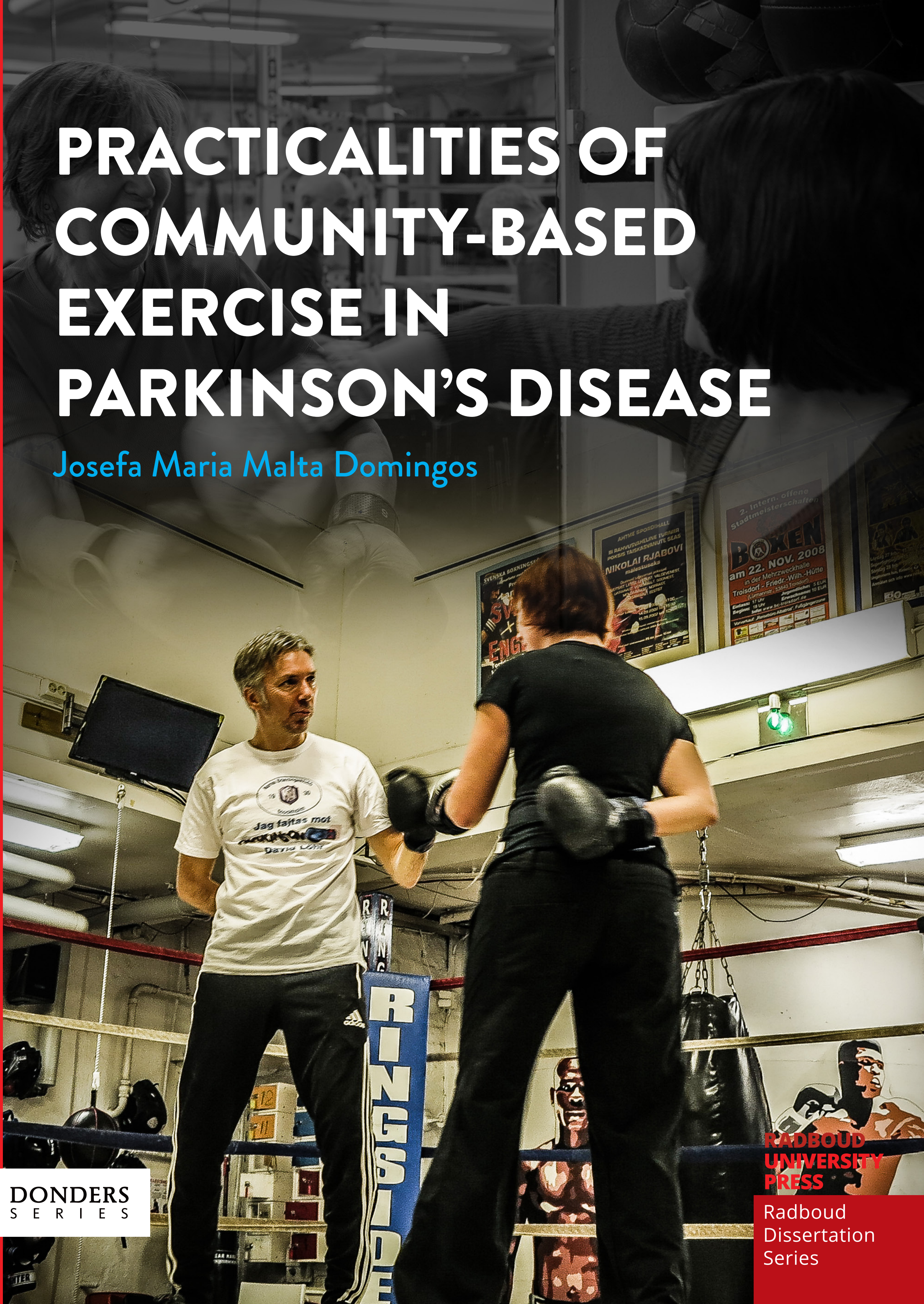
PRACTICALITIES OF COMMUNITY-BASED EXERCISE IN PARKINSON'S DISEASE

Josefa Maria Malta Domingos



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Part I

Community-based exercise in Parkinson’s disease

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General introduction and outline of the thesis

General Introduction

Physiotherapy and regular exercise are associated with better physical functioning in people with Parkinson's disease (PD) [1-4]. Continuous exercise is needed to maintain the beneficial effects, so a physically active lifestyle should be promoted [1, 5]. This can be achieved in hospitals or outpatient clinics, but preferably in a community setting.

Community-based exercise programs (e.g., dancing, boxing, Nordic walking, hydro gymnastics) designed explicitly for people with PD, are gaining popularity. The availability of such dedicated programs may better increase continuous exercise participation in actual daily life. However, we still require more evidence about these programs' benefits and long-term use. We also need more detailed information regarding safety, optimal modes of delivery, and implementation methods (i.e., barriers and limitations). This thesis offers a perspective on the practicalities of implementing community exercise programs for people with PD. This work is very timely, as it arrives at a time when community-based (or even home-based) interventions are becoming even more vital, given the physical inactivity and social isolation seen during the coronavirus disease 2019 (COVID-19) pandemic, where many people with PD were forced to interrupt their exercise habits and rehabilitation treatments to minimize exposure risk and to prevent further spread of the disease [6, 7]. In this chapter, I will first introduce PD and current care models for persons with PD. I will then briefly discuss the types of community-based exercise programs used in PD, the limitations in implementing them, and why community-based care is expected to be a valuable addition to our current care models. Lastly, I will describe the aims and outline of this thesis.

Parkinson's disease and current care

PD is the second most common progressive neurodegenerative condition after Alzheimer's disease, affecting approximately seven million people worldwide [8-10]. It is typically characterized by the presence of bradykinesia combined with either resting tremor, rigidity, or both. However, the clinical presentation is complex and also includes multiple non-motor symptoms (e.g., dysautonomia, pain, hallucinations, or dementia) that have been associated with higher disability in later stages of PD [11-14].

PD is managed through various pharmacological and non-pharmacological treatment options that have been proven beneficial [10, 15-17]. Levodopa is the gold-standard drug for the symptomatic treatment of motor symptoms such as rigidity, bradykinesia, and tremor [17, 18]. Dopamine agonists are often prescribed to improve motor symptoms, sometimes for additional reasons, such as alleviating other disabling symptoms such as restless legs syndrome, sleep fragmentation, or early morning dystonia. However, a purely pharmacological approach cannot optimally manage the complex overall phenotype that consists of a plenitude of motor and non-motor symptoms. Some motor or nonmotor symptoms do not respond adequately to dopaminergic pharmacotherapy (freezing of gait, balance, or speech impairment). In contrast, others can be worsened by drug treatment (for example, hallucinations or orthostatic hypotension). Moreover, as the disease progresses and response fluctuations begin to emerge, it becomes increasingly difficult to prescribe an adequate dopaminergic drug dose that provides a gratifying and consistent benefit throughout the day. This justifies the need for adjunctive interventions [19, 20].

Non-pharmacological treatment interventions such as physiotherapy [1, 4], speech therapy [21-24], PD nurse specialist care [25], and occupational therapy [26] help improve patients' functioning and assist people with PD and their families in coping with disability [1, 10, 15-17]. Physiotherapy is one of the most widely studied non-pharmacological interventions. It has shown benefits in improving motor impairments in transfers, posture, reaching and grasping, balance, freezing, falls, gait, and physical capacity [1].

Exercise is often studied as part of the overall repertoire of physiotherapy interventions, and growing evidence shows its effectiveness in alleviating several motor problems [1, 4, 27-31] and non-motor problems [32, 33]. Evidence also indicates that ongoing exercise is needed to maintain the health benefits [1, 3, 5]. People with PD can receive this care in various settings, such as inpatient, outpatient, home-based, and community-based care.

Current healthcare delivery is often complex and fragmented and has to deal with numerous barriers (e.g., geographical distances, lack of time, limited expertise, and poor communication) [34, 35]. These barriers also hamper the implementation of exercise strategies. In addition, on a personal level, people with PD experience various barriers and facilitators to becoming or staying physically active [36-41]. Importantly, people with PD are commonly positive towards participating in research studies on exercise [36]. However, after the study has ended, they find it difficult to remain active without ongoing encouragement typically offered as part of the research setting [37]. To keep up with their activity levels, they need explicit guidance on the benefits of exercise, greater availability of programs closer to home, and easily accessible contact with medical or non-medical providers [37]. Importantly, people with PD also indicate that exercise programs should consist of activities that are enjoyable, safe, and adaptable to the abilities of the individual while also including social engagement and social support [42].

As such, offering exercise in the community close to patients' homes can help overcome some barriers and may be an attractive, cost-effective solution to enhance ongoing exercise.

The use of community-based exercise programs in Parkinson's disease

Community-based exercise interventions commonly refer to using different exercises delivered in a group format, close to a person's home, in a community center or local rehabilitation center, and which is most frequently conducted by non-medical professionals. These community-based exercise programs are gaining popularity, which in turn assists people with PD to actively promote their health (i.e., self-management).

A wide range of Parkinson-specific community-based programs are currently used in PD. The most common ones that have been studied recently include dance [43-48], Tai Chi [49, 50], Qigong [51], Nordic walking [52-55], boxing [56-58], and aquatic exercise [59-62]. The quality of most studies was reasonable, although a general critique was the relatively small sample size in many publications, the relatively short follow-up, and, at times, the lack of an adequate control group. Overall, the level of evidence is therefore not definitive yet, and further large-scale studies with long-term follow-up remain needed.

Dance is one of the most widely researched forms of exercise in PD and has been shown to have a beneficial effect on motor symptoms, balance, and gait [4, 63, 64]. It has also shown potential benefits on cognitive function, mood, and quality of life [47, 65-67]. **Tai Chi** and **Qigong** challenge a participant's primary balance and are recognized by international guidelines as intervention options to improve balance and gait impairments [1, 15, 17]. Compared with no exercise or sham treatment, Tai Chi [49] and Qigong [51] revealed a beneficial effect on motor symptoms, balance, and gait parameters. The efficacy of **boxing** as an intervention for PD has also been researched [56, 57]. Preliminary findings [56] showed that community-based group boxing training was safe and feasible in seven people with PD, with immediate and long-term improvements in balance, mobility, endurance, and quality of life.

In another study [57], boxing significantly improved gait velocity and endurance over time compared to a conventional physiotherapy control group. **Nordic Walking** [53-55], when compared to no exercise or sham treatment, has also been shown to have a moderately large effect on motor symptoms and a large effect on balance (Berg Balance Scale - BBS) and gait (6 Minute Walking Test - 6MWT). Compared with standard physiotherapy or no exercise, **hydrotherapy** interventions have shown a moderately large effect on the Timed Up and Go test. A moderately large effect was found for fear of falling (FES) [4].

For several reasons, these community-based programs are an essential exercise resource for people with PD. First, it offers ongoing care with the potential to maintain physical and mental well-being through long-term exercise adherence and increasing healthy lifestyles in PD. After undergoing a dedicated physiotherapy intervention in a clinical setting, further efforts are needed to maintain any achieved beneficial effects. To achieve this, people with PD need access to a supportive and safe exercise environment, preferably led by professionals with relevant Parkinson-specific training [1, 68, 69].

Second, because these decentralized exercise opportunities are often close to the participants' homes, these programs improve accessibility and reduce transportation needs [41, 70] and care partner burden [71].

Third, if these programs are appropriately designed and delivered, they can be associated with powerful clinical outcomes and improve patient satisfaction with healthcare [38]. For example, community-based programs such as dance or Tai Chi [49, 50, 66, 67, 72] have been shown to potentially reduce fall risk factors (such as balance, gait, psychological symptoms, and cognition). Their usefulness to society is potentially tremendous, given the physical, social, and mental impact they may have on preventing falls and fall-related injuries. Finally, healthcare systems benefit from cost savings achieved by community-based care. Policymakers worldwide are, therefore, understandably keen to implement and spread low-cost models to improve the quality of care [73].

Challenges in the delivery and implementation of community-based exercise

The extent to which general exercise programs in the community can be translated into sustainable, adequate, and safe exercise programs specific to PD still needs to be determined. There is limited evidence on the optimal design, delivery, and implementation of PD-specific exercise programs that are easily accessible and generalizable.

Given the easy access, feasibility, and low cost of community-based exercise, these interventions deserve further research with an appropriate design, sufficient power, and proper attention to safety issues. In addition, several questions need better clarification, including the following: what is the ideal type of exercise to use (and when)? Which type of exercises do people with PD prefer (and why)? Exactly what kinds of benefits do different exercises provide to specific phenotypes of PD? What is the potential impact of demographics and subpopulation characteristics such as age, gender, educational level, and disease-specific disabilities on the preference for this type of program? What is the need for added expertise, training, or clinical education for those applying these programs to individuals with PD to guarantee safety issues? How can we better support patients' choices? With traveling difficulties and growing disability, can technology support online community expert care access? Finally, should this be included in current care models per se, or should it be organized outside the care system as an addition to formal care?

Understanding these issues is essential to consider community exercise as an addition to conventional rehabilitation PD programs. It is intended to complement current healthcare options more safely and beneficially and help to ascertain affordable healthcare. Importantly, favoring community-based exercise programs with improved quality and safety as part of routine care for people with PD does not aim to create an alternative to supervised clinical care (i.e., skilled services provided by licensed physiotherapists or other relevant healthcare providers). It counts on the active participation of informed people with PD to make the right decisions for their health, capable of working as partners with all professionals (medical and non-medical) to achieve optimal results.

Looking at the future of healthcare, using technology in community programs could effectively assess its benefit and simultaneously enhance long-term adherence [74]. Several reports demonstrated the benefits of telemonitoring and telerehabilitation to provide specialized care to people with PD with difficulty accessing it [6, 74]. Specifically, due to the coronavirus disease 2019 (COVID-19) pandemic, many people with PD were forced to interrupt their rehab treatments. They experienced severe sudden changes in daily routines, which ultimately led to reduced physical activity and social isolation, resulting in negative impacts on their disease symptoms and a poorer overall health status [6, 7]. Ultimately, there is a potential value in applying technology such as telemonitoring to facilitate patient access to specialized community-based programs within the safety and convenience of their own homes [74] or to participate in exercise classes delivered within community centers with supervision by remote trainers [75].

Aims and outline of the thesis

This thesis provides a starting point for reflections on the delivery, implementation, necessary expertise, assessment tools, and overall improvement of community exercise care in PD care.This thesis will address moving PD care towards ongoing community-based exercise programs. My research questions will include the following:

1. Which community-based programs have been used and studied in Parkinson’s disease?
2. What are community-based programs' current benefits, drawbacks, limitations, and future needs?
3. What educational material can be a common ground for improving expertise among professionals that apply community programs?
4. How to improve medical referrals to such programs?
5. How can community programs be better implemented?
6. How to support patients’ exercise choices?

In **Chapter 2**, I will present a viewpoint reflecting on two significant concerns regarding current community-based exercise programs: (1) limited evidence to support their use; and (2) application primarily by professionals without PD expertise. I will argue the need to enhance the expertise of the professionals applying such programs and increase appropriate referrals to improve care.

In **Chapters 3 and 4,** I will discuss how to **enhance expertise among professionals** based on the use of international educational tools, specifically the European Physiotherapy Guideline for Parkinson’s disease. I will reflect on how the guidelines can be adapted to other cultures (chapter 3). In **Chapter 4**, I will reflect on the relevance of enhancing expertise by stimulating referrals to non-pharmacological interventions in the community. We will propose referral criteria based on internationally recognized guidelines regarding when neurologists should refer people with PD to non-pharmacological interventions.

In **Chapters 5**, **6 & 7**, I will explore implementing local community programs for people with PD. In Chapter 5, I will study an example of how to implement a community-based exercise boxing program based on clinical mentorship and by boxing trainers appropriately educated in PD and specific boxing exercises. In Chapter 6, I will assess the benefits of adding kicking to a community boxing program in a randomized study. In Chapter 7, I will focus on how to facilitate participation in community exercise programs. I will determine the usefulness, satisfaction, and preferences regarding participation in a PD-personalized educational and exercise boot camp program.

In **Chapters 8, 9 & 10**, I will discuss and summarize the findings of this thesis and discuss these results. Limitations, needs, future challenges, and possible solutions will be addressed.

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2

The proliferation of community-based exercise programs with limited evidence and expertise: safety implications

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The Proliferation of Community Exercise Programs with Limited Evidence and Expertise: Safety Implications

A number of research studies underscore the beneficial effects that physiotherapy and exercise can have on functional activities involving gait, transfers, and balance in Parkinson's disease (PD) [1]. People with (PD) can receive this care in various settings from various professionals. Evidence is emerging that supports several community programs for people with PD that incorporate different non-conventional types of group exercises, including dance [2], boxing [3], Nordic walking [4], tai chi [5], and aquatic exercise [6].

There are reasons to be optimistic that these new initiatives may be a long-term, cost-effective, and easily accessible care strategy for ongoing exercise for people with PD. However, data regarding their true benefits and the best approaches to implementation are still limited. Notably, a minimal optimal level of disease-specific expertise is necessary, particularly with respect to safely integrating exercises and reducing the risk of falls and other possible safety issues [1,7]. By prematurely referring people with PD to exercise approaches that do not have robust evidence and are led by instructors with a lack of professional expertise, health professionals may favor unnecessary procedures, foster unrealistic expectations in people with PD (particularly those with less favorable profiles), and could ultimately be putting patients at risk of falls and/or injury (Fig. 1).

As such, several important questions regarding the specificity of PD and safety issues are now arising that should fuel future research. First, should we obtain more evidence about these community exercise programs and then implement them within the community setting, or should we start these programs first, even if little evidence is available? Second, considering the financial considerations, accessibility, and safety issues, and the progressive nature of the disease, who should implement such community programs? Should physiotherapists incorporate boxing, dance, or tai chi into their clinical practice? Or would training exercise instructors who teach community programs be more feasible and equally effective?

Safe evidence-based practices must be a priority for care in all settings, including the community. Several courses of action may be needed to address the gap between expertise, evidence, dissemination, and implementation into community exercise practices.

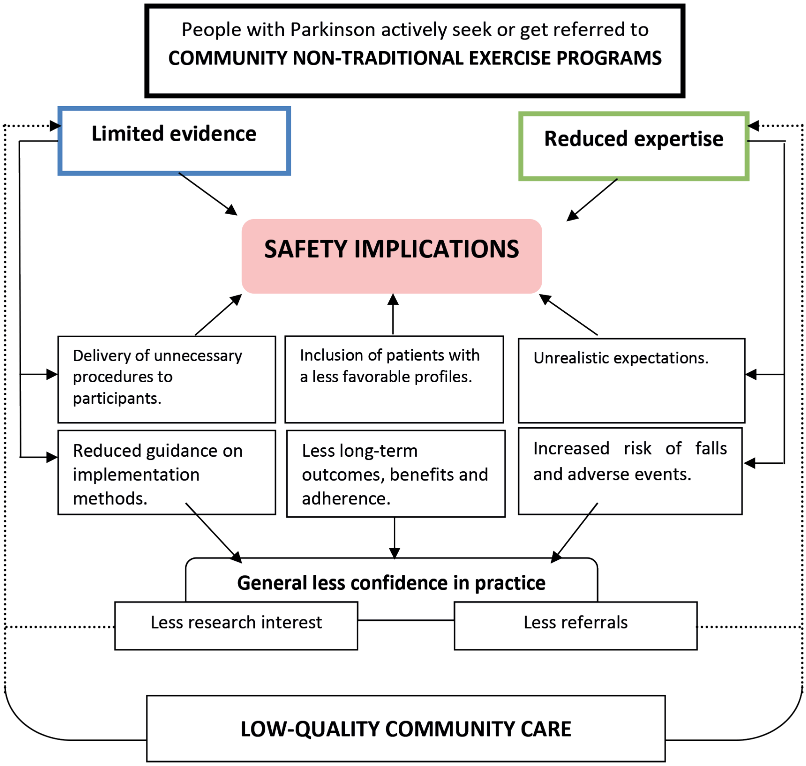

Figure 1 | Barriers to high-quality community care

Programs must be made available and accessible to people with PD by reducing critical financial and travel barriers. If evidence-based practices are not covered or are inaccessible, they will not be used. Even if people with PD may have limited access to evidenced-based care, that care, when delivered, should be delivered by instructors with PD expertise.

It is also critical to enhance expertise among professionals who deliver these exercise programs through specific training, adequate ongoing educational support, and continuous contact with people with PD. Professionals with advanced knowledge and skills are better equipped to design tailored exercise interventions that target specific PD symptoms, adapt programs to individual needs, and ensure safe and effective execution. Moreover, enhanced expertise enables professionals to provide comprehensive guidance on exercise progression, promote adherence, and facilitate long-term maintenance of physical activity habits.

Furthermore, there is a need to augment public and the PD community awareness regarding evidence-based exercise programs and their accessibility. By generating greater public interest in community exercise programs, we can potentially influence the trajectory of clinical research and advance clinical practice in a positive manner.

All these actions can begin to guide us away from care disparities and promote better care for people with PD. Without them, no amount of evidence will matter.

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Part II

Enhancing Expertise & Referrals among professionals

3

Facilitating the dissemination of knowledge

The European Physiotherapy Guideline for Parkinson's Disease: translation for non-English speaking countries

Published as:

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Abstract

Background: The use of the European Physiotherapy Guideline for Parkinson´s Disease is limited in countries where the official language is not English.

Objective: To provide practical steps to translate the European Physiotherapy Guideline for Parkinson´s Disease.

Methods: We used the translation process of the Portuguese version as an example of how to define the recommended steps. A combination of a forward-backward-translation and a dual-panel approach was used.

Results: Ten recommended translation steps were defined: (1) authorization, (2) translation of sample chapter, (3) physiotherapy expert panel review, (4) backward translation, (5) approval by copyright holders, (6) translation of the remaining sections of the guideline, (7) review of the complete translation by an expert panel, (8) review by a user panel, (9) conclude final draft, (10) publication and dissemination. Several adjustments were needed in the Portuguese version.

Conclusion: The additional adjustments required for the Portuguese version justify the need for the detailed and multifaceted translation process outlined in this manuscript.

