis; an over-emphasis on issues that were nonmodifiable, including too much emphasis on loss and degeneration; inadequate signposting and time to discuss available needs/services and self-management strategies; limited written information to take home; and a lack of empathy and privacy (especially for hospital in-patients) [26]. Furthermore, over 75% were not contacted by a healthcare professional in the weeks following diagnosis [26]. An earlier interview study with 19 PwPD and 12 family members in Ireland (2017) [27], which focused on the palliative care needs of PwPD, similarly found an overall lack of information at diagnosis. Participants in that study had suggested that information should be tailored to each person, available in many formats, with additional phone support from a PD nurse for general information or to clarify prior information.

In 2024, Agley et al. [28] explored the physical activity and exercise experiences, preferences, and priorities of PwPD living in the UK through an online survey (n = 405). They reported that many participants (68%) had not received education (n = 276) or an exercise intervention (54%) (n = 217) as part of their routine management by the national public health system since diagnosis; this resulted in seeking services privately [28]. The authors noted that the knowledge of the overall benefits of exercise was good; however, participants lacked specific knowledge on the impact of PD on posture, falls, and muscle strength [28]. Agley's et al. [28] conclusions echo the findings of this study. PwPD want physical activity and exercise education interventions that provide knowledge, skills, and access to activities [28]. For the most part, these interventions have not been provided as part of their routine care pathway [28]. Physiotherapists reported

that education should be provided early as soon as the patient is open to it (during diagnosis may not be appropriate) [9]. To align with the priorities and preferences of PwPD, physical activity and exercise interventions should be offered around the time of diagnosis, including relevant, individualised information and highlighting its value in mitigating PD symptoms [28].

4.3. Exercise Education and Self-Management Support

PwPD reported that education about the importance of exercise from physiotherapists was very important. But a delayed referral or access to physiotherapy can result in a delay in receiving this information. It is well recognised that all healthcare professionals promote exercise. However, additional information and support may be needed in the early stages. Surveying healthcare professionals working with PwPD in the UK (n = 29 doctors, 17 nurses, and 106 physiotherapists), Agley et al. [29] identified the main educators of physical activity in PD were physiotherapists. This included providing evidence on the role of exercise and signposting to support groups, providing early supports needed to promote exercise self-management.

The model of care from the Irish National Clinic Programme for Neurology [30] has an appendix on PD, which calls for timely and appropriate referrals to services, i.e., it is recommended that PwPD are assessed by relevant, specialised clinicians, with access to the required investigations, and that they have easy access to all the relevant professions, information, and services that enhance the short- and long-term management of their condition [15].

Similarly, the National Institute of Health and Care Excellence (NICE) guidelines on PD advocate that PwPD are seen within six weeks of the referral [31]. However, referrals to physiotherapy services usually only occur when function deteriorates, not around the time of diagnosis [19]. A delayed referral, leading to delayed self-management and exercise guidance, can prevent the opportunity to develop beneficial habitual exercise patterns, optimising both physical and psychological health. This further highlights the need for early referral to physiotherapy services at the point of diagnosis.

4.4. Emotion Burden on Family Caregivers

All family members expressed fear for the future and identified the need for supports for family members. Family members often assume the role of caregivers and respond to changes in patient symptoms. These circumstances can impact family members' mental health, more than their physical health quality [32]. Mc Ardle et al. [33] conducted a pilot study aimed to identify psychosocial factors of PwPD (n = 64) and carers (n = 40) associated with habitual physical activity. They found that higher carer anxiety and depression were linked to an increase in habitual physical activity volume, whereas poorer self-care among carers was associated with a decrease in activity volume over 18 months [33]. Greater carer strain was associated with longer walking sessions after 18 months [33]. This, therefore, emphasises that if family caregivers do not have a coping mechanism and adequate support from other family members and society, the condition may cause a decline in their health and quality of life [34]. Healthcare professional should discuss with family caregivers the need for personal support and refer them to available services if required. Providing caregivers with the necessary emotional support and information about available services can help reduce their strain and empower them to better support PwPD.

4.5. Strengths and Limitations

There is limited research that has investigated PwPD's experiences with the pathway to diagnosis and its disclosure and how it impacts self-management using qualitative interviews. Current research mainly focuses on the diagnosis experience [6,7] or experiences with self-management practices [8,35] in isolation, leaving a gap in understanding how the experience of diagnosis impacts a person's ability to self-manage the condition. Moreover, studies that have explored this relationship have often relied on surveys [5], which may lack the depth and richness of insight that qualitative interviews could provide. We believe this method allowed our participants to be open and honest about their experiences and provided us with rich data which may not have been acquired through surveys. The following strategies were employed to ensure the trustworthiness of this qualitative research. The interviewer (LA) is a registered physiotherapist, whose special interest and clinical expertise in PD may have led to informed iterative questioning and credibility. Data analysis was completed by three members of the research team, improving credibility. During data collection, dependability was enhanced and the interviews were video-recorded and transcribed verbatim, with transcripts including non-verbal data in brackets to further illustrate the discussion. A comparison between the transcripts and video recordings was conducted to ensure the data were correctly interpreted. Dependability was enhanced during data analysis; the data were peer-reviewed by members of the research team when collected. An audit trail of the research decisions, changes, and data analysis processes throughout the study were documented. Confirmability was enhanced throughout the data-collection process, with thick audit trails, and three additional research team members continuously reviewed emergent topics through critical peer review.
During data analysis, credibility and dependability were enhanced; independent initial coding was conducted by three members of the research team. After this, a consensus meeting discussing emerging themes took place. This process was repeated after recoding and then a peer-review of the final themes took place.