Key Words: Parkinson’s Disease; European Physiotherapy Guideline for Parkinson´s Disease; Physiotherapy; Translation; Implementation

Introduction

Parkinson´s disease (PD) is a complex disorder characterized by various motor and non-motor symptoms. Even with optimal medical management, many people with PD face mounting problems in daily functioning [1]. Therefore, a variety of multidisciplinary interventions can be applied in the management of PD [2]. Physiotherapy is the most commonly used of these interventions and is supported by growing scientific evidence [3]. The first evidence for practice recommendations for physiotherapy in PD was published in 2004 by the Royal Dutch Society for Physical Therapy (KNGF) [4]. This guideline was one of the few high-quality PD guidelines and unique in this field [5]. However, these guidelines required updating to reflect best practices and findings of new studies. Following a request from the Association of Physiotherapists in Parkinson's Disease Europe (APPDE), the KNGF agreed upon a proposal of ParkinsonNet to update and adapt the guideline to the European region of the World Confederation for Physical Therapy (ER-WCPT) and the European Parkinson´s Disease Association (EPDA). Twenty professional associations of the ER-WCPT took part, along with people with PD and their representatives. In 2014, the European Physiotherapy Guideline for Parkinson´s Disease was published. This evidence-based guideline was primarily developed to support decision taking for physiotherapy practice in PD, but it also provides information to clinicians regarding referral criteria for physiotherapy [6]. It also provides people with PD and career information on movement-related self-management and what to expect from physiotherapy.

The global implementation of the European Physiotherapy Guideline for Parkinson´s Disease is envisioned to ensure equal access to good quality and specialized care for all people with PD. To optimize implementation in non-English speaking countries, the Guideline Development Group (GDD) strongly recommended translation and adaptation of this Guideline as a first step. Currently, there are six translated versions of the Guideline: English, Portuguese, German, Dutch, Czech, and Finish, which are freely available for downloading at www.parkinsonnet.info/euguideline.

Defining practical standardized steps to know how to translate and adapt is critical as more countries seek to do it. There are two commonly used approaches for translation and cross-cultural adaptation processes, namely forward-backward (FB) translation and dual-panel (DP) [7]. In the FB approach, translations into the target language are produced by an independent translator, followed by another translator's back-translation to the source language. Differences in the forward- and back-translated versions are typically reconciled after each step. On the other hand, the DP approach is based on a consensus translation produced by a panel of people native to the target language, together with a representative of the copyright holders of the original document. After a second panel (users) will review the translation [8-11]. Even though translation studies have introduced these different methods to facilitate valid translations and adaptations of surveys and documents for cross-cultural use, there is limited agreement on which type of translation should be used [7]. This paper aims to define and provide practical steps on how to translate the European Physiotherapy Guideline for Parkinson's Disease to help guide future translations.

Methods

The definition of the steps for the translation of the guidelines was based on the use of information and expertise from a variety of our sources, namely (1) our results from a detailed example (Portuguese version), (2) copyright holders' input and experience with other ongoing translations, and (3) review of information available regarding protocols commonly used in the translation process of multi survey instruments and multicenter research [11, 12]. All information sources were carefully assessed.

Respectively, the Portuguese translation process was carefully described into 4 phases and registered as follows:

Phase I - Authorization

Authorization to use and adapt the European Physiotherapy Guideline for Parkinson´s Disease was requested from the copyright holders. To assure quality, conceptual equivalency, and translation transparency, the involvement of the copyright holders and, if available, a member of the GDG whose mother language equals the language for the translation was recommended.

Phase II - Translation and adaptation process

The Portuguese version of the European Physiotherapy Guideline for Parkinson´s Disease was based on combining the FB and DP approaches [6]. The process was led by an expert Physiotherapy panel (PT panel: TC, JD, and LA) consisting of three physiotherapists, Portuguese native speakers, experienced in reading and writing English, and experts in PD, who work in Movement Disorders Centers at Public Hospitals and in Specialized Private Clinics. The PT panel included one physiotherapist (JD) member of the original Guideline Development Group, whose mother language is Portuguese and who was also English bilingual.

Initially, an official Portuguese translator, experienced in translating texts from English to Portuguese (FB) and health terminology, was asked to produce a first draft version of a sample chapter of the Guideline (chapter four, 'Physiotherapy in Parkinson's disease') with a FB approach. Given the differences between the English and Portuguese languages, some specific instructions were discussed beforehand with the translator regarding, for example, general grammar aspects, avoiding long sentences with many clauses, the use of jargon, use of conceptual rather than literal translations, as well as the use of more acceptable and general terms. PT panel and translator perceived these specific initial indications as useful to potentially reduce the number of adjustments and time needed afterward.

When finished, the first draft version was then revised by an expert panel and combined into one version, considering conceptual problems, assessing clear language; and correctly using terminology. Another independent translator back-translated this version into English [6]. The copyright holders of the Guideline then evaluated and approved the back-translated version of this specific chapter.

After these initial FB steps, the official Portuguese translator produced a first draft of the entire Portuguese version of the Guideline. The expert PT panel then assessed all the material independently, looking for inadequate expressions/concepts of the translation and any discrepancies between the English and Portuguese versions of the Guideline. The panel also checked for clear language, spelling, grammar, writing style, consistency, understanding, correct use of terminology, and guideline message. Discrepancies were discussed as often as needed and solved by the expert PT panel and copyright holders via Skype calls and email exchanges.

Phase III - Feedback from people with Parkinson's disease, physiotherapists, and physicians

A user panel consisting of three people with PD, three physiotherapists, and two physicians were consulted and asked to provide feedback on the main document and the respective parts for people with PD and physicians. They were recruited from 3 clinics: the Movement Disorders Clinic - Department of Neurology - Faculty of Medicine from the University of São Paulo (HC FMUSP, São Paulo, Brazil), Private Clinic PHYSICAL (São Paulo, Brazil), Roberto Santos General Hospital (Bahia, Brazil) and movement disorder clinic (Lisbon, Portugal). There were no difficulties understanding the materials or complaints of irregularities in the item. Overall, there was a positive consensus regarding its understanding and reading ease.

Phase IV - Publication

When all reviewers agreed upon a final Portuguese version of the European Physiotherapy Guideline for Parkinson's Disease, it was published in a printed book format [13] and in a pdf format at www.parkinsonnet.info/euguideline and www.abneuro.org.br. The additional parts of the guidelines with information for people with PD [14] and the other with information for physicians [15] were also translated and published. The entire process took approximately eight months.

Results

Based on the results of the detailed Portuguese translation process and copyright holders' input and experience, ten practical steps to translate and adapt the European Physiotherapy Guideline for Parkinson's disease were officially defined and recommended to help guide future translations (Table 1).

The Portuguese-translated version was successfully launched and served as a base for the definition of recommended steps. To ensure translation trustworthiness, several decisions and adjustments had to be made. For example, some words and expressions that were not understandable to Brazil or Portugal were adjusted. As such, we included in the final version some words in both European and Brazilian Portuguese to make the reading friendly and understandable to both (i.e., the term "treadmill" was translated to *passadeira* (European Portuguese) and *esteira* (Brazilian Portuguese), and appeared in the guideline as "*passadeira/esteira*"). Also, to contemplate respective populations and cultural issues, some of the daily activities used as examples were removed, such as shuffling snow, since they were not commonly applicable in Brazil or Portugal. Additionally, some of the measurement and assessment tools recommended by the Guideline Development Group were previously validated in Portuguese. These tools were displayed in the Guideline in their published version on a specific chapter with their respective references taken from the Brazilian Academy of Neurology recommendations [16]. Tools not validated in Portuguese were only translated following the same process as the entire Guideline (i.e., the Modified Parkinson Activity Scale and the New Freezing of Gait Questionnaire). Importantly, reference was made that these scales were not yet validated in Portuguese and should only be used until the new validated versions are published. Of notice, there was a need to consult other materials, such as books and published papers in PD, that had been translated into Portuguese to ensure consistency with previously translated expressions. As such, the terminology from the Portuguese version of the International Classification of Function(ICF) was used throughout the Guideline [17].

Table 1 | 10 Practical recommended steps for a trustworthy translation and adaptation process of the guideline

	STEPS	TIPS
Step 1	Request authorization to translate guidelines.	• Contact copyright holders to request authorization. www.parkinsonnet.info/euguideline
Step 2	First translation of a sample chapter by an official translator.	• Use preferable official translator experienced in translating texts from English and in health terminology. • Giving initial indications to the official translator before beginning may be helpful (i.e., avoiding long sentences with many clauses, using jargon, and using more acceptable and general terms).
Step 3	Review of the first draft of a sample chapter by the PT panel.	• Create a PT panel composed of 3 physiotherapists native speakers, experienced in English, and experts in Parkinson's disease. • Check for clear language, correct use of terminology, and the overall message of the guideline.
Step 4	Back translation to English.	• Preferably, back-translated into English should be done with another independent official translator.
Step 5	Review and approval of back translation by copyrighters.	• Integrate copyright holders of the guideline to assess the back translation of the sample chapter.
Step 6	Translation of the remaining guideline by the official translator.	• The tool previously validated to the target language should be displayed in their published versions. • The tools not validated into the target language should be translated following the same process as the whole Guideline but replaced as soon as validated.
Step 7	Review by PT panel with ongoing discussion with copyrighters.	• Check for spelling, grammar, style, consistency, and cultural adjustment. • Consult other published Parkinson's disease-related papers/documents translated recently to the targeted language to assure consistency with previous official translated expressions.
Step 8	Review by a native-speaking physiotherapist, clinicians, and people with Parkinson's.	• Assess understanding, irregularities, and ease of use of each part of the guidelines.
Step 9	Finalize the pre-final draft of the translated version.	
Step 10	Publish and disseminate the final official translated version of the guideline.	• Publish pdf document on ParkinsonNet website www.parkinsonnet.info/euguideline and other local professional websites.

Discussion

Based upon information from our detailed example, combined with copyright holders' input and information available regarding translation processes, 10 steps were recommended on how to translate and adapt the European Physiotherapy Guideline for Parkinson's disease. These steps are needed to facilitate the validity and appropriateness of future translations. The multifaceted procedure outlined here represents a step forward in the international dissemination effort of evidence-based guidelines in PD (in this case, for physiotherapy, but the method appears readily able to also benefit other professional guidelines).

Defining these recommended steps is underscored by three primary reasons. First, the European Physiotherapy Guideline for Parkinson's Disease is becoming a key tool in clinical settings to provide practical help to ensure high-quality and specialized physiotherapy care for people with PD. It is expected to potentially help reduce the inadequate delivery of allied health care and increase appropriate referrals to physiotherapy. Second, to facilitate further global implementation and dissemination of the guidelines, recommended steps are critical to standardize procedures and help guide other non-English speaking countries that decide to translate the European Physiotherapy Guideline. Health researchers have only recently begun to identify best practices for the translation and assessment of translations of survey instruments into other languages [7]. Current standards for translation procedures are lacking, and few researchers report their translation methods [8-10]. Third, valid translations will also facilitate comparing results of the international implementation process ongoing in different countries and cultures. This is important given the number of ParkinsonNet initiatives that aim to improve the degree to which health professionals integrate care and their requirement for thorough evaluations and international comparison.

While the specific challenges in translating guidelines may differ across countries, the case of Portuguese translation demonstrates the practicality and benefits of incorporating contextual and cultural factors. Moreover, it highlights the feasibility of implementing a rigorous methodological translation and adaptation process within a relatively short and achievable timeframe of 8 months.

We identified several important factors facilitating the Portuguese translation process that merit discussion and sharing. First, the utilization of a panel of Portuguese-speaking researchers who were native speakers of the target language, possessed proficiency in reading and writing the source language, and held extensive experience in clinical practice related to Parkinson's disease within their respective healthcare services. Additionally, one member of this panel was a member of the initial guideline development group and bilingual. Second, the copyright holders were highly involved in the process and always available to clarify any issues. Third costs with the translation were based on a volunteer-run initiative of the expert physiotherapy panel and endorsed by the Academia Brasileira de Neurologia (ABN), PHYSICAL, Associação Brasileira de Fisioterapia Neurofuncional (ABRAFIN) and by the Sociedade Portuguesa Doenças do Movimento (SPDMov). This is important because the guidelines will continue to be updated; therefore, overly complex or expensive translation processes should be avoided. In situations where certain countries may lack the necessary resources to translate the entire Guideline, it becomes essential to engage in discussions with the copyright holders regarding the possibility of providing "expertise-based suggestions" for partial translations. This approach allows for the adaptation of the Guideline to specific contexts while considering the limitations and available resources of those countries.

ParkinsonNet and the APPDE remain committed to offering collaborative support in promoting education about the implementation and translation of this guideline. Moving forward, it is anticipated that future translations will be more streamlined and easier to undertake. It is crucial to ensure that the translation process adheres as closely as possible to the practical recommendations outlined in this paper, in order to maintain accuracy and effectiveness.

Conclusion

The European Physiotherapy Guideline for Parkinson's disease is a key instrument in physiotherapy care for PD. However, its use in countries where the official language is not English has been limited. Translations and cross-cultural adaptation must be applied in other countries, cultures, and languages. The multifaceted procedure outlined here represents a step forward in the international dissemination effort of evidence-based guidelines in PD (in this case, for physiotherapy, but the method appears readily able also to benefit other professional guidelines).

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4

European Physiotherapy Guideline for Parkinson: implications for neurologists

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Abstract

The evidence for physiotherapy is growing, showing a positive impact on functional activities involving gait, transfers, and balance. Specific recommendations for physiotherapists, physicians, and People with Parkinson's (PD) were published in the European Physiotherapy Guideline for Parkinson’s disease.

Here, we summarize the referral criteria, highlight the importance of accurate referral to specialized physiotherapists, and emphasize the potential benefits of expert care. As such, this chapter offers very practical guidance for clinicians working with people with PD and who consider physiotherapy treatments for their patients. By following these recommendations, clinicians can ensure that their patients receive appropriate and beneficial physiotherapy interventions.

Physiotherapy Guideline for Parkinson's Disease: Implications for Neurologists

The management of Parkinson’s disease (PD) presents many challenges for both people with PD and healthcare professionals. Despite optimal pharmacological treatment, many persons with PD increasingly experience motor and non-motor symptoms [1]. The evidence for non-pharmacological interventions such as physiotherapy is growing, showing a positive impact on functional activities involving gait, transfers, and balance [2-4].

In 2014, the European Physiotherapy Guideline for Parkinson’s disease was developed in a unique collaboration between 19 professional physiotherapy associations and persons with PD [2]. The guideline provides practical and evidence-based information for physiotherapists and information about the systematic development process and scientific justification. Moreover, two specific sections were written for people with PD and physicians. The medical section was mainly envisioned to help reduce potential factors for non-referral or misconceptions regarding physiotherapy among physicians (e.g., Physiotherapy only needed at later stages; there is no data supporting the efficacy of physiotherapy; reduced adhere; high dropout rate, etc.). The amount and strength of the evidence that supports the guideline recommendations [2], however, allow us to refute these misconceptions and firmly recommend physiotherapy for all people with PD.

Here, we summarize the specific recommendations for physicians. We summarize the referral criteria, highlight the importance of accurate referral to specialized physiotherapists, and emphasize the potential benefits of expert care.

Referral criteria

The guideline stresses the importance of accurate referrals to skilled physiotherapists as a key tool for improving the quality of care in PD.Medical specialists (mainly neurologists and geriatricians) play a central role in improving access to physiotherapy by initiating a timely referral for those people with PD with a specific indication for physiotherapeutic interventions. The European Physiotherapy Guideline is very helpful in this regard, offering referral criteria as to when and why physicians can consider referring patients for physiotherapy (Table 1).

Table 1 | Referral criteria for persons with Parkinson's disease to physiotherapy

Indication for referral	Examples of possible interventions
Newly diagnosed patient without disability	• Advice about staying physically active and preventing secondary complications
Reduced physical capacity	• Advice, education, and coaching aimed at increasing aerobic exercise • Supervised and individually tailored exercise programs
Difficulties with transfers, e.g., rising from a chair or bed, rolling over in bed, etc.	• Transfer training, e.g., using external and cognitive cueing strategies
Difficulties with gait	• Gait re-education with cueing • Treadmill training
Freezing of gait	• Training cueing strategies • Advice, education, and coaching aimed to increase physical activity and exercise
Balance problems, including falling	• Balance training • Lower limb muscle strength training • Advice on safety in the home environment • Functional mobility training • Support prevention of falls, e.g., using walking aids
Difficulties with manual activities	• Movement initiation training for reaching and grasping • Cueing strategies, advice, and training
Pain	• Exercise therapy or education on movement strategies • Generic management of pain
Bedridden at the hospital or nursing home	• Training to improve physical capacity or limitations in functional mobility • Support prevention of pressure sores, e.g., increasing mobility

These recommendations are consistent with those put forth by the American Academy of Neurology. According to these guidelines, it is advised that physicians engage in discussions with individuals diagnosed with PD about the potential benefits of physiotherapy at least once a year [5]. Shortly after the diagnosis, a referral can be considered, mainly for advice on exercise and self-management. For later disease stages, appropriate reasons to consider a referral to physiotherapy include people with PD who express difficulties with transfers, mobility, physical capacity, pain, gait (including freezing), balance, or falls [6-9]. By following these guidelines, healthcare providers can ensure that people with PD are regularly informed about the potential advantages of physiotherapy as part of their comprehensive care plan.

Various types of recommended interventions are available, such as (1) treadmill training, (2) teaching of compensatory strategies (including cueing), (3) training of dual-task performance, and (4) training of active, large amplitude functional-task exercising addressing gait, balance, transfers and physical capacity (e.g., LSVT BIG). There are also community exercises using, for e.g., dance, Nordic walking, boxing, or Tai Chi that are recommended for early stages (i.e., upon diagnosis) and upon completion of a physiotherapy treatment period to maintain a status quo or towards the reduced speed of deterioration.

Additionally, several standardized measurement tools are used to gain systematic insight into current problems and to decide whether physiotherapy intervention is indicated. Newly recommended tests in the guidelines include the Mini-BESTest, the Dynamic Gait Index, and the Five Times Sit To Stand. The Goal Attainment Scaling is recommended to describe and evaluate SMART (Specific, Measurable, Attainable, Relevant, and Time-based) goals the physiotherapist and patient collaboratively set.

Notably, some indications for non-referral may include (1) People with significant active psychiatric problems (for example, severe hallucinations, confusion, persistent depressed mood, or psychosis, etc.) that may be aggravated when doing exercises; (2) Presence of red flags that would motivate interruptions of physiotherapy (i.e., Severe cardiovascular impairments, Recent pulmonary embolism, etc.); and (3) People that can't productively participate in physiotherapy according to the referrers judgment.

Specialized or generically trained physiotherapists?

Are there any merits to referring people with PD to specialized care, or is a referral to usual care (generically trained physiotherapist) enough? The guideline recommends referral to a physiotherapist with expertise in PD. This recommendation is based on steadily increasing evidence that physiotherapy interventions are delivered best by therapists who have received dedicated training in managing people with PD [2, 10-12].

While there is no golden standard for 'Parkinson's-expertise' and specific training still varies among countries, this phenomenon is mainly associated with the number of people with PD treated annually (annual caseload of >7) [10]. As such, in the guidelines, Physiotherapists are advised to have a higher-than-average patient volume and to closely collaborate with other health care providers with Parkinson's expertise and engage in continuous, up-to-date Parkinson's-related education from (inter)nationally recognized experts».

There are several reasons why experts are better than generically trained therapists. First, Parkinson's experts are trained according to evidence-based guidelines, such as the new European Physiotherapy Guideline. These experts are more likely to adopt best practices and deliver better interventions, particularly regarding issues of safety and prevention of falls [2, 13]. Second, Parkinson’s experts are more likely to attract and treat many people with PD and thereby progressively accumulate more experience. Finally, expert physiotherapy delivered, for example, through the ParkinsonNet model of care introduced in the Netherlands in 2004, has been associated with better quality of care, fewer Parkinson's disease-related complications, and lower healthcare costs [12, 14]. The Tel Aviv Sourasky Medical Center interdisciplinary care model is another example. It reflects the benefits of specialized care in different settings such as inpatient facilities, community rehabilitation facilities, and multi professional modalities in the community [15].

Nearly all people with PD will follow their physician’s advice when referred for physiotherapy. Moreover, when people are already being treated by generically trained therapists, they are willing to switch to an expert therapist who understands their disease’s complexity and is up to date with current physiotherapy interventions for PD [16, 17]. Unfortunately, access to physiotherapy services varies widely, even in western countries. For example, a survey among 1752 persons with Parkinson’s from 32 European countries revealed significant differences in the availability and reimbursement of physiotherapy services across Europe [18]. Overall, around 68% of respondents indicated having access to physiotherapy, which was perceived as ‘very helpful’ by 54% of patients, making physiotherapy the best accessible and subjectively helpful allied health service [18]. When no physiotherapist is available with specialized training in PD management, it seems reasonable to refer people with PD consistently to a limited number of motivated therapists, aiming to increase their caseload. Treating a high volume of people with PD seems associated with better care delivery and better patient outcomes [10].

Concluding remarks

The European Physiotherapy Guideline for Parkinson´s Disease was developed and published to support physiotherapists in managing persons with PD based on a thorough review of the latest scientific evidence. The guideline was initially published in English, and now there are already several translated versions (Portuguese, Dutch, German, and Finnish), all freely available for downloading at www.parkinsonnet.info/euguideline. Importantly, we here draw attention to the fact that the guideline also offers a set of specific recommendations for physicians, particularly regarding referral criteria.

We hope this will lead to a timelier and more accurate referral of people with PD, allowing them to benefit from the growing menu of evidence-based interventions in this field. The same criteria can also help avoid inadvertent referral of people with PD without a real need for physiotherapy interventions, thereby reducing unnecessary treatments and reserving the sparse resources for people with PD requiring interventions most. Finally, the guideline also identifies gaps in knowledge and areas of unmet need, thus creating a basis for future clinical trials to obtain further evidence on optimal physiotherapy and other forms of non-pharmacological management.

Author roles

(1) Research Project: A. Conception, B. Organization, C. Execution; (2) Statistical Analysis: A. Design, B. Execution, C. Review, and Critique; (3) Manuscript: A. Writing of the First Draft, B. Review and Critique.