Several factors hinder the transferability of the findings. One of the main limitations of this research is that the findings of this paper emerged during initial interviews of a study aiming to explore PwPD's relationship with exercise, their motivations, needs, and supports. Therefore, the topic guide and research questions were not focused on exploring this topic and may have resulted in a mismatch between the research focus and underpinning method of study and the findings in this report. Future studies should employ targeted research questions and tailored topic guides specifically designed to explore the diagnosis experience, service access, and support needs in depth, ensuring alignment between methodology and emergent themes. Secondly, the sample size of PwPD included is small [36]; however, guided by information power versus data saturation [37], we gathered rich data from 12 PwPD with varying genders, years since diagnosis, and living circumstances. We believe that data saturation was achieved with no new emerging themes in the final interviews. Additionally, the sample size for the group of family members was very small and may not capture all experiences. Thirdly, the study mostly represents high-functioning PwPD. Although the recommendations provided by Mutrie et al. [38] were followed and every attempt was made to recruit people with varying exercise adherence, the sample included participants who were more interested/already engaged in exercising, only including study promotion, multiple mailings, and personal engagement [38]. The participants were not initially selected to explore the impact of diagnosis. Therefore, the participant variability must be noted. The participants varied significantly in terms of time since

diagnosis (1–17 years); this would have introduced substantial recall bias and variability in the interpretation of the diagnostic experience but it also highlighted the lasting significance of the event. For future studies, we recommend recruiting PwPD diagnosed within the last five years to limit recall bias. Lastly, the participants were recruited from the city of Cork and the surrounding areas, meaning that exploring experiences in a larger sample across multiple clinical services would be important.

5. Conclusions

People with PD continue to face similar challenges during their diagnosis experience as those that were reported nearly ten years ago. The findings of this study emphasise the need for healthcare professionals to deliver diagnoses with greater empathy and awareness of the psychosocial impact, ensuring that patients have time to ask questions and receive a follow-up appointment within a few weeks of diagnosis to allow for further questioning and information sharing of available services and supports. Embedding structured follow-up appointments within the early post-diagnosis period could improve patient understanding and connection to essential services. Our findings also highlight the critical role of physiotherapy in supporting exercise engagement and self-management. Ensuring that PwPD are referred to physiotherapy at the point of diagnosis—rather than waiting for functional decline—can empower individuals to adopt active lifestyles and maintain independence. Furthermore, healthcare professionals should provide tailored information to both patients and their families, acknowledging the emotional burden placed on caregivers and referring them to relevant support services to optimise both patient and caregiver well-being. From a policy perspective, there is a need to develop clear care pathways that incorporate early intervention, service signposting, and caregiver support.

Supplementary Materials: The following supporting information can be downloaded at: https://www.mdpi.com/article/10.3390/geriatrics10030073/s1, S1: COREQ: Consolidated criteria for reporting qualitative research: a 32-item checklist for interviews and focus groups; S2: Interview Questions: Semi-structured interviews: People with Parkinson's disease; S3: Interview Questions; Interview Group: Family Member/Carers.

Author Contributions: Conceptualisation, L.A., S.T. and R.M.; methodology, L.A.; formal analysis, L.A., C.C., S.T. and R.M.; writing—original draft preparation, L.A.; writing—review and editing, R.M., S.T. and S.E.L.; supervision, S.T., R.M. and S.E.L.; project administration, L.A. All authors have read and agreed to the published version of the manuscript.

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Institutional Review Board Statement: The study was conducted in accordance with the Declaration of Helsinki and was approved by the Clinical Research Ethics Committee of Cork Teaching Hospitals (ECM 3 (gg) 22 February 2022).

Informed Consent Statement: Informed consent was obtained from all subjects involved in the study. Written informed consent was obtained from the patient(s) to publish this paper.

Data Availability Statement: The datasets presented in this article are not readily available to protect participant confidentiality. Requests to access anonymised partial datasets should be directed to leanne.ahern@ucc.ie.

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D5: Publication 5

HRB Open Research

HRB Open Research 2024, 7:7 Last updated: 29 MAY 2024

STUDY PROTOCOL

REVISED Behavioural change for Parkinson's Disease: A randomised controlled feasibility study to promote physical activity and exercise adherence among people with Parkinson's: study protocol [version 2; peer review: 2 approved]

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Abstract

Background

Parkinson's is a common progressive neurological condition characterized by motor and non-motor deficits. Physical activity and exercise can improve health, but many people with Parkinson's (PwP) have trouble reaching the recommended dosage. Our recent literature review found improvements in exercise adherence with behavioural change interventions, but it remains unclear which are most effective. Further qualitative research and patient and public involvement has informed a novel behavioural change intervention to be tested alongside an existing exercise program.

Objective

Open Peer Review

Approval Status ✓ ✓

	1	2
version 2 (revision) 29 May 2024		
version 1 16 Feb 2024	✓ view	✓ view

1. **Hanna Johansson**, Karolinska Institutet, Stockholm, Sweden

2. **Chris Seenan**, Glasgow Caledonian University, Glasgow, UK

Any reports and responses or comments on the article can be found at the end of the article.

To examine the feasibility of behavioural change techniques delivered alongside an exercise programme to improve physical activity, function, and self-efficacy in PwP (and study procedures) to inform a future pilot RCT trial.

Methods

A parallel-arm single blinded randomised feasibility study. Twenty participants with Parkinson's (Hoehn and Yahr stage 1-3) will be recruited from a physiotherapy primary-care waiting list. Following written consent, and baseline assessment, the participants will be randomly allocated to the intervention (n=10) or the control group (n=10). Both groups will receive usual care, which includes a weekly programme of a multidisciplinary education, a supervised exercise class and a prescribed home exercise program. The intervention group will receive additional behavioural change techniques, targeting behaviour regulation, belief about capabilities and social influences. Class and home exercise adherence, behavioural component uptake and adherence, and negative events will be recorded. Outcomes will include enrolment and maintenance rates, physical function, falls, physical activity, and exercise self-efficacy measured pre- and post- the 12-week programme (in-person). Surveys will be used to compare experiences and satisfaction between groups. Exit interviews will be completed with the intervention group only, exploring their experience of the behavioural change techniques.