J.M.D.: 1A, 1B, 1C, 3A, 3B
N.V.: 3A, 3B
S.K.: 1A, 1B, 3A, 3B
J.D.: 3B
B.R.B.: 1A, 3B
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Part III

Facilitating implementation of exercise community programs

5

How to implement a community program: Using boxing as an example

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Abstract

Background: People with Parkinson's disease (PD) benefit from continuous exercise through participation in community-based exercise programs. However, community programs often lack the PD-specific knowledge needed to provide safe and adequately dosed exercise.

Objective: To evaluate the acceptability and safety of a PD-specific boxing program in the community.

Methods: We developed specific educational resources to facilitate the boxing instructors. We also organized an educational and practical workshop for people with PD (n=26) and instructors (n=10) and assessed: (a) participants' satisfaction; (b) instructors' appreciation of the educational resources; and (c) the number of patients interested in participating in the boxing program. After 18 months, people with PD and instructors completed a questionnaire evaluating: (a) participants' satisfaction; (b) adverse events; (c) facilitators and barriers; and (d) proportion of participants at follow-up.

Results: Twenty-six people with PD (62% men) and 10 boxing instructors participated in the workshop. 81% of patients and 80% of instructors were very satisfied. Instructors found the educational materials "very helpful" (60%) or "helpful" (40%). People with PD expressed a clear interest (54%) or possible interest (46%) in the program. We initiated classes with 10 participants. At the 18-month follow-up, the program consisted of four boxing sessions/per week, led by three instructors, with 40 participants. Seventeen people with PD responded to the questionnaire at follow-up. Participants were "very satisfied" (53%), "satisfied" (35%), and neither satisfied nor unsatisfied (12%) with the program. Adverse effects were mild (e.g., muscle aches). Transportation and physical disability were the main barriers to participation.

Conclusions: The boxing program was well-received, with an increasing number of participants at 18 months. The educational resources can support boxing instructors participating in current and future boxing classes delivered in the community.

Keywords: Parkinson's disease, community exercise, boxing training, physiotherapy.

Introduction

Parkinson's disease (PD) is a neurodegenerative progressive disorder that tremendously impacts daily life activities and social participation [1, 2]. Physiotherapy and exercise can improve physical functioning [3, 4]. However, continuous exercise is needed to maintain results and to promote a physically active lifestyle [5]. Compliance with such prolonged programs remains a critical challenge.

One possible solution to promote sustained exercise adherence is participation in different non-traditional types of group community-based exercise programs. Evidence supporting such programs for persons with PD is growing, with examples in dance [6, 7], boxing [8, 9], Nordic walking [10, 11], tai chi [12, 13], Qigong [14], and aquatic exercise [15, 16], among others. Despite these positive effects, implementation of community-based exercise programs is often hampered by limited information regarding the exact intervention, the delivery mode, and the lack of specific knowledge about PD that is needed to provide safe and adequately-dosed exercise programs tailored to the specific abilities of people with PD [3, 17, 18].

Some fundamental questions arise as community-based exercise programs in PD begin to spread globally. How should exercises be adapted to the capabilities of people with PD? Who should be responsible for developing and implementing these exercise programs (i.e., specialized physiotherapist, exercise instructor)? Is a community-based exercise instructor without a longstanding history in treating large numbers of people with PD capable of safely providing exercise to patients? Here, we propose a scalable method for implementation by presenting a community-based boxing program specifically designed for people with PD delivered by generically trained boxing instructors who received clinical education and supervision under an expert physiotherapist. Boxing was selected because it is a promising new intervention currently very popular among people in the PD community. Boxing has been shown to be safe and feasible [8] and more effective than conventional group exercise in improving gait velocity and endurance [9]. We present the implementation of this PD-specific, community-based boxing program and evaluate this program on the following items: (1) adherence (based on the number of people participating); (2) acceptability (based on satisfaction level, perceived benefits and barriers and facilitators); and (3) safety (based on the number and types of problems identified during the program) at 18-months follow-up.

Methods

Design

This study uses a qualitative descriptive design to address the implementation of a boxing program in a community setting. The following steps were taken: developing educational resources, organizing an educational workshop, and an 18-month follow-up evaluation.

Step 1 | Development of educational resources

First, we developed a toolbox including specific educational resources to support boxing instructors in delivering PD-specific classes. The toolbox was developed based on scientific evidence [3, 8, 9] in combination with expert opinion from (a) one expert physiotherapist [19]; (b) exercise instructors with experience in boxing (n=3); and (c) persons with Parkinson who currently participated in boxing classes (n=6). Three types of educational resources were developed and included in the toolbox: (1) an "Outline for Group Boxing Training" specific to PD (Supplementary data); (2) an example of the PD-specific boxing class structure (Supplementary data) 2); and (3) exercise videos. The outline consisted of recommendations in the following key areas: (1) inclusion and exclusion criteria; (2) assessments; (3) boxing goals; (4) core areas and principles of the intervention (e.g., use of amplitude-based movements), and content of a class; (5) progressing the level of difficulty; (6) PD-specific problems that may arise while boxing; (7) group size; (8) emergencies in PD; (9) organization of the class; and (10) adaptations to the gym.

Step 2 | Providing and evaluating the educational workshops

Second, we organized an educational workshop with sessions for future instructors (certified boxing trainers) and sessions separately for people with PD whom the local Parkinson's Patient Association recruited. All sessions in the 2-day workshop were delivered by a PD expert physiotherapist with boxing training and experience building community programs, accompanied by a person with Parkinson's (SR) who gave input from the patient's perspective.

The first educational session (4 hours in the morning) was provided solely to the instructors and focused on providing them with key information regarding PD and details regarding the core areas and principles of the intervention. Specifically, instructors learned: (a) how to perform baseline evaluations; (b) how to provide exercises safely and effectively (with respect to PD-specific problems); and (c) how to recognize red flags, such as medication interactions and other emergencies during training. The importance of assessing fall risks and providing instructions to prevent falls in people with PD was highlighted. Instructors were taught to identify people at risk of falling using a brief assessment.Instructors were then invited to participate in the patient sessions organized in the afternoon, allowing them to experience an example of a boxing session with people with PD, supporting at-risk patients and encouraging them at the individual stations.For the patient sessions, people with PD were organized into 3 groups with a maximum of 10 participants. Each group came in at different times throughout 2 days. The sessions for the patient included one hour of education on the potential benefits for PD followed by a one-hour practical session. Details of the educational sessions given to the instructors and people with PD are shown in Table 1.

Table 1 | Goals, actions, and safety issues of the educational sessions for the instructors and patients.

	For boxing Instructors	For people with PD
Main Aim	To deliver effective and safe application of boxing training in PD.	To allow people with PD to experience the beneficial effects of exercising with boxing and to receive social support from fellow patients.
Actions	(1) A 4-hour educational session covering: (a) general information on PD, (b) the benefits of using boxing in PD, (c) video demonstrations of adapted exercises, (d) examples of ways to structure and progress classes, and (e) going through the key areas defined in the developed toolkit. (2) Participating in an one-hour boxing session with people with PD.	(1) A 30-minute educational session covering: (a) the beneficial effects of physical activity; (b) the potential benefits of boxing in PD; (c) potential barriers to participate in boxing and possible solutions; and (d) education about the importance of safety during training. (2) An 1-hour boxing session led by a physiotherapist with support from boxing instructors.
Safety Notes	Assessing fall risk and preventing falls was strongly reinforced, and instructors were taught to identify participant's at risk with a brief assessment using: a history of falls in the past 12 months and the Timed Up & Go test (TUG) [3].	Before the boxing session, participants gave informed consent for participation, were asked if they had fallen in the last 12 months, and completed the TUG test for a quick fall risk screening. People with PD at risk of falling were provided additional support by boxing instructors, care partners, or volunteers (60+ aged non-PD boxing training participants).

Abbreviations: PD – Parkinson's disease; Patients - Person with Parkinson's disease: TUG – Timed Up & Go test

Importantly, care partners and other family members were also invited to participate in the patient sessions (both the educational and the training sessions) to provide support, encouragement, and enhance adherence [20].

For the practical boxing session, participants completed an informed consent form and two physical tests (Sit to Stand and Timed-Up-and-Go) to rapidly screen fall risks. The Timed Up and Go Test [21] provides detailed information on walking speed during functional mobility tasks. Fall risk is defined based on the time it takes to perform the test, with a cut-off for high risk set at ≥13.5 seconds. The Five Times Sit to Stand Test [22] is a test that measures the time needed to rise from a 43-centimeter chair. It is used to assess balance when performing transfers. The risk of falling is set as ≥16 seconds.

At the end of the workshop, people with PD were asked to rate their satisfaction on a brief self-administered questionnaire with 3 questions: (1) "How satisfied are you with participating in the workshop?" (1= Very satisfied; 2= Satisfied; 3= Neither satisfied nor unsatisfied; 4= Dissatisfied), (2) "Did any problems arise during the workshop?", and (3) "Would you like to participate in a boxing training program?" (yes, no or maybe). The questionnaire was purposely short to reduce patient burden after a long day [23] [24]. Instructors were also asked to rate their level of satisfaction with the workshop (1= Very satisfied; 2= Satisfied; 3= Neither satisfied nor unsatisfied; 4= Dissatisfied); how helpful they found the educational materials (1= Not helpful at all; 2= Helpful; 3= Very helpful; 4= Extremely helpful) and if there were any concerns or additional comments.

Step 3 | 18-month follow-up assessment

The boxing program was then delivered for 18 months before reassessment. The boxing program was delivered in a group format, but volunteers provided personalized support to people at risk of falling. Instructors could contact an expert physiotherapist anytime for clarifications or on any issues related to the program via email or Skype calls (clinical mentorship). After 18 months, we assessed the adherence by looking into how many people with PD started the program immediately after the workshop, how many of these were still following the program after 18 months, and the total number of people with PD in the program at 18 months. Second, we studied the acceptability based on the response to a questionnaire given to people with PD (those that participated in the initial workshop and also those that started afterward) during the sessions regarding (1) satisfaction at 18 months; and (2) the perceived barriers and facilitators for participating in this community boxing program. Finally, we assessed safety issues by asking about the types of problems reported by participants and instructors during boxing training.

Results

Educational workshop

Participants

Twenty-six persons with PD (62% men) and 10 boxing instructors participated in the workshop. Three sessions with people with PD were organized (3 groups with ≤10 patients). All participants ambulated independently; however, 3 (3/26; 12%) people with PD had an increased risk of falling based on the fall screening (Supplementary data Table 1). To reduce the fall risk during the workshop, each of these participants were supported by a volunteer.

Acceptability

High satisfaction with the workshop was reported by five people with PD (5/26; 19%) scoring “satisfied” and 21 (21/26; 81%) reporting to be “very satisfied.” Overall, 14 people with PD (14/26; 54%) said they would be interested in participating in the program and 12 (12/26; 46%) indicated a possible interest. Participants identified some general (non-PD specific) issues during the workshop, namely (1) feeling discomfort due to excessive sweating from wearing the gloves; and (2) experiencing more stress during the paired activities. They also indicated that involving care partners would likely enhance their attendance.

Eight instructors were (8/10; 80%) “very satisfied” with the workshop, and two were “satisfied” (2/10; 10%). Instructors found the educational resources either “helpful” (4/10; 40%) or “very helpful” (6/10; 60%).

Safety

All participants completed the workshop without any serious adverse events, except for one patient experiencing anxiety while descending the stairs. As such, the gym stairs were adjusted immediately by applying visual cues (white tape) on the stairs to improve visual contrast, facilitating movement and increasing the general sense of safety. Instructors also identified some concerns regarding their lack of PD-specific expertise and how to help people with PD navigate difficult environments, such as the stairs.

18-month follow-up assessment

Adherence/Participation

The boxing program (Narva Boxningklubb) initiated PD boxing classes one week after the workshop, with 10 out of the 26 people with PD participating in the workshop (38%). Initially, two boxing classes per week were offered for these 10 participants.

At the 18-month follow-up, the number of participants had grown to 40 people with PD, including eight of the 10 participants that initially started (80%) and participated in the workshop 18 months before. The Narva gym offers four boxing sessions per week provided by three instructors (out of the 10 trained instructors (30%)). Meanwhile, the other trained instructors had begun to participate in 13 other boxing classes across Sweden, serving up to 250 people with PD.

Acceptability

Seventeen participants (out of 40 participating) and all instructors responded to the follow-up questionnaires. Participants indicated that they were very satisfied (9/17; 53%), satisfied (6/17; 35%), and neither satisfied nor unsatisfied (2/17; 12%). None of the participants were unsatisfied. Self-reported problems, facilitators, and barriers are presented in Table 2. Transportation and physical disability were the most common barriers and facilitators reported. During the 18 months, instructors consulted the expert physiotherapist twice regarding training intensity and potential new activities.

Safety

At follow-up, instructors reported that (a) no major problems were encountered during the sessions; (b) participants needed to be monitored continuously (especially during transition among the exercise stations), and (c) some participants needed more assistance and time for learning than others.

Table 2 | Patient satisfaction with the boxing program and perceived facilitators & barriers at 18-month follow-up

Participant	Duration of participation (months)	Problems or adverse events that occurred during the training	Facilitators to participate	Barriers to participate	Level of satisfaction with participation *
1	10	‘Neck pain, but I am careful and doing better now.‘	None	‘Knee and neck pain‘	1
2	1	None	‘Good location to get to.‘	‘Difficult to combine with work hours and the training is not personalized enough.‘	3
3	12	‘None, just experience muscle pain after training.‘	‘Transportation is easy.‘	None	1
4	2,5	Knee pain	‘Feeling that exercises help‘	None	1
5	8	None	None	‘No care partner support‘	2
6	10	None	‘Not needing help getting to and from the sessions‘	None	1
7	6	None	None	None	1
8	8	‘sense of feeling unsafe’	None	‘Balance problems‘	2
9	8	None	‘Benefits of exercise‘	None	2
10	2.5	‘Difficult to say.‘	‘Having had DBS‘	Traveling	2
11	3	None	‘Feeling well with the exercises.‘	None	1
12	4	None	‘Able to train during work hours	None	2
13	6	None	None	‘Physical difficulties‘	2
14	18	None	‘Transportation is easy‘	‘Physical difficulties‘	1
15	6	None	None	‘Lack of transport‘	3
16	18	None	‘Makes me reduce my medication‘	None	1
17	5	None	None	None	1

* 1= Very satisfied; 2= Satisfied; 3= Neither satisfied nor unsatisfied; 4= Unsatisfied

Discussion

PD-specific community exercise programs have recently gained considerable attention to achieve long-term exercise adherence in PD. However, evidence regarding how these programs should be developed, delivered, and implemented is still limited. Here we describe the implementation of a PD-specific community boxing program as an example of this fast-developing field. Our findings indicate that the program was overall well-received and accepted by persons with Parkinson, both during the initial workshop and at the 18-months follow-up. Initial training for the boxing instructors with a specifically developed toolbox was perceived as useful and may serve as an example when developing similar programs.

We believe that several factors contributed to the success of this boxing program. First, we used an exercise modality gaining popularity within the PD community [8, 9]. Apart from being satisfied with the workshop, 38% of people with PD started the program immediately after the workshop, and 40 participated at 18 months follow-up. These results are in agreement with other studies showing a desire to participate in PD-specific community exercise programs [25]. Alongside previously published preliminary evidence on the safety, feasibility, and effectiveness of boxing to improve balance, mobility, and endurance, boxing is consistently highly regarded by participants in all these studies [8, 9]. In addition to its physical component, boxing is also cognitively demanding (e.g., memorizing the boxing combinations, quick decision-making tasks, and dealing with busy environments) [26, 27]. Given the importance of cognitive processes in maintaining balance and reducing falls, programs that include cognitive components may have additional benefits over exercise programs that are solely physical, such as pure aerobic training by running on a treadmill [28, 29]. Indeed, the V-time study showed that multimodal training – immersing people with PD in a three-dimensional virtual reality environment while exercising on a treadmill demonstrated that the multimodal training afforded greater benefits (in terms of fall prevention) than treadmill walking alone [30].

Second, we believe that the collaboration between physiotherapists/clinicians and boxing instructors played a significant role in the success of this program. Access to an exercise instructor with PD-specific expertise is not always available. Enhancing the expertise of community-based exercise instructors will therefore improve access to safe and effective community-based exercise programs for people with PD. While instructors initially highlighted concerns about their lack of knowledge about PD, they were also keen to learn. The workshop allowed them to learn about the typical signs and symptoms of PD and how to handle the specific limitations of people with PD during an exercise program (e.g., risk of falls or difficulties with handling multiple tasks simultaneously). We believe that just as physiotherapists [24, 31, 32], greater levels of PD-specific expertise among boxing instructors will improve both the benefits and the safety of the exercise program.Thus, we argue that with respect to safety, generically trained instructors who provide boxing, dance, or other activities to people with PD should deliver their interventions in close collaboration with other healthcare providers with Parkinson-specific expertise. This expertise also enables instructors to recognize specific limitations that may warrant an adequate referral to appropriate healthcare professionals when necessary [3, 33]. For example, previously undetected freezing may come to light during the exercise classes, which would usually merit referral to a neurologist or Parkinson's physiotherapist to deliver dedicated treatments for freezing [34]. We believe that the collective involvement of boxing instructors, physiotherapists, and people with PD in developing educational resources enhanced their usability.

Third, providing a workshop for people with PD may have positively motivated them to participate in the program [35, 36]. This session was designed to inform participants about the benefits of boxing as an exercise in PD. Also, the workshop allowed participants to experience the beneficial effects of social support and motivation from fellow patients while also seeing that they could successfully perform the exercises and tasks, increasing self-efficacy [37] [38]. Participants were assessed for fall risk to guarantee additional support for those at risk of falling during the workshop (a strategy reinforced to boxing instructors to use for future inclusion and safety issues). The involvement of care partners was perceived to be helpful and was even suggested by participants to improve future attendance. Also, the disease-specific and boxing knowledge of the leading physiotherapist allowed for adequate replies to all questions, an adaptation of the exercises to the groups' needs, and quick action on problems that arose. These environmental aspects may have contributed to overall patient satisfaction and motivation for future adherence. Similarly, in a study on dancing, persons with Parkinson's disease perceived teaching methods and environmental factors as the most relevant facilitating factors when undertaking a dance class [39].

This study is not without limitations. The underlying reasons for not initiating, dropping out, or being absent were not assessed and could be critical to improve long-term adherence [36] [40]. At 18 months follow-up, several barriers and facilitators for participation were identified, mainly related to transportation, class time, physical disabilities, and the program's content (e.g., not being personalized enough). This is in line with previous research on barriers and facilitators for exercise in PD [36, 40, 41]. As the disease progresses, transportation difficulties can increase significantly due to difficulties in driving [42, 43] and difficulties in using public transportation. Because of these reasons, people with PD can ultimately become dependent on their caregivers for travel. However, many of these caregivers have similar age-related issues impacting their driving ability, further complicating the problem. Travel support (possibly via volunteer initiatives) could help reduce this barrier.

In addition, we did not collect data on exercise intensity and volume of the training, even though these are important components of any training program. Gathering information on those components plus standardized assessments on fitness status/physical functioning is essential to interpreting the mechanisms underlying the effectiveness of an exercise program. However, our primary aim was to assess acceptability and safety; therefore, we did not collect such data. Another argument to consider is that in busy gyms, there may not always be enough time to perform careful assessments. We argue that having pre-program and periodic re-assessment consultations with a clinical therapist may support a better screening of fitness status, and that a periodic individualized assessment of participants may ensure better safety, while also creating an opportunity to set and adjust the intensity and volume of training, to set personalized goals and continuously adjust the program to the needs of each participant.

Adjusting scheduled class times can make them more appropriate for people with PD who are still working and may further improve the program. Additionally, we included participants that self-enrolled through the Parkinson Association, possibly creating a bias in the types of people with PD that participated. Referrals from other sources (e.g., physicians, physiotherapists, advocacy institutions) can be guided by specific referral criteria that promote the integration of patient subgroups that may better benefit [33]. Notably, even though the participation of individuals with cognitive impairment in exercise programs is often perceived as not feasible [44], it remains important to determine if they can participate with additional resources (e.g., volunteers or caregiver support). In our program, a volunteer-run initiative guarantees safety to individuals with a risk of falling, and this strategy could also apply to people with cognitive impairment. This may constitute an important future line of research. Further research is needed to test the effectiveness of this program in a randomized controlled trial with different time points for follow-up assessments. Finally, a detailed process analysis may help to understand better the reasons for not attending, whom to include, when the participant start getting better, what ongoing teaching methods to use, and how to assess the continuous educational needs of instructors. These assessments arerelevant to determine the program implementation and provide feedback to participants, but also to show a benefit to those providing funding for such programs.

Conclusion

People with PD indicate a desire to participate in specialized programs, but providing and maintaining safe, efficient, and cost-effective community-based exercise programs for PD poses many challenges. Enhancing the expertise of community-based exercise instructors and developing closer collaboration with other health care providers can be crucial factors to guarantee an optimal quality of the exercise intervention. Our boxing program was well-received, with an increase in participants at 18 months. The educational resources can support boxing instructors participating in current and future boxing classes being delivered in the community.

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Author roles

(1) Research Project: A. Conception, B. Organization, C. Execution; (2) Statistical Analysis: A. Design, B. Execution, C. Review, and Critique; (3) Manuscript: A. Writing of the First Draft, B. Review and Critique.

J.M.D.: 1A, 1B, 1C, 3A, 3B
N.V.: 3A, 3B
S.R: 1A, 3B
J.D.: 3B
C.G: 3B
M.G: 3B
J.F: 3B
B.R.B.: 1A, 3B

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Supplementary Data

Supplementary table 1 | Timed Up & Go and Sit to Stand test scores before and after the workshop

Participant	History of falling last 12 months (yes=1; no=0)	Sit-to-stand pre (≥ 16 at risk of falling)	TUG pre (risk if) score ≥13.5 seconds
1	0	10.82	6.02
2	0	6.8	6.3
3	0	8.37	6.5
4	0	12.63	8.05
5	0	13.33	9.43
6	0	11.43	7.88
7	1	12.1	14.26
8	0	7.61	5.86
9	0	15.21	9.15
10	0	13.06	9.23
11	0	13.43	9.65
12	0	6.73	7.48
13	1	15.86	13.53
14	0	7.6	7.26
15	0	10.61	9.09
16	0	8.56	6.35
17	0	9.35	7.38
18	0	7.91	6.78
19	0	9.38	6.36
20	0	6.76	4.48
21	0	11.28	6.34
22	0	12.05	9.87
23	0	6.43	6.38
24	1	11.41	13.92
25	0	6.91	6.08
26	0	6.3	5.81
		Mean = 10.07 (SD+/-2.86)"	Mean = 8.05 (SD+/-2.57)

Supplementary table 2 | Outline for Group Boxing Training Specific to Parkinson's disease

OUTLINE FOR GROUP BOXING TRAINING SPECIFIC TO PARKINSON'S DISEASE

RECOMMENDED TARGET POPULATION

- Individuals diagnosed with Parkinson's disease between stages Hoehn & Yahr I-III.
- Able to walk independently without major safety issues related to balance or risk of falling.
- Without significant active psychiatric problems (for example hallucinations, confusion, or psychosis, etc.) that may be aggravated when doing boxing exercises; ability to correctly participate in the classes according to the boxing instructor's judgment.
- Motivated and able to communicate with the trainer to understand and comply with the boxing exercises in a group format.

RECOMMENDED ASSESSMENTS

- Medical clearance before starting any type of exercise, especially if the participant has one or more risk factors for heart disease or is inactive.
- Evaluation of the history and risk of falling due to increased risk associated with dual-task interference when boxing, standing, or walking. Quick standardized assessment tools such as the Timed Up and Go test (High Risk ≥13.5s) and 5 times sit-to-stand test (High risk ≥16s) can be used to provide data about gait and fall risk.
- Individual exercise assessments before the program are useful to know participants' general health and current and past fitness and activity levels. Identifying any physical limitations of the participant (e.g., pain associated with shoulder movement) and considering these in the individual tailoring of exercises in circuit training is recommended.
- Exercise training intensity should be defined and evaluated using the Borg RPE scale or heart rate monitors. Define the overall volume of training for the group (assessed by a number of prescribed exercises and repetitions).

BOXING INTERVENTION GOALS

- General goals may include promoting (1) exercise for general health and well-being; (2) social interaction; and (3) feelings of belonging to a group.
- Performance of specific exercises to improve PD core areas such as (1) Physical capacity; (2) Stepping and balance; (3) Gait; (4) Transfers, and (5) Posture.

CORE AREAS AND PRINCIPLES OF THE INTERVENTION & CONTENT OF A CLASS

Disease-specific principles:

- Preferably, focus on combining boxing with functional-task exercises, for example: (1) sit, stand, and boxing sequences; (2) walking around and over obstacles with changes in walking direction and sudden stopping in conjunction with punching; and (3) turning around in large and small spaces.
- Provide continuous augmented feedback by using verbal or non-verbal cues that may aid in maintaining amplitude, good posture, and balance in movements (for example visual cues like tape on the floor that shows where feet are to be placed to keep a wide base of support).
- Focus on stimulating the more affected side with additional movement repetitions on that side (learned use). Enhance body awareness to ease functionality and avoid compensation.
- Be flexible regarding learning boxing techniques. Avoid anxiety and stress due to cognitive or physical overload when teaching new activities.
- Music is a key motivator and facilitates movement. However, it isn't easy to hear both the music and the instructions. Use music only during specific activities. Lower music when giving instructions.
- Allow for conversations and socialization among participants to occur.
- Inform people with PD to try to work out during ON periods or at those times of the day when they feel best, and their medication is working well. Make sure they take their medication.
- Encourage ongoing vigorous exercise and physical fitness.

Supplementary table 2 | Continued

Boxing-derived principles and modifications:

- Focus on punching actions that combine high-speed arm motions with trunk rotation and lower extremity stepping in different directions. Integrate movements that directly enhance physical and cognitive function.
- A more upright vertical-armed guard should be used, as opposed to the semi-crouched and full crouched positions common in contact boxing, to avoid exacerbating a flexed, kyphotic posture.
- Use bobbing defense maneuvers to evade or block punches for more effective lower limb strength training. Add isolated resistance exercises addressing large muscle groups and multiple joints first, then include smaller muscle group exercises and single joints.
- Pad training is one of the preferred training modes for people with PD. Placing numbers on the pads can facilitate initial learning of the boxing sequences.
- Group activities are enjoyed and preferred over individualized circuit exercises. Increase the time of activities done as a whole group, such as warm-ups, collective strength training, and cool down.

PROGRESSING THE LEVEL OF DIFFICULTY

- Progress physical capacity by considering the number of repetitions, load, or speed. Aerobic challenges should be progressed by increasing the total time spent boxing, up to 30 minutes, and the duration spent at moderate and vigorous intensity.
- Progressively focus on maintaining the amplitude during exercises and then add in speed-based challenges (e.g., maintaining a stable base of support, defined by a cue/lines on the floor, reaching out to punch at a given distance (amplitude), when increasing speed make sure to keep the amplitude by keeping feet in the defined base of support).
- Progressively address motor learning, from a stable to a variable task and context, from single (e.g., punch right then left) to dual-task (punch right left but say out loud the opposite, i.e., punch left then right).
- The exercises should not be too difficult inducing frustration but also not too easy for better motor learning and motivation. Consider increasing the difficulty of cognitive exercises following criteria: 2 or 3 errors – increase difficulty; 4 or 5 errors – maintain difficulty; or ≥ 6 errors – reduce difficulty. Additionally, a patient-perceived difficulty visual analog scale can be considered to get feedback on its difficulty.

PD-SPECIFIC PROBLEMS THAT MIGHT ARISE DURING TRAINING

- Excessive sweating with gloves might be perceived as uncomfortable. Boxing hand wraps may reduce this discomfort but imposes fine motor challenges for putting them on.
- People with PD may report that tremors might increase during or after training due to fatigue. Typically, this will return to normal levels after the session is over.
- Alert Patients on the risks of compulsive exercise behavior and excessive fatigue. Highlight the need for resting periods. Training dosage should be adjusted if fatigue persists after sessions, impacting the rest of the day.
- Impaired attention and executive functions may exacerbate difficulties with multitasking, which may contribute to compensation using bad postures and increase the risk of losing balance and falls. If the goal is not dual-task training, avoid talking to People with PD when moving around or exercising in less safe situations.
- Keeping balance and feet apart is difficult when distracted to punch. Place the visual tape on the floor to facilitate foot correction and increase safety.
- Pair activities may generate anxiety due to fear of failure. Reduce the complexity of activities when working in pairs.
- Always respect the person's autonomy and ask what specific guidance they would like to have from the instructors and others.

Supplementary table 2 | Continued

EMERGENCIES IN PARKINSON'S DISEASE

- Be aware of PD medical emergencies and know when to seek help or referral to other professionals, for example, with:
- Significant motor fluctuations (uncontrolled violent dyskinesias; severe on-off fluctuations);
- Active psychiatric problems (for example, hallucinations, confusion, psychosis);
- Excessive daytime sleepiness and sleep attacks; or
- Orthostatic hypotension.
- Seek immediate medical attention if people with PD:
- Becomes diaphoretic;
- Reports chest pain or tightness, nausea, and/or vomiting for more than a few minutes;
- Experiences unusual breathlessness, dizziness, or lightheadedness;
- Experiences any sensation of the heart skipping or adding beats.

GROUP SIZE

- A group size of 6 to 8 people at comparable levels of physical function is recommended per therapist/instructor to ensure positive group dynamics and safety.
- Additional helpers/volunteers may further enhance safety. Consider the help of care partners (if the Patient agrees).

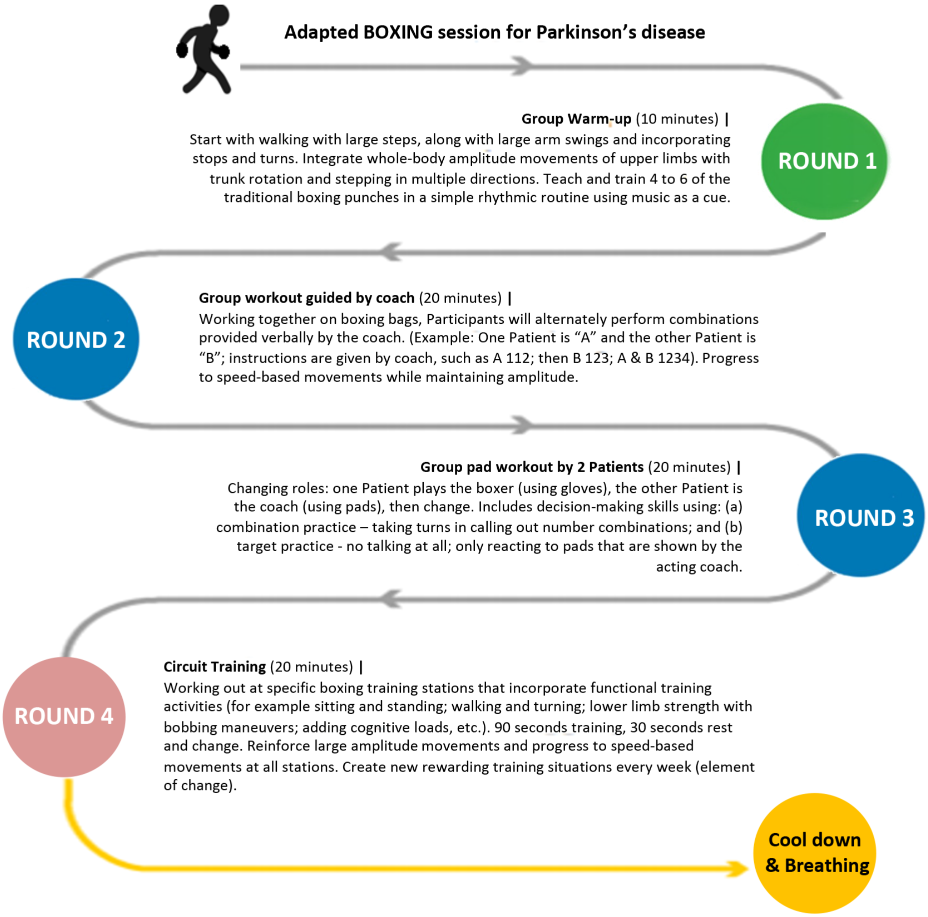
ORGANIZATION OF A CLASS

- Frequency and duration: Ideally, it is ongoing. The program could last at least 8 weeks, twice a week, for 1 hour to perceive benefits.
- Consider warming up by walking or bicycle training.
- Consider cooling down (relaxation) and progressing from standing to seated.
- Circuit training can be done individually or in pairs. Should include exercises relevant to people with PD but also be guided for reaching individual goals (personal diaries can help people with PD register what exercises have been done and what progress has been made).

ADAPTATIONS IN THE GYM SPACE

- Consider analyzing potential changes in the gym environment to positively influence the functional performance of each Patient, for example:
- Using cueing to minimize problems with accessibility and mobility throughout the building and gym;
- Avoiding placing objects on the floor that may become a tripping hazard; and
- Allowing for sufficient walking space throughout the gym.

Abbreviations: PD – Parkinson's disease; Patients - Person with Parkinson's disease.



Group Warm-up (10 minutes) | Start with walking with large steps, along with large arm swings and incorporating stops and turns. Integrate whole-body amplitude movements of upper limbs with trunk rotation and stepping in multiple directions. Teach and train 4 to 6 of the traditional boxing punches in a simple rhythmic routine using music as a cue.

Group workout guided by coach (20 minutes) | Working together on boxing bags, Participants will alternately perform combinations provided verbally by the coach. (Example: One Patient is "A" and the other Patient is "B"; instructions are given by coach, such as A 112; then B 123; A & B 1234). Progress to speed-based movements while maintaining amplitude.

Group pad workout by 2 Patients (20 minutes) | Changing roles: one Patient plays the boxer (using gloves), the other Patient is the coach (using pads), then change. Includes decision-making skills using: (a) combination practice – taking turns in calling out number combinations; and (b) target practice - no talking at all; only reacting to pads that are shown by the acting coach.

Circuit Training (20 minutes) | Working out at specific boxing training stations that incorporate functional training activities (for example sitting and standing; walking and turning; lower limb strength with bobbing maneuvers; adding cognitive loads, etc.). 90 seconds training, 30 seconds rest and change. Reinforce large amplitude movements and progress to speed-based movements at all stations. Create new rewarding training situations every week (element of change).

Supplementary figure 1 | An example of a PD-specific boxing exercise group class structure.

Patients = persons with Parkinson's disease.

6

Boxing with and without kicking techniques: a pilot randomized controlled trial

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Abstract

background: People with Parkinson’s disease (PD) benefit from non-contact boxing exercises. Adding kicking variations to the boxing may provide additional benefits to improve balance. However, the benefits, acceptability, safety, and adherence to such training are unknown.

Objective: To explore the feasibility, safety, and potential additional benefit on balance of boxing training combined with kicking techniques compared to boxing without kicking for people with PD.

Methods: Participants were randomized to group-based boxing training with kicking techniques (BK) or to group-based boxing alone training (BO). Both groups trained for one hour once a week, for 10 weeks. Participants completed baseline (T0) and ten weeks post-intervention (T1) assessments with blinded assessors. We assessed feasibility and safety. We also explored the effects within both intervention groups. The primary outcome was the difference in balance measured by the Mini Balance Evaluation Systems Test (Mini-BEST) at T1 between both groups. Secondary outcomes included: fear of falling, balance confidence, walking ability, and quality of life.

Results: Twenty-nine people with PD (median age 64 years; median disease duration 5 years) participated. Both interventions were feasible and acceptable for all participants.No adverse events occurred. Most participants (BK 80%; BO 75%) were satisfied with the training. We found no significant between group difference on either the primary (Mini-BEST) or secondary outcomes. The within-group comparison showed that balance improved in both groups after the intervention (BK 22.60 (2.7) to 25.33 (2.64) p= 0.02; BO 23.09 (3.44) to 25.80 (2.39); p= 0.01 on the Mini BEST test).

Conclusions: Both types of boxing seem to be feasible and safe. Adding kicking techniques to boxing does not improve balance significantly more than boxing alone. Incorporating kick techniques may be a valuable addition to the exercise therapy repertoire to make it even more engaging.

Keywords: Parkinson's disease; boxing; exercise; balance; kicking

Introduction

People with Parkinson's disease (PD) often present with gait and balance impairments [1, 2] and have a tendency towards an inactive lifestyle [3-6]. As such, people with PD benefit from several nonpharmacological approaches to prevent balance-related problems and promote a physically active lifestyle.

Research is showing that various forms of exercise can be effective in managing PD [7-11]. Apart from the more traditional types of exercise, such as balance, resistance, and endurance training [9, 11], alternative training methods are gaining popularity [11-14]. Boxing is one such popular and novel alternative training method. Just as in other medical conditions (i.e., obesity [15] or stroke [16]), preliminary studies have demonstrated some positive effects of boxing on mobility, balance, and quality of life in people with PD [17-20]. Another study showed that self-perceived QOL improvements were maintained throughout 20 weeks of non-contact group-based boxing training, despite the lack of improvements in disease severity [21]. Even though the safety and long-term adherence of community-based group boxing for PD have been described previously [22], concerns rise regarding its implementation and the significant mismatch between the positive grandiloquence on online information websites about boxing for PD versus the concretely available research evidence. Importantly, there is still limited evidence on the efficacy, safety, disease-specific modifications, limitations, and health professional training needed [23].

Recent research also shows that offering group-based PD-specific boxing programs that are adaptable, varied, open to input, and that encouraging social support and networking may be beneficial to increasing motivation for exercise and physical activity in PD [24]. Boxing classes commonly consist of a warm-up, boxing-specific exercise (boxing drills, shadow boxing, speedbag drills, jumping jacks, and strength exercises), and a cool down with stretching at the end [17-21]. Balance-demanding exercises (e.g., weight shifting, dynamic changes in balance, and postural adjustments) may induce synergistic effects for balance gains [9, 25]. As such, we believe that adding kicking techniques to boxing exercises may lead to a greater improvement in balance outcomes than boxing that only uses punches. However, in clinical practice, physiotherapists and trainers may be reluctant to add kicking techniques, which inevitably necessitates the participant to stand on one leg, challenging their balance, because of safety issues and potential fall risks. In PD, there isa progressive reduction in the ability to control anticipatory postural adjustment before to lifting one leg [26, 27] and an increased risk of falls associated to less than 10s one leg stance [28, 29]. The possible benefits of kicking, safety, feasibility and acceptability have never been studied. The primary aim of the current exploratory study was to explore the feasibility, safety, and potential additional benefit of boxing training combined with kicking techniques on balance compared to boxing without kicking for people with PD.

Methods

We performed a single-blinded exploratory pilot Randomized Controlled Trial. We included men and women with (self-reported) PD with sufficient knowledge of the Dutch language to complete the clinical tests and follow instructions during the training sessions. We excluded individuals who were unable to walk without using an assistive device or had significant cognitive impairment (i.e., mini-mental state examination of < 24) [30].

This trial was conducted in compliance with the Ethical Principles for Medical Research Involving Human Subjects, as defined in the Declaration of Helsinki. The study protocol was evaluated by the local Commission Human Research (CMO) Arnhem/Nijmegen (dossier number: 2019-5658). Before inclusion, all participants signed an informed consent form.

Procedures

Participants were contacted through posters and flyers in a local hospital and a local physiotherapy practice. Twenty-nine participants volunteered and were, after screening for eligibility and baseline testing, randomly assigned to group-based boxing training with the addition of kicking techniques (BK) or group-based boxing alone training (BO). An independent researcher performed the randomization in a 1:1 ratio using the data management system Castor (Electronic Data Capture, The Netherlands). Both groups trained once a week, one hour per session, for 10 weeks. No blinding was applied to the trainers and participants. The measurements were performed by a blinded researcher of the Radboudumc at baseline (T0), and after ten weeks (T1).

Intervention

Training sessions for both groups were led by one physiotherapist specialized in PD (part of the nationwide Dutch ParkinsonNet) [31] and one boxing trainer to guarantee safety and ensure appropriate training. Participants trained together in their respective groups with the same instructors. For the first group (BO), each session consisted of training punching movements and progressively adding in dual-task challenges (i.e., going through various punching combinations). The intensity and variety of exercises were increased according to the patient's capacity every week. The second group (BK) received 10 sessions of group-based boxing training comparable to the previous group, but with added kicking techniques weight-shifting exercises and multidirectional stepping. A complete overview of the training sessions can be found in Appendix 1.

Outcome measurements

We collected demographic information on age, sex, and years of education. Additionally, we registered years since diagnosis, dopaminergic medication use, and most affected side. We assessed feasibility (adherence to training, satisfaction, perceived benefits, recommendations to others) and safety (adverse events) using a self-administered questionnaire assessing participants experiences with the training. The complete questionnaire used can be found in appendix 2.

We also assessed effectiveness of the training. The primary outcome measure was balance as measured by the Mini-Balance Evaluation Systems Test (Mini-BESTest), which assesses four balance subdomains (anticipatory postural adjustments, postural responses, sensory orientation, and gait stability) [32]. The maximum score is 28 points, and each item is scored from 0 (unable or requiring help) to 2 (normal). As secondary outcomes, we measured fear of falling with the Falls Efficacy Scale International FES-I [33] and the Activities Balance Confidence Scale (ABC-scale) [34]. The ABC is a 16-item questionnaire designed to measure balance confidence in various everyday activities. For each item, the score ranges from 0% (no confidence) to 100% (completely confident) or from 0 to 10 points (total score will range from 0-160 points). The FES-I is a self-efficacy and balance confidence questionnair, with 16 items. The score ranges from a minimum of 16 (no concern about falling) to a maximum of 64 (severe concern about falling). These were collected by sending e-mails by the certified data management system castor EDC (electronically) when possible and on paper/pencil when participants preferred.

For walking ability, we used the 6-minute walk distance (6MWD) [35] and the Timed-Up-Go [36]. We also assessed health status and quality of life using the Parkinson's Disease Questionnaire (PDQ-39). We selected all measurement instruments according to recommendations in the European Physiotherapy Guideline for Parkinson's disease [9].

Data Analysis

We used the intention-to-treat principle in all analyses. IBM SPSS statistics version 26 (IBM, New York, United States) was used to perform the analysis. Shapiro-Wilk test was used to assess whether the data were normally distributed. Since the data were not normally distributed (p<0.05), we used non-parametric tests for further analysis. Mann Whitney U tests were used to test the difference between the two groups concerning balance, walking ability, and fear of falling, follow-up (T1). Secondarily, we used the Wilcoxon Signed-rank test to evaluate differences within groups. The level of significance was set to p<0.05. To measure the effect-size, we calculated Cohen's d. The effect size can be either small (0.20), medium (0.50), or large (0.80) [37]. We used descriptive statistics and analysis of content to evaluate the narrative of participants collected via the qualitative questionnaires.

Results

Participants

Twenty-nine people with PD (median age 64 (8.8) years; median disease duration 5 (4.3) years, time from first symptoms 7.5 (5.2) years) participated in this pilot explorative randomized controlled trial.

Both groups were comparable at baseline (p>0.05; Table 1). Fourteen individuals participated in the boxing with kicking (BK) and thirteen in the boxing-alone (BO). From those, twelve participants in the BK and eleven in the BO group had a complete dataset (figure 1).

Table 1 | Demographic and clinical characteristics of both Boxing with Kicking and Boxing Alone group

	Boxing with Kicking N=15	**Boxing Alone N=14**	**p-value**
Age*	63.69 (SD 6.63)	64.36 (SD 11.14)	0.98
Sex (men) †	73% (n=8)	60% (n=6)	0.17
Amount of education (years)*	15.18 (SD 6.5)	15.30 (SD 5.14)	0.94
Time since first symptoms (years)*	9.09 (SD 5.73)	6.10 (SD 4.72)	0.14
Disease onset*	5.82 (SD 4.16)	4.26 (SD 4.58)	0.13
Dopamine replacement medication (yes) †	13	10	1.00
Affected side †			
– **Left**	18% (n=2)	30% (n=3)	
– **Right**	64% (n=7)	50% (n=5)	0.85
– **Symmetrical**	18% (n=2)	20% (n=2)	

Missing values varies per variable and per group.
* Mean (Standard deviation)
† Percentage. All percentages reported are over the total of responders.