Discussion

The results will help inform a future pilot RCT, based on the intervention acceptability, consent rate, maintenance, and protocol integrity.

Trial Registration

ClincialTrials.gov NCT06192628

Keywords

Parkinson's Disease, behavioural change intervention, exercise selfefficacy, exercise adherence, physiotherapy, theoretical domains framework.



This article is included in the Ageing Populations collection.

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Author roles: Ahern L: Conceptualization, Formal Analysis, Methodology, Writing – Original Draft Preparation; **Timmons S**: Conceptualization, Methodology, Supervision, Writing – Review & Editing; **Lamb SE**: Conceptualization, Methodology, Supervision, Writing – Review & Editing; **McCullagh R**: Conceptualization, Methodology, Supervision, Writing – Review & Editing **Competing interests:** No competing interests were disclosed.

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REVISED **Amendments from Version 1**

Amendments that have been included in the new version are rephrasing and more in-depth descriptions of specific components to improve the readers understandability. For example, firstly, providing more information in our inclusion regarding diagnosis (was it self-reported or confirmed), and falls frequency (two or more falls in a year). Secondly, the addition of the Borg Rating of Perceived Exertion Scale to monitor exercise intensity. Lastly, more in-depth description of how to conduct the outcome measures (e.g. TUG).

Any further responses from the reviewers can be found at the end of the article

Introduction

Parkinson's is a progressive neurological condition characterized by both motor and non-motor features. Worsening motor features including balance, postural and gait impairments can lead to a sedentary lifestyle, which deteriorates with disease progression[1], contributing to poor quality of life[2], loss of functional independence[2] and reduced physical condition[2]. Exercise is important for people with Parkinson's (PwP) to help control motor and non-motor symptoms[3], improving sleep, mood, and memory; it may have a neuroprotective effect, possibly slowing disease progression[4,5]. Leisure-time physical activity has been found to reduce motor symptoms, regardless of nigrostriatal degeneration[6]. Despite this growing evidence, as little as 30% of PwP achieve the World Health Organisation recommended activity levels[1,7], some are inactive for 70% of the day, and most are one-third less active than age-matched peers[7,8].

Ellis *et al.*[9] has identified self-efficacy and outcome expectations as strong predictors of exercise adherence. However, PwP have reported that one of the primary reasons for poor participation in regular physical activity is lack of motivation[10]. Dopamine function, which is associated with motivated behaviour[11], is affected in Parkinson's thus compromising behaviour-reward processing in PwP[12,13]. With Parkinson's progression, there is reduced dopaminergic innervation of the ventral striatum, which is connected to motivational functions[14]. This may affect PwPs' well-being, compliance with and participation in exercise programmes and inclination to engage in physical activity[15]. It is thus necessary to develop programmes that can motivate people to engage in physical activity.

Such programmes, promoting engagement and adherence to physical activity and exercise in PwP, are limited, and few studies have investigated interventions consistent with behavioural change. Speelman *et al.*[16] has shown that behavioural techniques (coaching, goal setting, use of activity monitors) are widely accepted by participants, with 90% reporting benefits from the intervention and 73% reporting they would recommend it to other PwP[16]; the activity monitor being identified as the most useful tool[16]. The ParkFit trial[17], a 2-year, multi-centred, randomized controlled trial comparing physical therapy emphasising behaviour change (ParkFit program), with matched physical therapy emphasizing safety (ParkSafe program), reported no improvement in physical activity, measured by a self-report questionnaire (their primary outcome measure)[17]. However, both the activity diary and the activity monitor data suggested significantly more physical activity in ParkFit participants compared to the ParkSafe group[17]. Ellis *et al.*[18] implemented a single arm clinical study, with a virtual activity coach to promote daily walking. They showed that encouraging walking, monitoring progression, and overcoming barriers with collaborative problem-solving, was well accepted among participants, and led to improvements in adherence to walking, and improved walking speed[18]. We recently conducted a systematic review to examine the effects of behavioural change interventions on exercise selfefficacy and adherence in PwP[19]. We found that behavioural change methods combined with exercise showed no effect on exercise self-efficacy or adherence but brought small improvements in quality of life and physical function compared to exercise alone[19]. Furthermore, by mapping the data to the Theoretical Domains Framework developed by Atkins *et al.*[20] we identified *belief about capabilities*, *goals*, *behaviour regulation*, *social influences* and

reinforcement as the five most effective domains, which healthcare providers should encompass when developing a behavioural change program[19].

Limitations in the available literature includes inadequate sample sizes, with the majority of the studies being nonrandomised trials, and limited reporting of the theoretical perspectives, key barriers to implementing the intervention, and rationale for the intervention dose and type of activity[17,18]. To date, there is only one definitive multi-centred randomised controlled trial (RCT)[17] investigating the effectiveness of a behavioural change intervention on exercise adherence among PwP, highlighting the need for more large-scale RCTs. Furthermore, this RCT[17] did not assess exercise selfefficacy, which has been identified as a strong predictor of exercise adherence[18]. Our recent qualitative research[21] displayed difference exercise preferences between men and women (such as setting, type, group vs individual) and motivators to exercise, which we will further examine in this study. Clinicians should develop exercise programmes targeting individual's motivators and perceived needs, thus improving long-term participation[21].