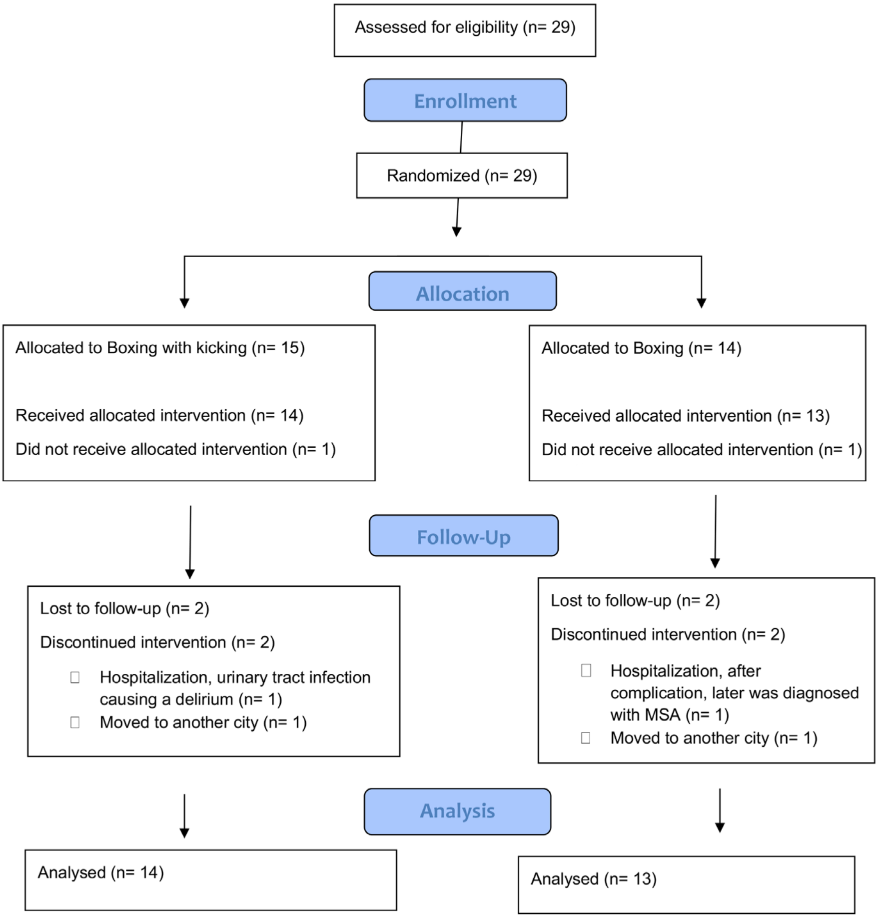

Figure 1 | Flowchart of the study participants

Safety & feasibility

Trainings were completed by 85% of the participants. During the trial, only four dropouts occurred, all for reasons unrelated to the program. No fall incidents or other adverse effects were reported during training in both groups.

Participants' acceptability and perceived benefits

A total of 18 participants (n=10 BK group and n=8 BO group) replied to the qualitative questionnaire (table 3). The majority (n=8, 80%) of participants in the BK group reported satisfaction with the training and that they had improved their balance after training. These subjective improvements in both balance and exercise capacity were reported as a motivating factor to keep practicing boxing by 60% (n=6) of the participants. When asked what the benefits of kicking techniques would be, most participants (60%, n=6) replied that they expected that BK would improve their balance more than conventional boxing. All participants in the BK group (100%, n=10) would recommend BK training to other people with PD.

Participants in the BO group reported similar improvements. Satisfaction and balance improvements were reported by 75% (n=6) of participants in the BO group. Motivations to attend BO training were either improvements in balance and exercise capacity (50%, n=4) or social contact (50%, n=4). The two most mentioned benefits of BO training were: improvement in exercise capacity (37%, n=3) and improvement in mobility (25%, n=2). All responders (n=8) in the BO group would recommend BO to other people with PD.

Table 3 | Participants experience and perceived benefitof both Boxing with kicking and Boxing group

	Boxing with Kicking N=10	**Boxing Alone N=8**
Satisfaction	80%	75%
Perceived improvements in balance	8	6
Areas of motivation to keep boxing	Improvements in balance and exercise capacity	Improvements in balance and exercise capacity or social contact
Would recommend to others	All	All

Balance

We did not find any additional benefits of kicking techniques (between-group differences, BK 25.33 (2.64) and BO 25.80 (2.39) p=0.53).

The within-group comparison showed that balance improved in both groups after the intervention (BK 22.60 (2.7) to 25.33 (2.64) p= 0.02; BO 23.09 (3.44) to 25.80 (2.39); p=0.01 on the Mini BEST test) (table 2). The effect size of both types of boxing modalities was large, 1.02 for BK and 0.91 for BO for the Mini-BESTest. Results showed that four people in the BK group and 4 in the BO group improved at least four points in the Mini-Best score, which has been reported as the Minimally Clinical Important Difference) [38].

Fear of falling

Fear of falling, as measured by the FES-I, did not show a significant between group differences after the intervention (BK 27.36 (6.56) and BO 24.00 (3.97) p=0.34).

Within-group, comparison showed that fear of falling FES-I did not change in either group (BK 27.54 (7.47) to 27.36 (6.56) p=0.81; and for BO 24.50 (8.24) to 24.00 (3.97) p=0.06). Similarly, the ABC-scale score for fear of falling showed no significant improvement between (BK 126.18 (26.83) and BO 126.60 (35.92) p=0.86) or within the groups (BK 126.72 (19.23) to 126.18 (26.83) p=0.47; BO 143.66 (19.54) to 126.60 (35.92) p=0.22) (table 2).

Walking Ability

Overall, no significant improvement of walking ability was found between groups (BK 464.36 m (78.07) and BO 458.40 m (67.87) p=0.70 or within (BK 467.91 m (76.91) to 464.36 m (78.07) p=0.64; BO 461.09 m (73.63) to 458.40 m (67.87) p=0.54), as measured with the 6MWD. We also found no significant between group differences for the Timed Up & Go score. However, we did see a tendency towards a decrease in the TUG score (longer time - worsening of function) within the BK group (8.03 s (3.05) to 9.14 s (2.28) p=0.06). In the BO group (7.74s (2.21) to 8.86s (2.36) p=0.007), there was a significant decrease in TUG score.

Health status and Quality of life

No significant differences related to quality of life were found between groups (p=0.46) after the intervention, measured with the PDQ-39. However, the BO group showed a significant within-group improvement (decrease) (26.26 (18.08) to 19.01 (10.62) p=0.04) in PDQ-39.

Table 2 | Pre and post-intervention values for balance, gait, fear of falling, and quality of life among groups.

Variable	**Boxing with kicking group (n=14)**				**Boxing Alone group (n=13)**				**Between groups**		
	Before	*After*	*p-value*	*Effect-size*	*Before*	*After*	*p-value*	*Effect-size*	*Before p-value*	*After p-value*	*Effect-size after*
Mini-BESTest (total)*	22.60 (2.70)	25.33 (2.64)	0.02	1.02	23.09 (3.44)	25.80 (2.39)	0.01	0.91	0.75	0.53	0.18
6MWD (m) *	467.91 (76.91)	464.36 (78.07)	0.64	0.04	461.09 (73.63)	458.40 (67.87)	0.54	0.03	0.84	0.70	0.08
TUG (sec)	8.03 (3.05)	9.14 (2.28)	0.06	0.41	7.74 (2.21)	8.86 (2.36)	0.007	0.48	0.94	0.72	0.12
TUG dual task (sec)	8.70 (3.17)	9.65 (2.79)	0.07	0,32	8.46 (2.65)	9.33 (2.19)	0.23	0,36	0,70	0.72	0,13
FES-I (total)*	27.54 (7.47)	27.36 (6.56)	0.81	0.02	24.50 (8.24)	24.00 (3.97)	0.06	0.07	0.35	0.34	0.61
ABC-scale (total)*	126.72 (19.23)	126.18 (26.83)	0.47	0.02	143.66 (19.54)	126.60 (35.92)	0.22	0.59	0.09	0.86	0.01
PDQ-39 (total)*	22.52 (12.75)	25.93 (21.95)	0.67	0.18	26.26 (18.08)	19.01 (10.62)	0.04	0.48	0.92	0.46	0.40

* Mean (Standard deviation). Missing values differs per variable. Within group differences calculated with Wilcoxon Signed Rank. Between group differences in change scores calculated with Mann-Whitney U. Effect-size calculated with Cohen's d.

Mini-BESTest=The Mini Balance Evaluation Systems Test, 6MWD=The 6-minute walk distance, FES-I=The Falls Efficacy Scale International. ABC-scale=The Activities-Specific Balance Confidence Scale. PDQ-39= Parkinson's Disease Questionnaire. TUG=Timed Up and Go Test

Conclusions

Here, we assessed the feasibility, safety, and potential effectiveness of a 10-week boxing training intervention with kicking techniques compared with an equivalent dose of boxing alone in people with PD. Our results show that both interventions were feasible, and safe and showed a potential improvement in balance in people with PD. Also, both boxing with kicking techniques does not lead to additional benefits over boxing training without kicking techniques. Nevertheless, incorporating kicking techniques may be a valuable addition to the exercise therapy repertoire by creating greater versatility and thereby assisting in long-term adherence to exercise.

The trainings were completed by 85% of the participants, and most reported being satisfied with boxing, both with and without kicking techniques. There were also no fall incidents or other adverse events during both trainings. During the trial, only four dropouts occurred for reasons unrelated to the program. Compliance and sustained adherence to prolonged exercise programs remain a critical challenge in PD [47-49]. Previous studies have shown that boxing is an engaging activity that can be sustained over the long term with additional benefits of social interaction during group trainings [18, 22, 50]. Our findings contribute to the existing body of evidence, underscoring the feasibility and enjoyment of boxing as an exercise modality for people with PD. Additionally, incorporating kicking techniques may offer a valuable augmentation to the expanding repertoire of evidence-based interventions in the realm of community-based exercise programs. Considering the individuality of preferences among people with Parkinson's disease, recognizing and offering a wider range of exercise options can play a crucial role in fostering long-term adherence to physical activity.

Although we expected that kicking techniques would further challenge the balance system, both interventions appear to be equally effective for balance outcomes. The average scores showed an increase in Mini-BESTest score of around 2-3 points for all participants, which is not clinically relevant. However, 4 people in both groups reached a clinically relevant increase in Mini-BESTest scores of at least 4 points [38]. These results may reflect the complex interplay between the many different factors related to balance control in PD, and we presume that balance interventions for PD will most likely need to take a multiple systems approach [25, 39-41]. Additionally, typically boxing trainings incorporate training exercises, including different agility, strength, and aerobic activities ([17-21]; that would challenge balance. Even the boxing drills, shadow boxing, and speedbag drills will ultimately require dynamic weight shifting and balance tasks. Another possible factor that could have benefited balance improvements in both groups was the dual-task training component of both boxing interventions. Even though we did not see improvements in the TUG cog in both groups, the ability to perform a motor task while simultaneously engaging in a cognitively demanding task (dual-task) is critical for balance control in PD. Several studies have shown that dual-task activities reduce balance, gait performance, and falls [39, 42, 43]. Training dual-task performance has been shown to improve balance and gait outcomes [44, 45]). Finally, the training dosage of once per week for 10 weeks and the small sample size could also play a role in the limited results. Ultimately, many factors can interplay and justify why both groups improved their balance and adding kicking did not bring greater improvements.

Additionally, despite the small improvements in balance in both groups, the fear of falling did not improve significantly. Improvement of balance may not directly lead to a diminished fear of falling because the fear of falling is not only based on balance performance [46].

Walking ability did not showimprovement in both groups. These results are inconsistent with previous boxing research that showed an overall improvement in stride length and walking ability [19]. This can potentially be explained by the shorter duration and lower frequency of the intervention (10 weeks - 1 time per week in this study versus twice-a-week for 12 weeks in earlier work [18]).

We need to mention several limitations of the present study. First, the small sample size may have hampered finding statistically significant differences between groups.We aimed to perform an exploratory pilot study aimed at evaluating the experiences/ feasibility, safety, and potential effects of two variants of boxing. Definitive results can, therefore not be drawn. Additionally, given the type of training in group formats, the size of the groups could not be too big to assure safety.

However, the lack of a trend toward significant between group balance difference indicates that a bigger sample size would probably not have led to different results. A second limitation is that we do not have UPDRS and HY scores for our population that would better characterize the groups. We used duration since symptom onset and diagnosis as a proxy for disease severity, indicating mild to moderate disease stages in both groups. In principle, randomization should warrant an equal distribution between groups, which is a strength of the current study. We did not find any significant differences between the groups at baseline in the demographics and outcomes we measured (Table 1), which makes us confident that both groups were comparable at baseline. Third, we did not measure the long-term effects; consequently, no predictions can be made about any lasting effects on balance improvements for each intervention. Fourth, the training frequency in future studies should be at least twice a week. Here, we chose a once per week frequency for feasibility reasons. Even though we believe though this dose may replicate real-world access as many people with PD program different exercises each week, in the study, this may limit the beneficial effects (which would be expected to be larger with a more frequent training program). Some studies that have looked at dosing effects suggest that more intense exercises come with greater benefits for people with PD [51, 52]. These limitations must be considered in future randomized controlled boxing trials in PD.

Ultimately, while we did not find additional benefits of kicking techniques, both boxing with and without kick techniques led to small balance improvements in people with PD. Importantly, participants were satisfied with the training, adherence was good, and no safety issues were reported. The implementation of boxing interventions has the potential to keep people with PD engaged and motivated in long-term exercise activities.

Supplementary Material: Appendix 1 contains a table with a description of each of the programs, including session components and exercises performed. Appendix 2 contains the Questionnaire of participants' experiences with the training.

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Appendix 1: Overview interventions

Session components	Boxing	Boxing with kick-techniques
Warm-up	• Same in both groups. • Walking through the hallway with variations in movement and speed. Alternating stepping while boxing with jab punches. Rotating trunk with hook punches and squatting on upper cuts (vertical punch).	
Mirror Exercise	• In front of the mirror, performing jab and hook punches while switching legs slowly. • Progressing weekly to faster changes in punches: • jabs, hooks, uppercut and the cross (opposite arm).	• In front of the mirror, performing jab and hook punches while switching legs. • Progressing weekly to faster changes in punches, jabs, hooks, uppercuts, and the cross. • Adding kick-techniques. E.g., Right foot in front of the left foot. Bringing the left knee to the front (remembering to turn hip), then placing the left foot back behind the right foot. Progressing weekly with switching legs at greater speeds and kicking towards the mirror.
Punch-bags	• Punching with jabs toward the Punchbag. Changing to the cross punch. Progressing to start with the hook and uppercut punch. Introducing punching combinations (e.g., 2 times jab, 1 hook, and 2 uppercuts). Increasing speed and the location of the punching on the Punchbag. Stacking combinations exercises. • Combining different game-like challenges to increase the enjoyment (e.g., pair activities: One stands in front of the bag, the other just behind them. ” Instructor” touches the “exerciser” on the arm to prompt which arm to use). • Focusing on posture by using the hook to punch the bag on a different location (high to low and vice versa). Repeat 10 times for 3 series. • Adding more combinations weekly increasing the intensity and speed of the exercises.	• All the same to boxing alone group. • Including leg challenges. The first kick will be the round kick, with a bended knee, using the bag to ensure balance. Next, adding the kick with a stretched knee. Increasing complexity with more combinations and changing speeds. • Focusing on posture by using the hook to punch and kicking the bag on different locations (high to low and vice versa). Repeat 10 times for 3 sets. • Adding more combinations weekly increasing the intensity and speed of the exercises.
Ending (fire-down phase)	• Ending sessions with free punching for 1 minute. • Cooling down with walking while moving arms in circles. Walking with big steps and whole-body movements and moving sideways and opening both arms wide. In standing position and legs wide apart, moving arms to the side and twisting upper body from the left to the right.	• Ending sessions with free punching and slow kicking for 1 minute. • Cooling down with walking while moving arms in circles. Walking with big steps and whole-body movements and moving sideways with a small kick and opening both arms wide. In standing position and legs wide apart, moving arms to the side and twisting upper body from the left to the right and standing on 1 leg for 10 seconds, switching legs and repeating twice.
Ending (Cool-down)	• Ending the session with a relaxation exercise with soft movement, stretching, and breathing.	

Appendix 2: Questionnaire of participants' experiences with the training

Questionnaire

1. In welke mate heeft het boksen uw balans beïnvloedt? Mijn balans is sinds het begin van het boksen….

○ Heel veel beter (1)
○ Veel beter (2)
○ Iets (enigszins) beter (3)
○ Hetzelfde (4)
○ Iets (enigszins) slechter (5)
○ Veel slechter (6)
○ Heel veel slechter (7)

English: To what extent did boxing influence your balance? My balance is since I started boxing:

very much better (1)
much better (2)
a little better (3)
the same (4)
a little worse (5)
much worse (6)
very much worse (7)

2. Hoe tevreden bent u over het boksen (één antwoord aanvinken) ?

○ Absoluut tevreden
○ Zeer tevreden
○ Enigszins tevreden
○ Niet tevreden, niet ontevreden
○ Enigszins ontevreden
○ Zeer ontevreden
○ Absoluut ontevreden

English: How satisfied were you with the boxing training?Absolutely satisfiedVery satisfiedA little satisfiedNot satisfied, but also not unsatisfied A little unsatisfiedVery unsatisfiedAbsolutely unsatisfied

3. Wat motiveerde u om te gaan (en te blijven) boksen?

English: What motivated you to start (and continue) boxing?

4. Waren er ook barrières om te gaan boksen of te blijven boksen? Zo ja, welke?

English: did you experience barriers for starting or continuing boxing training? If yes, can you indicate which barriers?

5. Wat heeft het boksen u opgeleverd?

English: what were the benefits of boxing for you?

6. Zou u het andere mensen met Parkinson aanraden om te gaan boksen? Zo ja, waarom?

English: would you recommend boxing to other people with PD. If yes, why?

7. Wat is, volgens u, de meerwaarde van het gebruik van traptechnieken naast stoottechnieken?

English: What is, in your opinion, the additional value of using kicking techniques in addition to using punching techniques.

Part IV

Facilitating participation in exercise community programs

7

Guiding Exercise Choices for People with Parkinson’s

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Abstract

People with Parkinson's disease (PD) often face challenges when it comes to choosing suitable exercise programs from the wide range of options available to them. The abundance of choices can make decision-making regarding the most appropriate exercise regimen a difficult task for these individuals.

This study aimed to assess the usefulness, satisfaction, and preferences regarding participation in a PD-personalized educational and exercise boot camp program. Attendees participated in a four-day program consisting of exercise sessions, workshops, and social activities. We collected demographic and clinical information. We assessed satisfaction and preferences immediately after. At the one-month follow-up, participants assessed usefulness and changes in exercise habits. Eight individuals diagnosed with PD, with a mean age of 59.5 ± 6.8 years, participated. All participants felt "very satisfied" and were likely to attend future events. The two favorite sessions were: cognitive stepping and dance-based movements. At the one-month follow-up, participants considered the program "very useful" and reported changes in their exercise routine. Our results suggest that the boot camp program was considered useful and capable of influencing participants' exercise habits.

Introduction

Parkinson's disease (PD) is a neurodegenerative disease that results in a gradual reduction in activities of daily living and quality of life [1]. Increasing evidence suggests that individuals with PD benefit from continuous ongoing exercise to improve and maintain physical functioning and help them better manage the disease [2,3]. As such, people with PD are currently encouraged to play an active role in self-management and acquire the exercise tools in their community to manage their disease [4]. Yet, there is a variety of rehabilitation, exercise, and physical activity programs that are now available for individuals with PD. Some of the more common approaches highlighted in recent literature include amplitude-based movements [5–8], dance [9–11], Tai Chi [12,13], Qigong [14,15], Nordic walking [16,17], boxing [18–20], and aquatic exercise [21,22].

Translation of therapies into practice in the community setting has, however, proven difficult. Engaging in regular rehabilitation and clinical exercise interventions and guaranteeing ongoing adherence requires finding the proper program that fits the patient's needs and preferences and bypassing commonly perceived barriers to exercise in PD [23,24]. Just telling people about the benefits of these exercises and expecting them to make decisions is debatable.

Making a choice about which type of exercise programs to perform and understanding the evidence, safety issues, and the adaptations needed for each program [25] may be difficult. Considering the benefits of such programs, there is a need to overcome these translation issues. Several lines of evidence have suggested that boot camps represent an effective and useful means of teaching [26,27]. Despite knowledge of this success, few studies have investigated the usefulness of delivering exercise education via boot camps for individuals with PD. No study has attempted to encompass the range of these different approaches all in one intervention or program in PD. Providing access to a boot camp program that allows participants to familiarize themselves with types of exercise programs while guiding them as to what works best and potentially guiding their exercise choices may be of critical importance. Here, we present a PD-personalized educational and physical activity boot camp program that allows participants to familiarize themselves with common evidenced exercise programs. Our primary objective was to assess the patients' perceived usefulness (or helpfulness) and utilization (or how much they changed their exercise routines and used the knowledge) of the program to facilitate exercise choice and lifestyle behavior over time. Secondary objectives included the assessment of satisfaction, preferences, and adverse events.

Methods

Design

We used a single-group pre-test and post-test design.

Sampling and Recruitment

The sampling method selection was non-probabilistic by convenience. Following European Parkinson's guidelines regarding the recommended number of individuals per group [3], we included eight individuals with PD, invited via email from a Parkinson's patient association. All participants had to be able to ambulate independently, able to tolerate a minimum of 1 h of exercise and be able to attend all 4 days of the boot camp. Care partners were also invited to attend. 2.3. Participants Eight individuals with PD (5 women) participated in the program with a mean age of 59.5 ± 6.8 years. All participants participated for the first time in a boot camp. The participants' demographics and clinical characteristics are described in Table 1.

Ethics and Procedures

This study follows the principles of the Declaration of Helsinki. The study was approved by the Egas Moniz Research Ethics Board (Institutional Ethics Committee of Egas Moniz Higher School of Health (ID 948; Date: 25/03/2021). Participants completed an informed consent form before starting the program and received an information sheet explaining how their data would be used.

Program

The boot camp program consisted of four days of training featuring 30–60 min sessions each for a total average of 4 h per day. The boot camp began with an overview of general group goals based on a pre-assessment questionnaire. After, it focused on alternating between exercise, educational sessions, and social patient–family interactions. See Table 2 for topics presented on each day. To provide an engaging educational experience, therapists used various teaching formats, including multimedia presentations, hands-on activities during lectures, exercise sessions, and interactive discussions (question-and-answer periods that allowed participants to learn from the therapists and each other). For example, the tips and tricks sessions included trying the cueing strategies taught and exploring solutions for better management of issues associated with PD reported on a pre-camp questionnaire. Presenters' slides and tangible information to easily reference later were shared with all participants.

Table 1 | Participants´ general and clinical characteristics.

Participant	Gender	Age	Time since diagnose	Main problems	Perceived health (now and compared to last year)	Fall history
1	F	66	10 years PD	• My inability to help my husband in a casual, spontaneous way • The lack of reliability and independence • Fear of loss of mind, dignity, feeling powerlessness • Fear of falling • Dyskinesia and appearing to be drunk	• Poor, the same as last year	• 1 fall outdoors 2 months ago • Near falls occasionally
2	F	61	2.8 years PD	• Slowness • Balance and walking • Speech & swallowing • Apathy	• Very good and about the same	• 1 fall outdoors 6 months ago, and couldn't get up. • Near falls occasionally •
3	M	59	8 years PD	• Stiff neck and bad posture • Walking •	• Good, about the same	• No falls • Near falls occasionally •
4	M	60	8 years PD	• Walking indoors • Walking outdoors • Time management & relaxing	• Good, somewhat worse than one year ago	• Frequent falls. Weekly, don't pick my feet up. • Daily near falls • A little fear of falling
5	F	57	4 years PD	• Walking • Walking and talking	• Good, somewhat worse than one year ago	• No Falls • No Near falls
6	F	70	6.5 years PD	• Imbalance • Walking coordination • Anxiety, frustration, self-confidence • Driving, being able to see in the dark	• Fair, much less now than a year ago	• 2 Falls last 6 months • Near falls once per week

Table 1 | Continued

Participant	Gender	Age	Time since diagnose	Main problems	Perceived health (now and compared to last year)	Fall history
7	F	60	1.8 years PD	• Night (early morning) and morning stiffness (pre-medication) OFF phases Lower back and sometimes neck pain • Memory/ Concentration - recalling names or a particular word • Being able to stay focused on one thing	• Fair, much less now than a year ago	• No Falls • No near falls • Some fear of falling
8	M	45	9 years PD	• Lack of sleep, Restlessness • Freezing/walking • Unfit/overweight • Stiffness	• Good, about the same	• No Falls • Near falls occasionally •

Table 2 | Description of the boot camp educational and exercise sessions' topics.

Days	Educational and exercise sessions	Format
Day 1	One-on-one brief assessments and introductions	Education
	Exercise in Parkinson's Disease: why, what and how.	Education
	Introduction to a variety of exercises.	Practice
	New exercise ingredient in PD: cognitive-motor training.	Education
	Cognitive Stepping with amplitude-based movements.	Practice
Day 2	Review of Day 1, goals for the day	Education
	Changes in voice, communication, and swallowing in PD	Education
	Voice, Breathing & Movement session	Practice
	Educational session: Walking/freezing/talking difficulties	Education
	Walk & Talk dual task program.	Practice
	Nordic walking with an integrated voice training session	Both
Day 3	Review of Day 2, goals for the day	Education
	Hydrotherapy: impact on mobility	Education
	Exercise Session: Using boxing for mobility and voice training in PD	Practice
	Tips & Tricks for transfers in daily life and exercise	Both
	Exercises for transfers: rhythm, amplitude & speed	Practice
Day 4	Review of the Camp, future goals & community resources	Education
	Tips & Tricks for bypassing barriers to exercise.	Education
	Goodbye Drum-based dancing activity	Practice
	Adapted Tai Chi	Practice
	'Take home messages' test activity	Education

The exercise sessions included practicing examples of amplitude-based interventions [5–8], Nordic walking [16,17], multitasking cognitive and motor exercise challenges [2,28–30], hydrotherapy [21,22,31], and tai-chi [12,13], dance-based movements [9–11], as well as a boxing session [18–20]. All sessions were delivered in a group format. To guarantee safety, two volunteers were available to support people if needed. The intensity of the physical activity sessions was delivered according to the patient's tolerance and started ranging from a low to moderate intensity of aerobic exercise (40–60% HRR (or VO2R). Due to the group format, people with PD were taught to self-assess and monitor their effort throughout each session. The volumes of the aerobic-based sessions were ≥30/40 min of continuous or intermittent exercise per session based on the exercise recommendations in European guidelines for physiotherapy for Parkinson's disease [3]. The program was led by a physiotherapist and a speech therapist with specialized training and experience in PD. A local physiotherapist was invited to the program to be able to carry on exercise classes if requested by participants. Social activities (e.g., mealtimes, resting breaks) promoted interaction with peers and contributed to peoples' feeling more acquainted, adding to a positive group dynamic.

Data Collection

Participants completed an online pre-assessment structured questionnaire before the program, a post-assessment immediately after, and a one-month follow-up. The pre-assessment collected general information on demographics, top 5 clinical problems, past medical conditions, disease management strategies, current exercise, preferred exercise modalities, and perceived barriers/facilitators to performing exercise. The pre-assessments also inquired about the participant's goals and expectations for attending the boot camp. Immediately after the program, we assessed satisfaction, preferences, and adverse events via an anonymous online questionnaire. People with PD were asked to rate on a 4-point scale how satisfied they were with boot camp (1 = not satisfied, 2 = neither, 3 = satisfied, and 4 = very satisfied), whether they would recommend the program to a friend (1 = Yes, 2 = No, 3 = Maybe), and how likely are they to return to a similar program (1 = very likely, 2 = likely, 3 = neither, and 4 = unlikely). They were also asked which sessions they preferred (1 = Educational sessions; 2 = Dance-based amplitude movements; 3 = Voice & Breathing; 4 = Boxing session; 5 = Walk & Talk dual-task training; 6 = Cognitive stepping program; 7 = Hydrotherapy activity; 8 = Nordic walking; 9 = On the floor activities; 10 = Drum-based dance activity) and if there was any problem encountered during the program. An anonymous follow-up questionnaire emailed to each participant one month after the boot camp asked the participants to assess the perceived usefulness of the program in the management of the current participant's exercise habits, as well as to assess the utilization (or how much they changed their exercise routines and made use of the knowledge and experience of the boot camp). Usefulness was assessed based on the patient's perceived (self-reported) usefulness of the program. People with PD were asked to rate on a 4-point scale how useful the boot camp was in helping them manage their current exercise habits (1 = not useful, 2 = neither useful nor useless, 3 = useful, and 4 = very useful). Utilization was based upon changes in exercise habits that were made after the program.

Data Analysis

Data were extracted into a spreadsheet. Using the IBM Statistic Package for the Social Sciences software, version 26.0, descriptive statistics were adopted to analyze data.

Results

Participants most frequently reported that their expectation for the boot camp was to learn more about specialized exercise. See participants' exercise habits and expectations for the boot camp in Table 3.

Table 3 | Participants' current exercise habits, perceived exercise barriers, facilitators, and expectations for the boot camp.

Participant	Current exercise habits	Perceived Barriers to Exercise	Perceived factors that would facilitate exercising	Expectations for the exercise camp program
1	• Current: yes • Which: stretching • Frequency: daily • Average time: 15 minutes	• Fluctuations in health	• Caregiver/partner are supportive, accessing instructors with PD expertise	• "To try to find a way back, relearn how to exercise, get a shared goal. Learn from others. Reduce the need to take pills."
2	• Current: yes • Which: walking and ball activities. • Frequency: every other day • Average time: 20 minutes	• Poor coordination • Fear of looking silly • Accessing instructors with PD expertise is difficult	• Perceived benefit and visible improvement after exercising, able to work out during working hours	• "Improve my coordination and health without the use of drugs."
3	• Current: yes • Which: cycling, walking • Frequency: cycling twice a week, walking every day. • Average time: 60 minutes	• Fluctuations in health • Not easy to access specialized exercises	• Perceiving benefits and visible improvement after exercising, accessing instructors with PD expertise	• "To understand what exercises would be best for me, also being with fellow sufferers of similar abilities."
4	• Current: yes • Which: Cycling • Frequency: 1 per week • Average time: 45 minutes	• Fluctuations in health • Lack of time to exercise. • Always something to do for Parkinson's society	• Perceiving the benefit after exercising	• "To access the "feel good factor" & challenge myself more, see what I should do for exercise."
5	• Current: yes • Which: walking the dog • Frequency: Daily • Average time: 30 minutes	• Fluctuations in health • Lack of time to exercise • Job restrictions	• Accessing instructors with PD expertise	• "I would like to gain knowledge and further my skills in managing the disease through exercise."

Table 3 | Continued

Participant	Current exercise habits	Perceived Barriers to Exercise	Perceived factors that would facilitate exercising	Expectations for the exercise camp program
6	• Current: yes • Which: golf, walking • Frequency: 2 times a week • Average time: 60 minutes	• Fluctuations in health • Lack of confidence exercising outside of the rehab setting • Weather conditions • Living in a rural area without access to specialized care	• Perceiving benefits and improvement after exercising, easy access to the gym or exercise facility, accessing instructors with PD expertise, fun things in a group with people fitness same as me	• "To boost confidence and fitness levels in fun environment."
7	• Current: yes • Which: Parkinson Choir, Conductive Education • Frequency: choir 1 per week; education 1 per month • Average time: 75 minutes	• Fluctuations in health • Fear of falling, effect of weather conditions	• Caregiver/partner being supportive, easy access to the gym or specific exercise facility, accessing instructors with PD expertise	• "To identify a daily/weekly exercise regime with ones that will be more beneficial to me."
8	• Current: yes • Which: Jiu-jitsu • Frequency: once a week • Average time: 60 minutes	• Fluctuations in health • Lack of time to exercise • Lack of interest • Job restrictions	• Easy access to the gym or exercise facility, accessing instructors with PD expertise, ability to workout during working hours	• "Get tips for getting fitter and do more specific exercises."

Perceived Usefulness and Utilization

Participants considered the boot camp very useful (seven in eight; 87.5 %) and useful (one in eight; 12.5%) in managing their current exercise habits. At the one-month follow-up, seven participants reported changing their exercise routine after the boot camp, and one participant said, "Not really changed anything; I need more time in my day." The participants that made changes mentioned specifically: "I do exercise more frequently now,"; "Introduced the "power" breathing that I learned in the program," "Taking a daily commitment to exercise seriously," "Joined a gym to do more exercise," "I do more walking periods and cognitive games," "I started Nordic walking" and, "started sessions with the physiotherapist involved in the program."

Satisfaction

After the program, all participants had favorable feedback, with all (100%) feeling very satisfied, likely to attend future events, and “would recommend to another person with PD.”

Preferences

About six in eight (75 %) participants felt that many of the exercises and activities were new to them. The two training sessions participants enjoyed the most were: dual-task cognitive stepping (six in eight; 75 %) and dance-like movements (six in eight; 75 %). The two sessions participants enjoyed less were: Nordic walking (two in eight) and boxing training (two in eight).

Safety

No falls, major injuries, or adverse events occurred during the program. One patient could not attend boxing sessions due to a superficial finger injury.

Discussion

Our study assessed the usefulness, utilization, satisfaction, and preferences regarding participation in a PD-personalized educational and clinical exercise boot camp program. Based on our results, all eight participants with mild and moderate PD perceived the boot camp to be useful. Overall, seven out of eight participants said they had changed their exercise routines one month after. The participants reported high satisfaction levels and no severe adverse events. Given the benefits of ongoing exercise in PD and the number of current options, the importance of offering guidance for safe, PD-specific exercise programs for this population cannot be underestimated [18,25]. Importantly, this paper could help pave the way forward to delivering personalized exercise education through online boot camps during the COVID-19 pandemic crisis. After the program, the participants were highly satisfied.

Several positive aspects may have contributed to the high patient satisfaction reported. First, the information from the questionnaire before the program allowed for better tailoring of the program to all the participants’ needs. Besides clinical information on health status, the questionnaires also provided logistical information based on questions such as “What would be a good time for you to start the activities?”, “If you are bringing someone, please tell us who and what you would like them to learn from the boot camp?” and “What topics and activities would you like to be addressed in the boot camp?”. Personalized exercise programs that are appropriately designed and delivered increase patient satisfaction with care options [32]. Shared goal setting should always be considered during the initiation and implementation of exercise interventions. Second, intrinsic motivation, via experiencing the actual benefit of each exercise and enjoying participation, are important factors for long-term training adherence [33,34]. The ability to try out the exercises can significantly affect one's ability to judge the preference, usefulness, and long-term utilization of the varied exercise options. It ultimately determines the degree to which individuals can judge information effectively and use it to make smart exercise selections. Third, delivering the program in a group format allowed participants to experience the beneficial effects of social support and motivation from fellow patients [35]. Fourth, most of the participants (six in eight; 75 %) felt that many of the exercises and activities were new to them, even though all participants were already doing some exercise on a weekly basis. They reported initially having clear expectations for the boot camp to gain more knowledge on specific PD exercises. Accessing specialized care was considered one of the most common factors facilitating exercising (six in eight participants).

Implementing such a program was not without some limitations. First, some people with PD might not have future access to personalized exercise programs presented. As such, we invited a local physiotherapist to the program to help ensure that participants would have an opportunity to access specialized care if needed. This was an innovative solution to facilitate access to personalized care. Interestingly, most participants preferred to include changes in their daily routine activities, with only one choosing to book sessions with the physiotherapist after completing the program. However, measuring participants' knowledge immediately after the program would have brought better insights concerning reasons for change or no change (utilization) one month after. Second, even though participants were told to invite their families and caregivers, only one decided to bring a caregiver. Nevertheless, all participants were confident they could contact the physiotherapist whenever they needed additional information or insight. The influence of the caregiver should be a key factor to be better explored in future programs. Third, the group format imposed some safety concerns. We limited registrations to eight people with PD to ensure a safe and efficient setting according to current recommendations [3]. Fourth, the nature of the study, with a small sample size and single-center design, imposes restrictions on the generalizability of the findings. We included a heterogeneous group of people with PD with different backgrounds and did not specifically include participants with more advanced stages of PD. Further research is needed to measure its effectiveness on other subtypes and profiles of people and against other educational programs.

Conclusions

Our findings indicate that the process of trying out various exercises can play a significant role in facilitating informed judgments and decision-making regarding exercise programs for people with PD. This approach has the potential to enhance the effectiveness of exercise prescription programs tailored to the PD community. Moreover, the method is easily reproducible, enhances patients' understanding of exercise, and, considering the participants' expressed interest in attending similar programs again and the perceived benefits they reported, it is likely to be well-received by healthcare professionals globally.

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Part V

Discussion & Summary

8

General Discussion

Introduction

In high-income countries, depending on the country of origin and, consequently, depending on the specific nature of the national healthcare system, a person with PD might typically see their neurologist once or twice a year for approximately 30 minutes each session. They may spend an additional 15 hours per year with their physiotherapist (figure 1). But during the rest of the year, people with PD spend their time in self-care at home or in the community [1]. Of note, a study that followed 187 people with PD showed that after 20 years following the initial diagnosis, 47% received physiotherapy, and 54% participated in some form of exercise in the community [2]. This illustrates well that, even in the later stages of the disease, people significantly depend on local community resources.

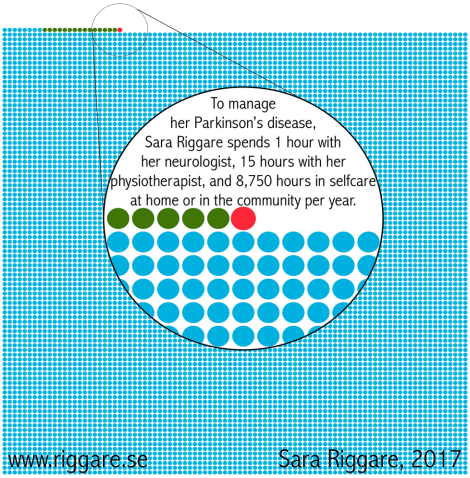

Figure 1 | Patient's perspective on everyday care [1]. The figure was created and reproduced with permission from Sara Riggare.

Community-based care is an attractive solution to enhance a long-term commitment to exercise and to help people with PD actively participate in managing their health. However, we still need better insights into the benefits of community-based care and the best approaches for implementation. Throughout the thesis, I reflected on key questions that could revolutionize PD care and fuel future research, including the following questions: What is the role of community programs within current PD care models? What are the benefits, drawbacks, and future needs for implementing and delivering such community programs? What initiatives and actions can be implemented to achieve a greater degree of PD-specific expertise among professionals applying these programs? How can we support medical referrals to such programs? How can evidence-based community programs be better implemented? How can patients' choices be best supported? And the ultimate question is, should these programs be considered part of current care models *per se* ororganized outside the care system as an addition to formal care?

To answer these questions and challenges, we defined several courses of action in this thesis at four levels: instructor, referral, research, and patient (Figure 2).

Figure 2 | Main challenges that limit community care delivery in Parkinson's disease.

We will now discuss these challenges and their potential solutions in more detail.

Current challenges and potential solutions in community care

Instructor level - Limited expertise among professionals delivering community programs

International Physiotherapy guidelines advise people with PD to participate in ongoing, unsupervised exercise in their communities while also recommending that people with PD access expert care [3]. Importantly, people with PD perceive the lack of PD-specific expertise in community exercise programs as an important limitation. Many individuals with PD express a strong interest in accessing community-based exercise programs led by professionals with expertise in PD within their community [4]. More expertise is an important factor in promoting safety in exercise interventions. Thus, there need to be more initiatives to enhance expertise among professionals delivering exercise programs to people with PD.

In this thesis, I studied two initiatives to enhance knowledge of professionals working with people with PD. In **Chapter 2**, I highlighted the safety concerns with the current proliferation of community exercise programs with limited evidence and without expertise [5]. In **Chapter 3**, I guided the translation process of the European Physiotherapy Guideline for Parkinson's Disease to other languages [6] to facilitate access to high-quality evidence by local professionals.

Safety Alert

Safety is commonly determined by the number and severity of adverse events during interventions. There is a clear need for a supportive and safe exercise environment, preferably led by professionals with relevant Parkinson-specific training. In **Chapter 2**, I argued that exercise programs led by professionals without PD-specific expertise could ultimately put the person's safety at risk [3, 7]. For example, simply encouraging a person to move more might lead to a higher rate of falls if complicated factors such as freezing of gait or posture instability are not carefully considered. Professionals with expertise will have a deeper understanding of the risks involved and are better equipped to identify strategies to reduce those potential risks.

Of notice, most exercise studies report no adverse events during the intervention [8-13] or only minor adverse events such as wrist pain [14] or lower limb musculoskeletal pain [15] directly related to the intervention. However, in some studies, an increased fall risk can be noted, and caution may be needed, especially with at-risk individuals when the intervention challenges different balance components. A study on Irish dancing reported one fall during a therapy session [16]. Another study on Tango reported 11% falls in the tango group versus 7% in the control group [17]. A highly challenging dual-tasking balance-training group program reported 13 falls during training [18].

Caution may also be needed with specific at-risk individuals due to greater disease severity. For example, one study [19] compared a minimally supervised exercise program (40 to 60 minutes, three times weekly for six months) with a usual-care control group. A preplanned subgroup analysis revealed a significant interaction between falls and disease severity. In the lower disease severity subgroup (motor UPDRS score ≤ 26), there were fewer falls in the exercise group when compared with controls (IRR = 0.31, 95% CI 0.15-0.62); however, in the higher disease severity subgroup, the exercise group had a trend towards more falls (IRR = 1.61, 95% CI 0.86-3.03).

But how do we increase safety in community-based exercise programs? As a community, we need to 1) further study which individuals are at risk during what specific type of interventions, 2) report adverse events in research more precisely, and 3) assure the instructors boost their level of knowledge of PD, including better insights as to how to reduce risks in a specific PD population.

Access to evidence

Providing high-quality, safe care is best achieved through evidence-based practice [20, 21, Dean, 2021 #1641], and instructors should also base their practice on this available body of evidence. The European Physiotherapy guidelines for Parkinson's disease [3] indicate that a minimal level of disease-specific expertise is necessary, particularly concerning the safety of exercises and reducing the risk of falls. These guidelines are a vital instrument in physiotherapy care for PD but can also be applied to other professionals. It includes indications on exercise-based interventions and PD-specific information relevant for anyone working with people with PD, including physiotherapists, occupational therapists, exercise physiologists, and sports instructors.

Implementing the recommendations of the European Guideline into daily clinical practice is essential to enhance the expertise of professionals, improve patient outcomes, and reduce the risk of adverse events [22, 23]. However, its use in countries where the official language is not English has thus far been limited. As such, in **Chapter 3,** our guide to the translation process represents a step forward in the international dissemination effort of implementing evidence-based guidelines in PD. Specifically, I have shared 10 practical steps on how to translate and adapt the European Guideline to help guide future translations.

Nevertheless, some considerations still exist.The community exercise instructors are responsible for recognizing limitations in their knowledge base. Besides accessing the best evidence available, the instructors will still need a practical educational component, given that the guideline was developed for a population with different educational backgrounds. They must continuously improve their ability to instruct and modify exercise approaches appropriately and closely review their clinical needs in conjunction with their personal preferences to produce long-term benefits [4]. Also, the instructors should learn to differentiate good evidence from flawed evidence, given the current proliferation of information on exercise and PD. In addition, given the safety issues and progressive nature of PD, these instructors should seek additional guidance from other professionals when needed [3].

Overall, adequately updated ongoing research, specific educational training, and continuous contact with people with PD will be needed for any professional to practice in a manner supported by emerging evidence [7].

Referral level - Reduced support for accurate referrals to community programs

Experience in working with the PD population is a significant source of expertise in and of itself. Treating a high volume of people with PD has been associated with better care delivery and patient outcomes [7].

Physiotherapists with an annual treatment volume of at least seven people with PD report higher self-perceived expertise [7, 24]. Medical specialists (mainly neurologists and geriatricians) play a central role in improving access to physiotherapy by initiating a timely referral for those patients with a specific indication for physiotherapeutic interventions. Referring people with PD consistently to a select number of motivated therapists and professionals will help to increase their caseload and thereby to enhance their practice-based knowledge. Even though physiotherapists are perhaps the first professional discipline that comes to mind when applying exercise-based interventions, other exercise professionals can also deliver these interventions. As such, there is a clear need to support accurate referrals to community exercise programs, independently of who is applying them, to increase access to a higher volume of people with PD and to further increase the knowledge base of the professionals providing these programs.