The Parkinson's Exercise and Education Programme (PEEP) is an on-going programme run in a Primary Care Centre in Cork city. Informed by existing literature, the programme was developed by the first author (LA) in 2021 and modified according to physiotherapy colleagues' and patients' reviews. The programme is targeted for PwP, at Hoehn and Yahr stage 1-3 (i.e., still physically independent). The programme runs for 12 weeks and consists of weekly disease self-management education (45-minutes) an exercise component (45-minutes) and a prescribed home exercise plan. Research objectives

The aim of this study is to examine the feasibility and acceptability of adding behavioural change techniques to an existing Parkinson's Exercise and Education Programme for people with mild-to-moderate Parkinson's disease and the study procedures for a future pilot trial. The behavioural change techniques are designed to improve their confidence in managing and progressing their exercise and physical activity independently.

Using mixed methods, the research objectives are:

a) To evaluate the recruitment process and resulting sample characteristics (screen failures, consent refusals).

b) To examine the feasibility of the data collection procedures and outcome measures

c) To explore the acceptability and suitability of the intervention and the study procedures to participants.

d) To assess the time resources required to manage and implement the study and intervention.

e) To explore the trends in outcome measures in terms of range and variability across the entire group.

Methods

This protocol is reported in line with the SPIRIT 2013 Statement: Defining standard protocol items for clinical trials guidelines[22,23] and the intervention description is guided by the Template for Intervention Description and Replication (TIDieR)[24]. The protocol is reported according to the Consolidated Standards of Reporting Trials (CONSORT) statement extension for randomised pilot and feasibility studies[25]. *[Extended Data: SPIRIT Checklist].* Patient and Public Involvement (PPI)

We held two one-hour meetings with a PPI group (consisting of 4 PwPs; 3 female and 1 male). In one meeting, the findings of our systematic review and qualitative study were presented, and we gained their input on the draft design for the feasibility intervention. In the second meeting, the PPI group read and provided feedback on the participant information sheet and consent form. Study design

A parallel single-blinded feasibility study comparing an existing Parkinson's Exercise and Education Programme (PEEP, control) and an

augmented Parkinson's Exercise and Education Programme with behavioural change supports added (PEEP + BC, intervention). Ethical approval has been granted from the local research ethics committee (CREC registration number: ECM 4 (m) 20/06/2023 & ECM 5 (4) 06/07/2023).

Participants and recruitment

Participants will be recruited from the current waiting list to attend the existing PEEP Program. We plan to recruit 20 participants (10 in each arm) – to optimise numbers while keeping safety paramount in the classes (n=5 per class). We will aim to recruit an equal representation of both sexes (based on self-report). We estimate an attrition rate of 20%, based on previous PEEP programmes and available literature[26,27]. Prior to random concealed allocation, a member of the research team (LA) will screen participants for eligibility, as follows:

- Diagnosis of idiopathic Parkinson's Disease, confirmed by neurologist or geriatrician.
- Early Stages of Parkinson's, as determined by Hoehn & Yahr Stage 1–3 using the United Parkinson's Disease Rating Scale).
- Ability to drive or obtain transport that will drop and collect at the health centre.
- Ability to independently walk (with or without a walking aid).
- Reported by the referring healthcare provider or carer as able to follow instructions and carry out the exercise programme independently at home.

Participants will be excluded if they have:

- A diagnosis of atypical Parkinson's (e.g., progressive supranuclear palsy, multiple system atrophy, etc) or vascular Parkinsonism or drug-induced parkinsonism
- Previously completed the PEEP program.
- Had a hospital admission < 6 weeks ago.
- Immobility, or are a wheelchair-user.
- Severe visual or auditory impairment
- Serious medical conditions in major organs (heart, lung, or kidney) or other illnesses which prevent independent ambulation or safe exercise.
- Been identified as a high falls risk (identified during the pre-screening using objective measure the Short Physical Performance Battery (a score of ≤6 indicates a higher fall risk in old adults[28]) and subjective reporting of two or more falls in the past year.

All participants must provide GP clearance letters deeming them medically safe to partake in the exercise component prior to enrolling in the study. Written consent will be obtained from the participants (by LA) before data collection. Participants will be informed that they may withdraw from the study at any time for any reason.

Randomisation

Following written consent and baseline assessment (to ensure blinded assessment), a research staff member (RMcC), not involved in the screening or data collection, will randomly assign eligible participants in a 1:1 ratio, stratified by sex, using a computer-generated randomisation sequence and concealed allocation (sealed envelopes), to the PEEP or the PEEP + BC group. Outcome assessors will be blinded to group allocation. Study participants will be instructed not to share any information on group allocation with the assessor or with other PwP outside the intervention. Every attempt will be made to ensure the assessor is not unblinded; if this occurs, a substitute assessor will be used. The assessor will not be in the facility while the programme is being delivered. A full CONSORT[25] flow diagram is presented in Figure 1 and will be populated throughout the study. The participant timeline is documented in Table 1. Usual care and intervention details

Materials include gym and exercise equipment [chairs, steps, resistance bands, ankle weights, water bottles (will be used as hand weights)], an Exercise Diary [*Extended Data: Appendix A]* and a Behavioural Change Template [*Extended Data: Appendix B*]. One registered physiotherapist (LA) with a special interest in Parkinson's Disease will be leading the programme, as part of their doctorate training. A physiotherapy assistant, with additional training as a Postural Stability Instructor will be present at all the exercise sessions to ensure safe, correct exercise completion, which will allow the physiotherapist to focus on the behavioural change techniques.