In **Chapter 4** ofthis thesis, I summarize the referral criteria, highlighting the importance of accurate referral to specialized professionals and emphasizing the potential benefits of expert care for clinicians working with people with PD who consider referring people with PD to physiotherapy and exercise-based interventions in the community. Ideally, there should be a balance between efficacy, safety, and usefulness of a given intervention to be considered for referral. Shortly after the diagnosis, a referral to physiotherapy should be considered, mainly for advice on exercise and self-management. For later disease stages, appropriate reasons to consider a referral to physiotherapy specifically include people with PD who express difficulties with transfers, mobility, physical capacity, pain, gait (including freezing), balance, or falls [3, 25-27]. However, further work is needed to clarify the indications for non-referral in situations where the risks outweigh the benefits. For example, in the case of (1) people with PD with significant active psychiatric problems (e.g., severe hallucinations, confusion, or psychosis, etc.) that may be aggravated when doing exercises or that would markedly interfere with compliance to the exercise intervention; and (2) the presence of red flags that would motivate interruptions of any physical activity (i.e., severe cardiovascular impairments, recent pulmonary embolism, etc.).

Importantly, when the benefits clearly outweigh the risks, such as physiotherapy or exercise interventions, facilitating access could ultimately benefit society. Health systems should make access to self-referral as easy and straightforward as possible for people with PD [28]. In such situations, people with PD themselves should, of course, be aware of the benefits, and this requires a consistent stream of patient education for which national or regional patient associations are of vital importance. Well-informed people with PD could thus access physiotherapy (or any other evidence based allied health) if they feel in need of specific care or specialized community exercise programs themselves, without a referral from a clinician. Again, this requires a continuous effort to empower people with PD to have the insight and ability to make such important decisions relating to their health. Interestingly, offering people with PD more room for self-management could provide clinicians with more productive time for their consultations.

Research Level – Limited evidence and implementation methods

The extent to which general exercise programs in the community can be translated into sustainable, adequate, and safe exercise programs specific to PD still needs to be determined. Recommendations on adapting exercise protocols used in research settings to those applicable in a "real-world" community setting, integrating the complexity of context and people participating, are lacking. These recommendations are urgently needed to clarify future implementation efforts of specific evidence-based practices.

In this thesis, I explored the implementation of two community programs for people with PD (**Chapter 5** and **Chapter 6**). First, I defined recommendations for implementing a program in the communityusing boxing as an example (**Chapter 5**). I showed that the boxing program implemented was well-received and accepted by people with PD during the initial workshop and at the 18-month follow-up. Initial and ongoing training for the boxing instructors with specific educational material was perceived as useful. It may serve as an example when developing similar programs in current and future boxing classes delivered in the community.

Second, I tested the added benefit of adding kicking to boxing **(Chapter 6)** as it may provide additional benefits to improve balance. Interestingly, I showed that both interventions were feasible and safe, while both were accompanied by a potential improvement in balance in people with PD. Boxing with kicking techniques does not lead to additional benefits over boxing training without kicking techniques. Nevertheless, incorporating kicking techniques may be a valuable addition to the exercise therapy repertoire by creating greater versatility and assisting in long-term exercise adherence in PD.

At the research level, there are, however, several considerations that persist. One important consideration is that in trials, the descriptions of the exercise-based interventions are frequently suboptimal, not allowing for replication of the intervention. Often, the exact content of the program should be made more explicit, as well as how adherence was guaranteed. There is also a need for greater accuracy in reporting any adverse events. There are guidance documents that could help address these limitations. For example, the Consensus on Exercise Reporting Template (CERT) applied to exercise interventions in musculoskeletal trials demonstrated good rater agreement and incomplete reporting - PubMed (nih.gov) [29, 30]. It is a tool that can facilitate the provision of explicit details about exercise interventions in clinical trials as a primary standard. Its routine use in the world of publishing is yet limited. It can, however, easily be achieved with specific guidance to authors aiming to publish exercise trials. Journals can undoubtedly require the CERT to accompany the manuscript submitted for publication and request reviewers to use it during the review process.

In addition, detailed information on the optimal delivery, guidance for specific settings (for example, rural as opposed to urban environments), ways to bypass barriers to exercise, and knowledge on the adaptation of general exercise to PD-specific programs are necessary for the optimal translation of evidence into clinical practice.

More work is also needed to study appropriate implementation strategies in the community to improve long-term adherence. People with PD are typically motivated to participate in research. Still, following participation in an exercise intervention study, there is a general decline in activity levels following the cessation of the study. Research has shown that to maintain ongoing activity and to keep being physically active beyond the research setting, people with PD want evidence supporting the benefits of exercise in addition to greater availability of programs closer to home and guidance from health care providers regarding exercise studies [31, 32]. People with PD also believe that these exercise programs should consist of activities that are enjoyable, safe, and adaptable to the abilities of the individual, as well as include social engagement and social support [33].

These expressed needs should point to developing and implementing programs that are easily accessible (with suitable transportation to the location and accessibility to the exercise room). With mobility difficulties and progressive disability, technology can support access to online community exercise programs via online exercise programs, such as online dance classes [34] and even more challenging cognitive-motor exercise programs [35]. This was a feasible form of physical activity during the pandemic and may complement health care now and in the future, given that we find ways to bypass identified barriers to its use, such as high costs, unfamiliarity with technology, or technologies adapted to PD motor and cognitive challenges, etc.) [36].

We also need various programs capable of maintaining motivation, considering differences in disease severities (more advanced vs. recently diagnosed). Besides the safety implications of combining different levels of severity, the discomfort of seeing symptoms of more advanced peers when exercising in a group can limit ongoing participation [32]. Notably, the design of exercise programs should also consider differences in personal preferences, as some people prefer to exercise in classes, whereas others prefer to exercise by themselves. The nature of the preferred exercise intervention may also differ considerably across different individuals. Fortunately, a wide range of different exercise interventions is available for which at least some evidence exists, including, e.g., dancing or boxing. But there is also growing practice-based evidence for the merits of exercise interventions such as widely differing as walking football, badminton, or fencing.

Further research is still needed that will provide a better understanding of what types of benefits different exercises provide to specific phenotypes of PD. We also need to know the impact of demographics (age, gender, and educational level) and disease-specific disabilities on the preference for a specific program. Individuals with cognitive impairment will ultimately require programs that include the support of their care partners and that should be delivered by highly skilled professionals with ample experience in working on such complex scenarios. In several studies, the generalization of the interventions to people with cognitive impairment in PD could be more straightforward as most studies exclude people with cognitive impairment at baseline [37]. More funding opportunities are needed to generate research that is adequately designed, sufficiently powered, with a sufficiently long follow-up, and with proper regard for safety issues.

Patient level – Difficulty choosing from a variety of treatment strategies

Therapists and people with PD can currently choose from various treatment strategies based on the specific symptoms they seek to improve and the patient's personal preferences regarding what exercise modality they relate to [27]. This will facilitate a more patient-centered approach, where people with PD and therapists have an evidence-based choice between interventions. Adjusting the treatment according to patient preferences will enhance motivation and increase long-term adherence to therapy. However, different exercise strategies have thus far rarely been compared back-to-back; hence any specific choice should be made cautiously until direct comparisons of the various treatment modalities become available.

Due to the complexity of these many factors, people with PD should be supported by clinicians and other health professionals who can refer people with PD to trustworthy sources of information and good care options, thus facilitating a process of shared decision-making. Awareness campaigns, patient helplines, and associations may help in this regard. Additionally, as I showed in this thesis in **Chapter 7**, some guidance can be achieved through research-based boot camp programs [38]. The boot camp program was considered useful and capable of influencing participants' exercise habits and could thus pave the way to delivering personalized exercise education.Notably, seven out of eight participants referred made changes in their exercise routines one month after. Given the benefits of ongoing exercise in PD and the number of current options, the importance of offering guidance for safe, PD-specific exercise programs for this population should not be underestimated.

People with PD express a desire to become more active in managing their care, obviously with support from healthcare professionals [39]. Active participation of informed people with PD will help them make the right decisions for their health and allow them to work as equal partners with all professionals (medical and non-medical) to achieve optimized results [1, 40]. However, given the recent proliferation of exercise programs (supported by variable levels of evidence), people with PD may find it challenging to make the right choice. Making sense of these programs may also be complicated by the tendency among popular media to promote research results without considering the quality of the study design or the research team's expertise. As a result, specific media sources might highlight a new exercise approach that still needs a more rigorous evidence base, which may be much less effective than initially hoped. For people with PD, this may result in disappointment and blunting enthusiasm for participation in other interventions that could be more beneficial or more directly applicable to their specific context. In addition, financial resources utilized in pursuing less effective or possibly unhelpful exercise approaches will not be available for approaches with a proven track record of benefit.

What additional initiatives can be explored to facilitate choices? We can improve the awareness among people with PD of evidence-based exercise programs and where such programs can be received. At a societal level, there is a need to make clearer strategies available to facilitate the quick dissemination of novel, evidence-based practices into an ever-increasing number of unmonitored community programs. Strong leadership or care models would help maintain patients' trust in clinical practice and long-term adherence. An organized infrastructure (e.g., ParkinsonNet, an innovative Dutch model for network-based allied healthcare for people with PD [41, 42]) could support exercise instructors and other implementers to introduce updated practices and embrace additional changes whenever new evidence emerges. Additionally, raising awareness about these programs increases the public interest in these exercise programs, which will, in turn, influence the course of clinical research and consequently develop clinical practice. Patient associations could be excellent advocates, informing and stimulating people with PD and their families.

Other potential future solutions

Healthcare organizations significantly influence how professionals apply evidence, practice, and assess care outcomes. A particular focus should be placed on building solutions for participation barriers, including financial, traveling, and physical and cultural barriers [1, 32].

First, evidence-based practices should be covered as part of a health insurance benefit. Health systems could deliver or reimburse exercise as part of the overall care strategy, thereby facilitating its use. Second, developing community initiatives (e.g., setting the concept of an exercise bus, creating safe places for exercise, and walking paths that are accessible for parking) to support transportation can be put in place to reduce challenges in access. Third, taking advantage of technology to facilitate access and delivery of specialized care and favor long adherence [43]. Several reports have shown the benefits of telemonitoring and telerehabilitation to provide specialized care to people with PD with difficulty accessing it, particularly during the coronavirus disease 2019 (COVID-19) pandemic [44, 45]. Future studies may look at the potential value of technology to facilitate patient access to telemonitoring and specialized community-based programs in their homes [43] or in community centers with remote trainers [46]. A co-approach combining technology and local in-person care community-based programs, which could be easily implemented in senior centers, is an intuitive example of how technology can facilitate access to experts worldwide. The presence of a person for technical support represents a unique ability to provide a safe, facilitated, and remote intervention. It will also bypass concerns technology raises regarding usability, safety, and compliance in the elderly Parkinson's population [36, 47, 48].

As a parallel solution, patient education initiatives in the use of technology could be helpful. Online exercise programs could always include teaching courses on how to use technology to bypass limitations and barriers in its use in these more vulnerable populations [36]. Both these strategies would allow more people with PD to participate in such programs and access PD expert care.

One of the clinical situations where technology applications deserve particular future interest is monitoring people with PD with cognitive impairment. We should focus on building systems that could assist people with PD with remembering daily activities, tracking medication and exercise compliance, and monitoring their daily behavior for early signs of deterioration, allowing such people to live independently for longer [49-51].

Conclusion

Some changes in thinking within the healthcare community are needed to delineate how community services can better complement current clinical care and to prepare for their integration into the overall management plan for people with PD. These changes require shifting views, changing behaviors, new incentives, and better capacities to support these changes. We should also develop novel models that allow these complementary areas to interact and coordinate effectively.

We need to be more comprehensive in understanding the many heterogeneous factors at play that can interact. Several courses of action may already be possible to address the gap between expertise, evidence, dissemination, and implementation of community exercise practices. I summarize potential actions developed in the thesis and add others needed in Table 1.

Ultimately, people with PD should be encouraged to use safe, evidence-based practices. Such programs must be made available and accessible to the entire community of people with PD to promote better care, improve wellbeing, and ultimately reduce costs to health care systems. Additionally, care should be provided by professionals with PD expertise for better outcomes, reducing unnecessary procedures and avoiding unrealistic expectations in people with PD, particularly for those with less favorable profiles for specific exercises. When successful, improving and favoring community exercise programs with improved quality and safety can complement current healthcare options more beneficially and affordably.

Table 1 | Summary of potential courses of action needed to improve quality community care

Levels	Current Challenge	Potential Actions/Measures	Overall aim
Research level	• Limited evidence for benefits and effective assessment measures.	• Continue to build specific evidence for different disease severity, PD phenotype subpopulations among persons with cognitive impairment, and all practice settings. • Develop research with proper design, sufficient power, and proper regard for safety issues. • Make available more funding opportunities for non-pharmacological interventions.	• Generating evidence to inform best practice
	• Limited translation of the research evidence to practice.	• Define recommendations on how to adapt research studies into practice. • Use trained, clinical Parkinson experts to consistently deliver interventions in experimental studies, with slight variation across practices and under guideline recommendations or research protocols.	• Refine the care strategy and its implementation. Inform future implementation efforts.
Instructor	• Limited expertise among professionals delivering the programs	• Continue to support PD expertise among instructors via specific training, adequate ongoing educational support, and continuous contact with people with PD.	• Provide safe evidenced-based practices (better care). • Reduce unnecessary procedures. • Reduce unrealistic expectations in people with PD, particularly those with less favorable profiles for specific exercises.
Referral level	• Reduced referrals to all professionals	• Raising awareness for clinicians by increasing referrals to professionals applying exercise in PD (physiotherapists, exercise professionals, etc.). • Healthcare models facilitating self-referral to physiotherapy and specialized exercise programs.	• Refer to safe evidenced-based practices (better care). • Increasing knowledge via increased caseload of key professionals. • Facilitating access and reducing logistical dependency and workload on clinicians.
Patient level	• Barriers to participation in specialized exercise	• Implement strategies to bypass common barriers such as fluctuations in health, concerns about safety, time management strategies, culturally appropriate care, insufficiently engaging exercise options, and the use of technology to facilitate access to expert care. • Provide programs that cost less, involve less travel, provide physical or psychological benefits, and are supervised by qualified professionals without needing a direct clinician referral.	• Increase participation • via easy access to safe, cost-free, engaging exercise opportunities by experts.
	• Reduced awareness of such programs as options of care.	• Inform about access to these programs through awareness campaigns for people with PD regarding the existence of evidence-based exercise programs and where such programs can be received.	• Generate informed people with PD who actively participate in making the right decisions for their health.

Table 1 | Continued

Levels	Current Challenge	Potential Actions/Measures	Overall aim
Organizational & societal level	• Slow dissemination of the new evidence-based practices.	• Create an organized infrastructure to provide support to exercise instructors and other implementers to introduce consistently changing practices and embrace additional changes when never new evidence emerges. • Use online communities to disseminate new research findings.	• Facilitate quick, efficient dissemination of new evidence-based practices. • Develop an evidence standard infrastructure for assuring and assessing the implementation of community practice.
	• Access to programs in the community.	• Reduce PD-specific critical barriers to participation: • Traveling barriers with organized community transportation systems (e.g., "exercise bus"). Deliver online services with teaching courses on how to use technology. • Financial barriers via providing affordable services with covered services either through nonprofit, volunteer-run initiatives, or integrated as part of the healthcare systems. Include a community exercise program as a health insurance benefit. • Location barriers via creating safe places to exercise. • Cultural barriers via hiring translators to favor underserved populations.	• Make programs available and accessible to people with PD to promote better care and ultimately reduce overload and costs to health care systems.
	• Reduced public awareness of existing programs in the community.	• Improve public understanding of how to access the most beneficial exercise programs. Role for patient's associations.	• Raise awareness of evidence-based exercise programs to increase public interest in community exercise programs (and influence the direction of clinical research, thus advancing clinical practice).
	• Unmonitored proliferation of programs	• Redefine new care strategy for the health system, defining clear desired outcomes and penalties for imposing practices upon people with PD that are not sufficiently evidence-based, including financial support and limited resources.	• Guarantee safe, effective programs delivered.

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9

Summary in English

General Summary

Part I - Community-based exercise in Parkinson's disease

Chapter 1 - Introduction and Outline of the Thesis

This chapter introduces the concept of community-based exercise programs for people with Parkinson's. It briefly discusses the types of community-based exercise programs used in PD, the limitations in implementing them, and why community-based care is expected to be a valuable addition to our current care models.

Community exercise programs can be defined as using different exercises delivered in a group format, close to persons' homes, in community centers, or local rehabilitation centers, most frequently conducted by non-medical professionals. A wide range of Parkinson-specific community-based programs are currently used in PD. The most common ones that have been studied recently include dance [1-6], Tai Chi [7, 8], Qigong [9], Nordic walking [10-13], boxing [14-16], and aquatic exercise [17-20]. These community-based programs are an essential exercise resource for people with PD for several reasons: they facilitate long-term exercise adherence, improve clinical outcomes and improve satisfaction with healthcare [21]. Providing decentralized exercise opportunities close to participant's homes improves accessibility, reduces transportation needs [22, 23], reduces care partner burden [24], and facilitates a healthcare systems with low-costs to enhance the quality of care [25].

Despite the knowledge of these positive effects, several questions still need better clarification, including: What is the ideal exercise type (and when)? Which type of exercises do people with PD prefer (and why)? What is the role of community programs within current PD care models? What are the benefits, drawbacks, and future needs for implementing (and delivering) such community programs? What actions can be implemented to achieve a greater degree of PD-specific expertise among professionals that apply these programs? How can we support medical referrals to such programs? How can evidence-based community programs be better implemented? How can patients' choices be best supported? Finally, should these programs be considered part of current care models *per se* ororganized outside the care system as an addition to formal care?

This thesis aims to provide a starting point for reflections on the delivery, implementation, necessary expertise, and overall improvement of community exercise care in PD. The underlying problem is described in Chapter 2, identifying the current proliferation of community-based exercise programs with limited evidence and expertise. Chapter 3 discusses how to enhance expertise among professionals based on international educational tools, specifically the European Physiotherapy Guideline for Parkinson's disease. Chapter 4 reflects on improving expertise via increased referrals to non-pharmacological interventions through defining referral criteria based upon internationally recognized guidelines. Next, I explored practicalities regarding implementing community programs for people with PD, focusing on how to implement a community-based exercise boxing program (Chapter 5) and, later, the benefits of adding kicking to a community boxing program in a randomized study (chapter 6). Chapter 7 assesses the usefulness, satisfaction, and preferences of a PD-personalized educational and exercise boot camp program to help people with PD make more informed decisions regarding what type of exercise to choose.

Chapter 2 - Proliferation of community-based exercise programs with limited evidence and expertise: safety implications.

This chapter reflected on two primary safety concerns regarding current community-based exercise programs: (1) limited evidence to support their use and (2) application mostly by professionals without PD expertise. There are reasons to be optimistic that community-based exercise programs may be a long-term, cost-effective, and easily accessible care strategy for ongoing exercise for PD. However, an optimal minimal level of disease-specific expertise is necessary, particularly concerning safely integrating exercises and reducing the risk of falls and other possible safety issues [26, 27]. By prematurely referring people with PD to exercise approaches that are not supported by robust evidence and led by instructors with a lack of PD expertise, we may induce unnecessary procedures, foster unrealistic expectations in people with PD (particularly those with less favorable profiles), and this could ultimately put people with PD at risk of falls and injury. As such, several important questions regarding the specificity of PD and safety issues are now arising that should fuel future research. First, should we obtain more evidence about these community exercise programs and implement them within the community setting, or should we start these programs first, even if little evidence is available? Second, considering the financial considerations, accessibility, safety issues, and the disease's progressive nature, who should implement such community programs? Should physiotherapists incorporate boxing, dance, or tai chi into clinical practice? Or would training exercise instructors who teach community programs be more feasible and equally effective? Safe, evidence-based practices must be a priority for care in all settings, including the community.

We argue that the right initiatives must be put in place in all settings of PD care, including the community, to achieve high-quality, evidence-based care.These initiatives can include enhancing the expertise of the professionals applying such programs and increasing appropriate referrals to improve care. It is critical to enhance expertise among professionals who deliver these exercise programs through specific training, adequate ongoing educational support, and continuous contact with people with PD. In addition, we also need to increase the public and people with PD awareness of evidence-based exercise programs and their locations. Increasing public interest in community exercise programs may also potentially positively influence the direction of clinical research and advance clinical practice. All these actions can begin to guide us away from care disparities and promote better care for people with PD. Without them, no amount of evidence will matter.

Part II - Enhancing Expertise among Professionals

Chapter 3 - Facilitating the dissemination of knowledge: Translation for non-English speaking countries of the European Physiotherapy Guideline for Parkinson's Disease.

In Chapter 4, we provided practical steps to translate the European Physiotherapy Guideline for Parkinson’s Disease published in 2014. This evidence-based guideline was primarily developed to support decision-making for physiotherapy practice in PD. It also informs clinicians about referral criteria for physiotherapy and people with PD regarding self-management. Yet, the use of the European Physiotherapy Guideline for PD is limited in countries where the official language is not English.

We used the translation process of the Portuguese version as an example of how to define the recommended steps for an appropriate translation. A combination of a forward–backward-translation and dual-panel approach was used. Ten recommended translation steps were described: (1) authorization, (2) translation of sample chapter, (3) physiotherapy expert panel review, (4) backward translation, (5) approval by copyright holders, (6) translation of the remaining sections of the guideline, (7) review of the complete translation by an expert panel, (8) review by a user panel, (9) conclude final draft, (10) publication and dissemination. Several adjustments were needed in the Portuguese version, which justifies the need for a detailed and multifaceted translation process.

These steps are needed to guarantee the validity and appropriateness of future translations. The multifaceted procedure outlined in this chapter represents a step forward in the international dissemination effort of evidence-based guidelines in PD aiming to ensure equal access for all people with PD to good quality and specialized care.