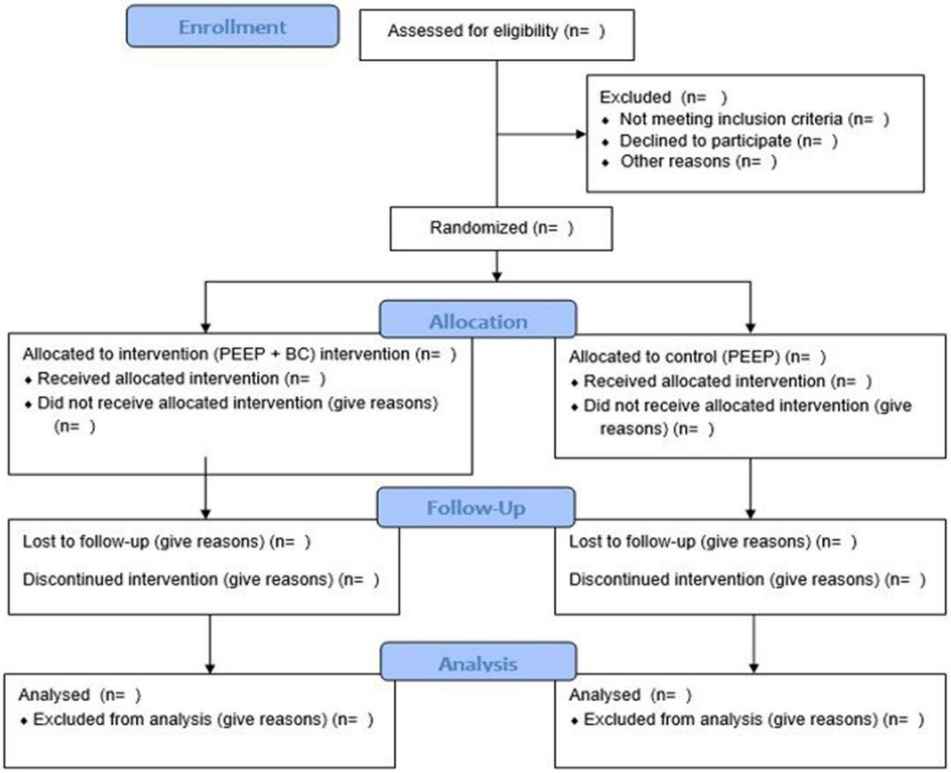


Figure 1. Consort Flow Diagram detailing the participants planned pathway through the trial[25].

Usual Care: Parkinson's Exercise and Education Programme (PEEP). The usual care consists of three components:

(1) Weekly group exercise class. Classes will be delivered in a primary care physiotherapy gym. They will last approximately 45 minutes, including a five-minute warmup and cool-down. The exercises class will include eight different exercises (focusing on strength, dynamic balance, coordination, flexibility, and dual tasking). The exercise type will remain consistent throughout the 12 weeks (to aid memory retention), however the progression of exercises will be tailored to each participant's capability, weekly, by increasing the number of repetitions and step height, heavier resistance bands, addition of hand and ankle weights and adding a cognitive element while performing the exercises. Thus, adjustments in intensity or complexity will be tailored to the individual and progressed with time. Participants will be asked to attend for one hour, to allow 15 minutes for people to settle in, and give an opportunity to socially engage before the exercise class begins. During this time, the physiotherapist (LA) will have a brief 1:1 conversation with each participant about adverse events that may have occurred that week (see section *Safety).*

(2) Twelve weekly 45-minute group education sessions will be delivered by a range of healthcare professionals and guest speakers including a physiotherapist, speech and language therapist, an occupational therapist, dietician, geriatrician, Parkinson's specialist nurse, psychologist, social prescriber, and social worker.

These sessions will be delivered in a conference room located next to the Physiotherapy gym in the primary care centre and will include general information to signpost people to services, the role of the healthcare profession in question. Education is provided on medication, symptoms, diet, and aids, but information that could improve exercise self-efficacy and self-management of exercise programmes (such as rest, pacing, goal setting etc) is not provided. Following each education session, a hardcopy of the lecture presentation will be provided, and any pamphlets and leaflets recommended by the speaker. The education sessions will be delivered to both groups together, on the day of the usual care group's exercise classes (the intervention group will have their exercise class on a separate day). All efforts will be made to keep contamination to a minimum as the participants will sit with their own group and will be asked not to discuss the exercise classes with others, and staff will be monitoring conversations in the room. Family-members will also be encouraged to attend the education sessions.

(3) At home, the participants will be expected to independently complete the exercises twice weekly, and this will be discussed at each exercise class with the registered physiotherapist.

Intervention: Parkinson's Exercise and Education Programme with the Behavioural Change Techniques (PEEP + BC). The BC intervention will consist of usual care and four additional techniques to address behavioural regulation, belief about capabilities and peer support.

SAM: StepWatch Activity Monitor; **ESES**: Exercise self-efficacy scale; **6MWT**: 6-minute walk test; **PDQ-39**: Parkinson's Disease Questionnare-39 **Safety**:

Table 1. Participant Timeline.

	Enrolment		Allocation	Post Allocation	
Timepoint	**$-T_2$** (two weeks before baseline)	**$-T_1$** (Week before baseline)	**0**	**T_0** (baseline)	**T_1** (post-intervention – Week 12)
Enrolment:					
Eligibility Screen	X				
Informed Consent	X				
StepWatch Activity Monitor distributed to patients		X			
Baseline Assessment		X			
Group Allocation			X		
Intervention:					
PEEP + BC				⟷	
PEEP				⟷	
Primary Outcome measures:					
Walking Activity (SAM)				X	X
Gait and Balance (APDM Mobility Lab system™)				X	X
Exercise self-efficacy (ESES)				X	X
Secondary Outcome measures:					
Physical Endurance (6MWT)				X	X
Quality of Life (PDQ-39)				X	X
Exit Interviews					X
Safety					X

Falls, hospitalisation, muscle soreness

(1) During the weekly exercise class, the intended functional benefit of the exercises will be explained to everyone.

Support will be given to self-select personal exercise intensity and to manage their own exercise and progressions at home. Peer support, competition, reward, and fun will be strongly encouraged and supported by the registered physiotherapist and physiotherapy assistant. By week six, the participants will be invited to lead the class, with the class leader rotating each week, aiming to be independently managing the class by week 12.

(2) An exercise diary to be completed independently at home daily [*Extended Data: Appendix A*]. Details will include the type of exercise or physical activity of choice, and its duration and intensity (using Borg Rating of Perceived Exertion Scale). Furthermore, they will be asked to reflect on the exercise; their confidence/skill completing the activity, consequences of the activity (both positive and negative) and reasons for non-completion. Daily diary completion will take less than 5 minutes.

(3) Individual one-to-one weekly conversations between the registered physiotherapist and the participant, covering the domains of behavioural regulation, peer support and belief about capabilities. The conversations will be held before each weekly exercise class, when the participants are coming into the gym, while others are settling into the room. All topics will be covered frequently but not weekly, to avoid repetition [*Extended Data: Appendix B*]. The conversation will last two to five minutes per person (approximately 15 minutes in total per class). During this time, the participant's exercise diary will be reviewed with the physiotherapist to support the participant to explicitly reflect on progress and their expectations, to identify solutions to any barriers, and to set activity goals for the following week.

(4) Peer support will be further supported with the suggestion of a WhatsApp group. To encourage self-management and to limit the influence of sharing their personal information, the physiotherapist will suggest this at the first visit, when, if possible, a participant will volunteer to lead the WhatsApp group. From this point onwards, the physiotherapist will remain uninvolved but will ask about the use of group chat in the individual conversation.

All participants will be asked to continue their usual exercise during the study period.

Outcomes measures

Feasibility outcomes. Feasibility outcomes of interest include methodological, procedural and clinical uncertainites[25,29,30], examination of recruitment rates, consequences of eligibility criteria, attrition once recruited, data collection completion, resources needed to complete the intervention and the data collection, participant adherence to the intervention, and acceptability of the intervention and study procedures to participants. Feasibility outcomes are shown in Table 2[31].

Process outcomes. The following will be collected to indicate the study process feasibility:

1. Fidelity of delivery of exercise-only and exercise- behaviour change classes (duration; range of exercises included progressing intensity as per plan, etc)
2. Class attendance; drop-out rates; set-up administrative time required (participant queries between classes, room preparation, etc)
3. Completion of home-based (self-reported) exercise activity (exercise type, number of repetitions, intensity)
4. Fidelity and barriers of delivery of the behaviour change intervention (review of the records of one-to-one discussions [*Extended Data: Appendix B*] and researcher completion of a reflective log after each exercise session.

Acceptability. The acceptability of the class and independent exercise (both groups) will be

explored by surveys [*Extended Data: Appendix C*], and the behavioural component

Table 2. Overview of feasibility outcomes[31].

Outcome	Evaluation
Recruitment and eligibility	- Number of patients on current waitlist - Percentage assessed for eligibility; fulfilling inclusion criteria, and included (of total number identified) - Ambiguities regarding eligibility criteria - Reasons for ineligibility - Reasons for non-participation
Data Collection	- Percentage of completed assessments. - Ease of completion and number of missing items - Types and number of potential clinical uncertainties in interviews
Attrition	- Rate of study dropout - Rate of intervention dropout
Resources needed to complete the study and intervention	- Length of time required for: - Participants to work through intervention. - Participants to complete questionnaires and interviews - Study personnel to administer the study
Adherence to the intervention	Number of: - Completed activity diaries. - Exercise classes attended. - Education sessions attended.
Acceptability and experience of the intervention and data collection and exploration of mechanisms of impact	- Reasons for poor attendance and withdrawal from the study and intervention - experience and perception of the behavioural change intervention (including positive and negative consequences) - perceived value of completing home exercise diaries - perceived value of WhatsApp group - perceived value of one-to-one conversations at each exercise class - perceived confidence in self-management - Number and severity of negative events

will be explored through additional exit interviews, using a semi-structured interview, with the intervention group only [*Extended Data: Appendix D*].

Safety. Falls (number and frequency), injuries (cuts, bruises, muscle pains, other injuries), ED attendance or hospitalisation, and death will be considered as adverse events and will be discussed and recorded during the weekly conversations held before each exercise class. If a participant does not attend (without prior explanation) they will be contacted. Family members will be contacted if the participant does not answer over one week, for those who do not have family, the GP will be contacted. Any serious adverse events will be reported to the Chief Medical Officer of UCC.

Performance outcomes. For performance outcomes see Table 1. We will complete all mobility-related assessments during the participants' ON phase for consistency (i.e., 1–2 hours post medications, and stated "good time of day")

Walking activity and falls events. The Stepwatch Activity Monitor will be used to measure step-count and physical activity. This is a validated accelerometer, with excellent accuracy in PwP[32]. The device is ankle-worn and is fully waterproof, allowing seven days of uninterrupted data collection. Participants will be asked to wear the accelerometer for the week before the programme begin, and again, for the final week of the programme. Within-person differences in average daily step count will be used to examine changes in physical activity. As it is well known that activity diaries are unreliable measures of activity[33], we will focus on accelerometery data only as a measure of physical/walking activity.

Falls and 'near falls' are the only measures that will be taken from the Activity Log. These events will be discussed in both groups during weekly one-to-one discussions about adverse event with all participants (at the beginning of the exercise class) and recorded.

Gait and balance. Physical performance will be measured objectively before and immediately after the programme using the APDM Mobility Lab system™ (http://www.apdm.com/ mobility/). The APDM Lab system uses coordinated, wearable inertial sensors to precisely analyse quality of gait and balance[34]. It is a portable gait and balance laboratory and allows streamlined gait and balance assessment by making it easy to collect, store, analyse, and interpret balance and gait data from a large set of prescribed tasks[34]. It is a validated device to objectively measure walking and balance in PwP[34]. Five Opals™ (accelerometers) will be attached to participants two feet (ankles) and two arms (wrists) and one at the waist using Velcro straps (provided). The participants will be asked to stand, walk a 3-metre distance, turn around, walk back to the chair, and sit down (Timed Up and Go Test (TUG)). A 2-minute free walk (at the participants self-selected pace) will be recorded also to examine stride length and turns specifically.

Exercise self-efficacy. Exercise self-efficacy will be measured using the Exercise Self-Efficacy Scale[35] (ESES) at baseline, immediately post-intervention. The ESES is a self-report instrument, validated in PwP[34], containing ten statements about how confident the person is performing physical activity and exercise[36]. Responses are chosen from a four-point scale with 1 = not at all true to 4 = always true (score range 10–40, higher indicating more confidence[36].)

Secondary outcome measures. We defined two secondary measures:

Physical endurance
Physical endurance will be measured with the six-minute walk test[35] (6MWT) at baseline and post-intervention. Participants walk continuously for six minutes at their self-selected pace. As recommended, an indoor hallway with the 10m distance will be used, and total distance will be recorded.

Quality of life (QoL)
QoL will be measured using the Parkinson's Disease Questionnaire[37] (PDQ-39) at baseline, and post-intervention. The PDQ-39 assesses Parkinson's disease-specific health-related QoL in the previous month across eight dimensions of daily living[37], with specific dimensions of functioning and wellbeing[37]. Data collection
Baseline data will include personal information such as demographics (including age and self-reported sex), social history, medical history, disease severity (using the United Parkinson's Disease Rating Scale – motor exam) and medication history will be collected before randomisation by the research physiotherapist (LA) and the Stepwatch Activity Monitor will be programmed and, as per the manufacturer's instructions, attached to the participants ankle at the end of the assessment. They will be instructed to wear the accelerometer continuously for seven days, until they return the following week, when the device is removed the data will be downloaded onto a password protected file on the research laptop. Participants will be encouraged to contact the research physiotherapist with any concerns about the accelerometer during the week, and a courtesy call will be made during the week to ensure data collection.

Similarly, the participants will be asked to wear the accelerometer for the final week of the program. On the last day of the program, the accelerometer will be removed, and the data will be downloaded. The outcome assessments will be completed by a blinded registered physiotherapist, who is fully trained in the completion of the assessments.

Adherence. Full adherence to the intervention will be defined as follows: 1) attending the baseline and immediate postintervention assessments, 2) completing 12 weekly activity diaries and 3) attending all 12 exercises classes, attending all 12 education sessions. Attendance at the exercise classes and education sessions will be documented each week by the registered physiotherapist. Activity diaries will be viewed each week during the weekly one to one weekly conversations between the registered

physiotherapist and the participant before each exercise class.

Qualitative process evaluation. All participants will be asked to complete a feedback survey [*Extended Data: Appendix C*] with open-ended questions exploring what they liked/disliked about the PEEP program, elements of the programme they felt were not required, or elements they believe should have been included in the program, and their opinions of the topics covered during the education sessions. On-line semi-structured interviews exploring the acceptability of the behavioural change techniques will be conducted a research physiotherapist (RMcC) with the intervention participants only, immediately post-intervention (12 weeks). Participants will be asked to discuss the perceived impact and value, and how the intervention address barriers to exercise and physical activity. The interview guide will be informed by previous research examining the acceptability of BC interventions[38–40] coded under the domains of the Theoretical Domains Framework[20]. [*Extended Data: Appendix D*] Data analysis

Quantitative analysis. With small numbers in each group, we will present and treat all continuous data as non-parametric data. Suitable summary statistics (e.g., median, interquartile range, and frequency, percentages) will be provided for all outcomes.

These summary statistics will be used to assess the feasibility of the intervention. Potential ambiguities regarding standard safety procedures, types and numbers of measures undertaken to assure patient safety, and types and numbers of unforeseen safety issues will be reported and disaggregated by sex. We will analyse the results according to a modified intention to-treat principle, whereby we will exclude only patients with no follow-up measurements at all.

Qualitative analysis. Data from the semi-structured interview questions will be audio- recorded, transcribed verbatim, and analysed with the data from the surveys using qualitative content analysis. Difference between the sexes will be carefully considered.

Dissemination of data

A paper describing the main outcomes of the feasibility study, including the qualitative data, will be submitted to a peer review journals and the results will be presented both locally to physiotherapy clinical colleagues, and at international conferences and will be presented to the Cork Branch of the Parkinson's Association of Ireland. A poster summarising the results in simple terms will be produced and placed on the wall of the Primary care centre.

Amendments

The publication of the study's result will include any amendments to this protocol in tabular format including the date, description, and rationale of each amendment (section "Differences between protocol and study"). The clinicaltrials.gov register will remain updated with the protocol and any amendments made.

Ethical application

Full ethical approval has been granted for the study by Clinical Research Ethics Committee of the Cork Teaching Hospitals (Registration number: ECM 4 (m) 20/06/2023 & ECM 5 (4) 06/07/2023). **Study status**

The feasibility study is due to commence participant recruitment in November 2023.

Discussion

This intervention has been informed from our previous systematic review[19] and qualitative studies[21] with participants and healthcare

providers. These studies showed us that people want to exercise but are frustrated by the barriers and reliance on healthcare providers or family to manage or motivate them to exercise. We propose to examine the feasibility of a behaviour change intervention to address behaviour regulation, belief about capabilities and peer support by encouraging self-progression, reflection, competition, fun and reward to drive adherence and self-management of exercise behaviours.

The results of this feasibility study will inform a future pilot trial, by examining responsiveness of outcome measures, consent rate, and qualitatively exploring acceptability and experiences of the intervention which will help to refine the intervention and may explain uptake and adherence rates. We will consider sex differences, if any that emerge from the qualitative interviews.

The effects of behavioural change intervention on exercise adherence and exercise self-efficacy remains unclear. There is a clear need for participatory research to design interventions that help PwP to maintain health and wellbeing. While not definitive, this study will help further behavioural change intervention design informed by the published literature, stakeholder input and PPI involvement.

Data availability

Underlying data

No data are associated with this article.

Extended data

Dryad: Extended Data for Behavioural change for Parkinson's Disease: A randomised controlled feasibility study to promote physical activity and exercise adherence among people with Parkinson's: study protocol, https://doi.org/10.5061/dryad. prr4xgxt5[41]. Reporting guidelines

Zenodo: SPIRIT checklist for 'Behavioural change for Parkinson's Disease: A randomised controlled feasibility study to promote physical activity and exercise adherence among people with Parkinson's: study protocol', https://doi.org/10.5281/ zenodo.10407626[42].

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The article details a protocol for a randomized feasibility trial comparing standard care to additional behavior change intervention in people with Parkinson's disease. Feasibility and acceptability of the novel approach will be explored recruiting participants from an existing exercise and education class. The objectives and planned outcomes from the study are well matched and described. The protocol is presented according to appropriate reporting guidelines and the additional material provides adequate information that would enable replication.
Overall, this is a well-presented protocol describing a useful and well-designed study in an important area of practice. The findings of the study will enable progression within the field and for people with Parkinson's disease.

Is the rationale for, and objectives of, the study clearly described? Yes

Is the study design appropriate for the research question? Yes

Are sufficient details of the methods provided to allow replication by others?
Yes

Are the datasets clearly presented in a useable and accessible format? Yes

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: My expertise is within cardiovascular disease, physiotherapy and developing behaviour change interventions for long term conditions. I have experience designing and implementing feasibility trials in clinical practice.

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.

Reviewer Report 08 May 2024

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The authors here describe a study protocol for a parallel-arm single blinded randomised feasibility study involving people with mild-to-moderate Parkinson's disease. Both groups will receive multidisciplinary education, a supervised exercise class and a home exercise program, but additional behavioural change techniques will be added to the intervention group. Exercise studies, and especially those involving elements of behavioural change, are highly needed in the Parkinson's research. Evaluating the feasibility of a study design before commencing with a larger scale RCT is of utmost importance, and I commend the authors for doing this valuable groundwork.

Below are some questions and suggestions for the authors to consider and address as they find appropriate.

Feasibility/methodology

- Consider formulating progression criteria to better help you assess whether and how to progress to a full-scale RCT (see Mellor K, et.al.,2023 [Ref 1] for recommendations.)
- Considering that the authors plan to perform a RCT on a smaller scale, and to assess most elements of this process, I would say that this is in fact a pilot RCT. How come the authors do not intend to use the results of this study to inform a larger scale RCT, instead of planning to perform yet another pilot study?
- Please consider evaluating the randomization process as well as the ability to maintain blinding throughout the study.
- Will the results of this study help inform the choice of a primary outcome for the planned RCT? If so, please describe how.

Participants/recruitment/screening

- How will a diagnosis of idiopathic PD be confirmed?
- How will Hoehn and Yahr stage be confirmed? Using the MDS-UPDRS III?
- Fall risk and fall history will be assessed during pre-screening. Please describe the cut-off used to define "frequent falls".
- Have the authors considered excluding participants who are already highly physically active in their daily life? It is a common problem in exercise studies that people who are already active tend to sign up, thereby resulting in biased samples and lowered ability to show effect. If physically active people are recruited, please make sure participants are willing to continue with their usual exercise during the intervention period.

Outcomes/assessments

- Have the authors considered evaluating cognitive function?
- Have the authors considered evaluating symptoms of depression or anxiety since this can negatively affect exercise adherence/motivation etc?
- Why not use accelerometers the week after the intervention has ended, instead of letting participants wear them the last week of the intervention?
- Perhaps just a typo, but I can only see two secondary outcome measures (6-min walk test and PDQ-39) even though the authors state that there should be four.
- What is the rationale for performing both the 2-minute walk test and the 6-minute walk test? Will both tests be performed at self-selected (i.e., usual) pace?
- The authors state that the recommendation for the 6-minute walk test is to conduct it in an indoor hallway over a 10-meter distance, but this is not correct. The American Thoracic Society recommends it be performed over 100 ft (apx 30 meter). If possible, I therefore suggest that both the 2- and the 6-minute walk test be performed over a 30 meter distance.
- The TUG test is not described correctly (does not describe the first turn and the 3 meter walk back to the chair).
- Why use five and not six opals? Please consider adding the sternum opal as well so that you can assess sit-to-stand/stand-to-sit transfers during the TUG.

Intervention

- Regarding the home exercise diary, I am curious as to how difficulty level will be explained to participants. Is this based on physical exhaustion or other? If so, have you considered letting participants rate this using for example Borg RPE instead?
- The behavioural change template (Appendix B) seems a bit too exhaustive to complete in 25minutes. The authors state that not all questions will be addressed each week, but how will you choose which ones to focus on each week?
- I think the authors have done a great job of describing both the control group and the intervention group, but I wonder whether it would be good to have a table outlining all elements as well to get a better overview of which elements are overlapping versus those that are group specific.

References

1. Mellor K, Albury C, Dutton SJ, Eldridge S, et al.: Recommendations for progression criteria during external randomised pilot trial design, conduct, analysis and reporting.*Pilot Feasibility Stud*. 2023; **9** (1): 59 PubMed Abstract | Publisher Full Text

Is the rationale for, and objectives of, the study clearly described? Yes

Is the study design appropriate for the research question? Yes

Are sufficient details of the methods provided to allow replication by others? Yes

Are the datasets clearly presented in a useable and accessible format? Not applicable

Competing Interests: No competing interests were disclosed.

Reviewer Expertise: Parkinsons disease

I confirm that I have read this submission and believe that I have an appropriate level of expertise to confirm that it is of an acceptable scientific standard.