Chapter 4 - Improve care by increasing referrals among health professionals.

The management of PD presents many challenges for both people with PD and healthcare professionals. Despite optimal pharmacological treatment, many persons with PD increasingly experience motor and non-motor symptoms [28]. The evidence for non-pharmacological interventions such as physiotherapy is growing, showing a positive impact on functional activities involving gait, transfers, and [26, 29, 30] balance. Specific recommendations for physiotherapists, physicians, and people with PD were published in the European Physiotherapy Guideline for Parkinson's disease. In Chapter 4, we summarized the referral criteria, highlighted the importance of accurate referral to specialized physiotherapists, and emphasized the potential benefits of expert care.

Shortly after the diagnosis, a referral can be considered, mainly for advice on exercise and self-management. For later disease stages, appropriate reasons to consider a referral to physiotherapy include people with PD who express difficulties with transfers, mobility, physical capacity, pain, gait (including freezing), balance, or falls [31-34]. Various types of recommended interventions are available, such as (1) treadmill training, (2) teaching of compensatory strategies (including cueing), (3) training of dual-task performance, and (4) training of active, large amplitude functional-task exercising addressing gait, balance, transfers and physical capacity (e.g., LSVT BIG). There are also community exercises, e.g., dance, Nordic walking, boxing, or Tai Chi, that are recommended for early stages (i.e., upon diagnosis) and upon completion of a physiotherapy treatment period to maintain a status quo or towards the reduced speed of deterioration. Notably, some indications for non-referral may include (1) People with PD with significant active psychiatric problems (for example, severe hallucinations, confusion, persistent depressed mood, or psychosis, etc.) that may be aggravated when doing exercises; (2) Presence of red flags that would motivate interruptions of physiotherapy (i.e., severe cardiovascular impairments, recent pulmonary embolism, etc.); and (3) People with PD that cannot productively participate in physiotherapy according to the referrers judgment.

This chapter offers practical guidance for clinicians working with people with PD who consider physiotherapy treatments for their patients. We hope this will lead to a timelier and more accurate referral of people with PD, allowing them to benefit from the growing menu of evidence-based interventions in this field. The same criteria can also help avoid inadvertent referral of people with PD without a real need for physiotherapy interventions, thereby reducing unnecessary treatments and reserving the sparse resources for people with PD requiring interventions most.

Part III - Implementation of exercise community programs

Chapter 5 - How to implement a community program: Using boxing as an example

People with PD benefit from continuous exercise through participation in community-based exercise programs. However, community programs often lack the PD-specific knowledge needed to provide safe and adequately dosed exercise. This chapter evaluated the acceptability and safety of a PD-specific boxing program implemented in the community.

We described implementing a PD-specific community boxing program as an example of this fast-developing field. We developed specific educational resources to facilitate the boxing instructors. We also organized an educational and practical workshop for people with PD (n = 26) and instructors (n = 10) and assessed: (a) participants' satisfaction; (b) instructors' appreciation of the educational resources; and (c) the number of people with PD interested in participating in the boxing program. After 18 months, people with PD and instructors completed a questionnaire evaluating: (a) participants' satisfaction; (b) adverse events; (c) facilitators and barriers; and (d) the proportion of participants at follow-up. Twenty-six persons with PD (62% men) and ten boxing instructors participated in the workshop. 81% of people with PD and 80% of instructors were very satisfied. Instructors found the educational materials "very helpful" (60%) or "helpful" (40%). People with PD expressed a clear interest (54%) or possible interest (46%) in participating in the program. We initiated classes with 10 participants. At the 18-month follow-up, the program consisted of four boxing sessions/per week, led by three instructors, with 40 participants. Seventeen people with PD responded to the questionnaire at follow-up. Participants were "very satisfied" (53%), "satisfied" (35%), and neither satisfied nor unsatisfied (12%) with the program. Adverse effects were mild (e.g., muscle aches). Transportation and physical disability were the main barriers to participation.

Our findings indicated that the program was well-received and accepted by persons with PD during the initial workshop and at the 18-month follow-up. Initial training for the boxing instructors with a specifically developed toolbox was perceived as useful. It may serve as an example when developing similar programs in current and future boxing classes being delivered in the community.

Chapter 6- Boxing with and without kicking techniques: a pilot randomized controlled trial.

People with PD benefit from non-contact boxing exercises. Adding kicking variations to the boxing may provide additional benefits to improve balance. However, the benefits, acceptability, safety, and adherence to such training are unknown. Here we aimed to explore the feasibility, safety, and potential additional benefit of the balance of boxing training combined with kicking techniques compared to boxing without kicking for people with PD.

Participants were randomized to group-based boxing training with kicking techniques (BK) or to group-based boxing alone training (BO). Both groups trained for one hour once a week for 10 weeks. Participants completed baseline (T0) and ten weeks post-intervention (T1) assessments with blinded assessors. We assessed feasibility and safety. We also explored the effects of both intervention groups. The primary outcome was the difference in balance measured by the Mini Balance Evaluation Systems Test (Mini-BEST) at T1 between both groups. Secondary outcomes included: fear of falling, balance confidence, walking ability, and quality of life.

Twenty-nine people with PD (median age 64 years; median disease duration five years) participated. Both interventions were feasible and acceptable for all participants.No adverse events occurred. Most participants (BK 80%; BO 75%) were satisfied with the training. We found no significant between group difference in either the primary (Mini-BEST) or secondary outcomes. The within group comparison showed that balance improved in both groups after the intervention (BK 22.60 (2.7) to 25.33 (2.64) p= 0.02; BO 23.09 (3.44) to 25.80 (2.39); p= 0.01 on the Mini BEST test).

Our results show that both interventions were feasible, safe, and showed a potential improvement in balance in people with PD. Also, boxing with kicking techniques does not provide additional benefits over boxing training without kicking techniques. Nevertheless, incorporating kicking techniques may be a valuable addition to the exercise therapy repertoire by creating greater versatility and assisting in long-term exercise adherence.

Part IV – Facilitating participation in exercise community programs

Chapter 7 - Guiding Exercise Choices in People with Parkinson's: A Novel Boot Camp Program to Help Guide Personalized Exercise in People with Parkinson's Disease

People with PD are currently encouraged to participate actively in self-management and acquire the exercise tools in their community to manage their disease [35]. Given the variety of exercise programs available for people with PD, individuals may struggle to decide what exercise to perform. Several lines of evidence have suggested that boot camps represent a practical and useful means of teaching [36, 37]. However, few studies have investigated the usefulness of delivering exercise education via boot camps for individuals with PD.

In Chapter 7, we assessed the usefulness, utilization (or how much participants changed their exercise routines and used the knowledge), safety, satisfaction, and preferences regarding participation in a PD-personalized educational and exercise boot camp program to facilitate exercise choice and lifestyle behavior over time. Attendees participated in a four-day program consisting of exercise sessions, workshops, and social activities. We collected demographic, clinical information, and exercise preferences before the program. We assessed satisfaction and preferences immediately after. At the one-month follow-up, participants assessed usefulness and changes in exercise habits. Eight individuals diagnosed with PD, with a mean age of 59.5 ± 6.8 years, participated. All participants perceived the boot camp to be useful. Seven out of eight participants indicated they had made changes in their exercise routines one month after. Moreover, participants reported high satisfaction levels, and there were no severe adverse events. Given the benefits of ongoing exercise in PD and the number of current options, the importance of offering guidance for safe, PD-specific exercise programs for this population cannot be underestimated [38, 39].

Our results suggest that the boot camp program was considered useful and capable of influencing participants' exercise habits and thus could help pave the way forward to delivering personalized exercise education through boot camps.

Part V – Discussion and Summaries

In **Chapters 8, 9 & 10,** the main findings of this thesis were discussed and summarized. I addressed recurring questions regarding enhancing expertise, referrals, implementation methods of community-based programs, and guidance to people with PD. Furthermore, challenges and potential solutions for future research and care initiatives were discussed.

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10

Summary in Dutch

Samenvatting

Deel I - Bewegen bij de ziekte van Parkinson

Hoofdstuk 1 - Inleiding en overzicht van het proefschrift

In dit hoofdstuk wordt het concept van ’community-based exercise’ voor mensen met de Ziekte van Parkinson (ZvP). Geïntroduceerd als groepstraining/ sport buiten het reguliere zorgaanbod. In deze samenvatting gebruik ik hiervoor de termgroepstraining. De volgende onderwerpen komen aan de orde in de inleiding: de soorten groepstrainingen die bij mensen met de ZvP worden gebruikt, de beperkingen bij de uitvoering ervan en waarom groepstrainingen naar verwachting een waardevolle aanvulling zijn op het huidige zorgaanbod.

Bij groepstrainingen worden verschillende oefeningen uitgevoerd in groepsverband. Dit gebeurt over het algemeen dicht bij huis, zoals in een sportcentrum of fysiotherapiepraktijk. Meestal wordt de groepstraining begeleid door niet-medisch geschoolde professionals zoals sporttrainers. Bij de ZvP is er momenteel een groot aanbod aan parkinson-specifieke trainingsprogramma’s, waar onder: dans [1-6], Tai Chi [7, 8], Qigong [9], Nordic Walking [10-13], boksen [14-16] en oefeningen in het water [17-20]. Deze programma’s zijn om verschillende redenen belangrijk voor mensen met de ZvP: ze helpen mensen sporten langdurig vol te houden en resultaten te onderhouden. Bovendien heeft deelname aan groepstrainingen een positieve invloed op de tevredenheid over de gezondheidszorg [21]. Doordat groepstrainingen vaak dicht bij huis worden uitgevoerd, is hulp bij vervoer vaak een minder groot probleem [22, 23] wat wellicht de belasting van de zorgpartner vermindert [24]. Tot slot is het een relatief goedkope manier om om de kwaliteit van de zorg te verbeteren [25].

Ondanks de kennis over deze positieve effecten zijn er nog vele vragen over onder andere wat de beste training is en wanneer deze toegepast moet worden. Ook is het nog onduidelijk aan welk type oefeningen mensen met de ZvP de voorkeur geven (en waarom). Welke voordelen bieden de verschillende oefeningen precies voor specifieke subgroepen van mensen met de ZvP? En, wat is de behoefte aan extra expertise of training van degenen die deze programma’s begeleiden. Kunnen sporttrainers de veiligheid garanderen? Ten slotte, blijft een belangrijke vraag of deze groepstrainingen onderdeel moeten zijn van de zorg, of dat zij buiten het zorgsysteem moeten worden georganiseerd als aanvulling op de formele zorg?

Dit proefschrift biedt een startpunt om discussies te voeren over implementatie, benodigde expertise, evaluatie en algehele verbetering van beweegzorg bij de ZvP. Het onderliggende probleem wordt beschreven in hoofdstuk 2, waarin het huidige aanbod van groepstrainingen wordt besproken. Hoofdstuk 3 gaat over hoe de deskundigheid van professionals verbeterd kan worden met behulp van educatieve materialen zoals de Europese richtlijn voor fysiotherapie bij de ZvP. Hoofdstuk 4 gaat over deskundigheidsbevordering via een toename aan verwijzingen naar fysiotherapie door het vaststellen van verwijzingscriteria op basis van internationaal erkende richtlijnen. Vervolgens onderzocht ik de praktische aspecten van het implementeren van diverse trainingsprogramma's voor mensen met de ZvP. Hoofdstuk 5 gaat over het implementeren van een boksprogramma en hoofdstuk 6 over en de meerwaarde van het toevoegen van trap technieken aan een boksprogramma. De effecten daarvan onderzocht ik in een gerandomiseerde studie (hoofdstuk 6). Hoofdstuk 7, tenslotte, evalueert de meerwaarde, de tevredenheid en de voorkeuren van een bootcamp programma.

Hoofdstuk 2 - Aanbod van groepstrainingen: beperkt bewijs en met expertise vande instructeur: implicaties voor de veiligheid.

In dit hoofdstuk wordt ingegaan op twee belangrijke aspecten van de huidige groepstrainingen: (1) beperkt bewijs ten aanzien van de effectiviteit en (2) de toepassing die meestal plaatsvindt door professionals zonder deskundigheid op het gebied van de ZvP. Er zijn aanwijzingen dat groepstrainingen een langdurige, kosteneffectieve en gemakkelijk toegankelijke strategie zijn om langdurig een actieve leefstijl vol te houden. Echter, enige ziekte specifieke deskundigheid bij de trainer is noodzakelijk om de veiligheid (het voorkomen van vallen) te garanderen [26, 27]. Als mensen met de ZvP verwezen worden naar groepstrainingen waarvoor (nog) geen degelijk bewijs bestaat en die daarnaast worden geleid door instructeurs met een gebrek aan professionele deskundigheid, kunnen onrealistische verwachtingen ontstaan bij mensen met de ZvP en kan dit uiteindelijk ook tot een hoger (val)risico leiden. Daarom moet er meer onderzoek gedaan worden naar de effectiviteit van groepstrainingen. De vraag is of we nieuwe programma's direct moeten implementeren, of dat er eerst meer bewijs beschikbaar moet zijn? Ten tweede is het de vraag wie deze trainingsprogramma's moet begeleiden. Moeten fysiotherapeuten boksen, dansen of tai chi opnemen in hun behandeling ? Of zou het haalbaarder en even effectief zijn om trainers of instructeurs op te leiden om deze groepstraining te geven? Veilige, evidence-based programma's moeten de basis zijn voor de zorg, ook voor groepstrainingen.

Toekomstige initiatieven kunnen bestaan uit het vergroten van de deskundigheid van de professionals die groepstrainingen geven en het vergroten van de juiste verwijzingen vanuit de zorg. Daarnaast moeten we het algemene publiek en mensen met de ZvP beter bekend maken met bewezen effectieve groepstrainingen en aangeven waar zij deze kunnen volgen. Deze initiatieven kunnen bijdragen aan het wegnemen van zorgverschillen en het bevorderen van betere zorg voor mensen met de ZvP.

Deel II - De deskundigheid van professionals vergroten

Hoofdstuk 3 - De verspreiding van kennis bevorderen: Vertaling van de Europese richtlijn voor fysiotherapie bij de ZvP voor niet-Engelstalige landen

In hoofdstuk 4 bespreek ik de manier waaropde in 2014 gepubliceerde Europese richtlijn voor fysiotherapie bij de ZvP te vertaald is. Deze evidence-based richtlijn is primair ontwikkeld ter ondersteuning van de besluitvorming voor de fysiotherapeutische behandeling bij de ZvP. Ook bevat het informatie voor artsen, onder andere over verwijscriteria voor fysiotherapie en voor mensen met de ZvP over zelfmanagement. Het gebruik van de richtlijn is echter nog beperkt in niet Engels sprekend landen.

In dit hoofdstuk gebruik ik het vertaalproces naar het Portugees als voorbeeld voor de aanbevolen stappen voor een adequate vertaling. Er werd een combinatie van een voor-achterwaartse-vertaling en een tweeledige aanpak gebruikt. Er werden tien aanbevolen vertaalstappen beschreven: (1) autorisatie, (2) vertaling van een voorbeeldhoofdstuk, (3) beoordeling door een fysiotherapeutisch expertpanel, (4) achterwaartse vertaling, (5) goedkeuring door auteurs, (6) vertaling van de overige delen van de richtlijn, (7) beoordeling van de volledige vertaling door een expertpanel, (8) beoordeling door een gebruikerspanel, (9) afronding van het definitieve ontwerp, (10) publicatie en verspreiding.

De hier beschreven stappen zijn nodig om de geldigheid en de geschiktheid van toekomstige vertalingen te bevorderen. De in dit hoofdstuk geschetste procedure betekent een stap voorwaarts in de internationale verspreiding van evidence-based richtlijnen voor de ZvP, met als doel gelijke toegang tot gespecialiseerde zorg van hoogwaardige kwaliteit voor alle mensen met de ZvP.

Hoofdstuk 4 - De zorg verbeteren door een toename van verwijzingen

De behandeling van de ZvP gaat gepaard met vele uitdagingen. Ondanks een optimale behandeling met medicijnen krijgen mensen met de ZvP in toenemende mate te maken met motorische en niet-motorische symptomen [28]. Het bewijs voor de meerwaarde niet-farmacologische interventies zoals fysiotherapie neemt toe. We zien onder andere een positief effect op functionele activiteiten zoals lopen, transfers en [26, 29, 30] evenwicht. Specifieke aanbevelingen voor fysiotherapeuten, artsen en mensen met de ZvP werden gepubliceerd in de Europese richtlijn voor fysiotherapie bij de ZvP. In hoofdstuk 4 heb ik de verwijscriteria voor artsen naar fysiotherapie samengevat. In dit hoofdstuk beschrijf ik een richtlijn voor artsen die werken met mensen met de ZvP en die fysiotherapeutische behandelingen voor hun patiënten overwegen. Wij hopen dat dit zal leiden tot een tijdige en adequate verwijzing van mensen met de ZvP naaf de fysiotherapeut. Ook kan door gebruik van deze criteria onnodige behandeling voorkomen worden.

Deel III - Implementatie van groepstrainingen

Hoofdstuk 5 – De implementatie van een groepsprogramma: Boksen als voorbeeld

Mensen met de ZvP hebben er baat bij om voldoende lichaamsbeweging te krijgen en dit langdurig vol te houden. Deelname aan groepstrainingen kan helpen on langdurige actief te blijven Het ontbreekt bij de trainers van deze programma's echter vaak aan de parkinson specifieke kennis die nodig is om veilige en adequaat gedoseerde lichaamsbeweging aan te bieden. Dit hoofdstuk evalueert de uitvoerbaarheid en veiligheid van een boks trainingsprogramma voor mensen met de ZvP.

De implementatie bestond uit de ontwikkeling en het aanbieden van educatieve middelen voor boksinstructeurs en een educatieve en praktische workshop voor zowel mensen met de ZvP (n = 26) als instructeurs (n = 10). We evalueerden dit door te vragen naar: (a) de tevredenheid van de deelnemers; (b) de beoordeling van de instructeurs over de educatieve middelen; en (c) het aantal mensen met de ZvP dat geïnteresseerd was in deelname aan een compleet boks trainingsprogramma. Na 18 maanden vulden deelnemers en instructeurs een vragenlijst in met een evaluatie van: (a) de tevredenheid van de deelnemers; (b) ongewenste voorvallen/ incidenten; (c) bevorderende en belemmerende factoren; en (d) het percentage deelnemers dat nog steeds het boks trainingsprogramma volgde ten tijde van de follow-up. Zesentwintig personen met de ZvP (62% mannen) en tien boksinstructeurs namen deel aan de workshop. 81% van de mensen met de ZvP en 80% van de instructeurs waren zeer tevreden. De instructeurs vonden het lesmateriaal "zeer nuttig" (60%) of "nuttig" (40%). Mensen met de ZvP toonden duidelijk interesse (54%) of mogelijke interesse (46%) in deelname aan het programma. We startten de lessen met 10 deelnemers. Bij de follow-up na 18 maanden bestond het programma uit vier bokssessies per week, geleid door drie instructeurs, met 40 deelnemers. Zeventien deelnemers beantwoordden de vragenlijst bij de follow-up. De deelnemers waren "zeer tevreden" (53%), "tevreden" (35%), en noch tevreden noch ontevreden (12%) over het programma. De gemelde incidenten waren licht (bv. Spierpijn). Problemen met Vvrvoer en lichamelijke beperkingen waren de belangrijkste belemmeringen voor deelname.

Onze bevindingen geven aan dat het programma goed werd ontvangen en geaccepteerd door mensen met de ZvP tijdens de eerste workshop en bij de follow-up na 18 maanden. De initiële training voor de boksinstructeurs met een speciaal ontwikkelde toolbox werd als nuttig ervaren. Dit kan als voorbeeld dienen bij de ontwikkeling van soortgelijke programma's in huidige en toekomstige bokslessen of andere type beweegvormen

Hoofdstuk 6- Boksen met en zonder traptechnieken: een gerandomiseerde studie.

Mensen met de ZvP hebben baat bij non-contact boksoefeningen. Het toevoegen van schoppende variaties aan het boksen kan extra voordelen bieden om het evenwicht te verbeteren. Echter levert dit ook een risico op meer vallen op. De meerwaarde, uitvoerbaarheid, en veiligheid van een dergelijke training zijn nog onbekend. In deze studie onderzochten wij dit door een groep mensen met de ZvP die bokstraining met traptechnieken kreeg te vergelijken met een groep zonder traptechnieken

Deelnemers werden op basis van toeval ingedeeld in twee groepen: groepsgewijze bokstraining met traptechnieken (BK) of groepsgewijze bokstraining zonder traptechnieken (BO). Beide groepen trainden één keer per week gedurende 10 weken. Deelnemers voerden metingen uit bij aanvang (T0) en na tien weken training. (T1). De primaire uitkomst was het verschil in balans gemeten met de Mini Balance Evaluation Systems Test (Mini-BEST) op T1 tussen beide groepen. Secundaire uitkomsten waren: valangst, loopvaardigheid en kwaliteit van leven.

Negenentwintig mensen met de ZvP (mediane leeftijd 64 jaar; mediane ziekteduur vijf jaar) namen deel. Beide trainingen waren haalbaar en aanvaardbaar voor alle deelnemers. Er zijn geen incidenten of complicaties gemeld. De meeste deelnemers (BK 80%; BO 75%) waren tevreden over de training. Wij vonden geen significant verschil tussen de groepen op zowel de primaire (Mini-BEST) als de secundaire uitkomsten. De vergelijking binnen de groep toonde aan dat de balans in beide groepen verbeterde na de interventie (BK 22,60 (2,7) tot 25,33 (2,64) p= 0,02; BO 23,09 (3,44) tot 25,80 (2,39); p= 0,01 op de Mini BEST test). Onze resultaten laten zien dat beide interventies haalbaar en veilig zijn en een potentiële verbetering van het evenwicht geven. Boksen met traptechnieken gaf daarnaast geen extra voordelen in vergelijking met bokstraining zonder traptechnieken. Niettemin kan het inbouwen van traptechnieken een waardevolle aanvulling zijn op het oefentherapeutische repertoire, omdat het een grotere veelzijdigheid creëert en wellicht helpt bij het langdurig volhouden.

Deel IV - Bevordering van deelname aan groepstrainingen door mensen met de ZvP

Hoofdstuk 7 - Begeleiden van het kiezen van de beste training bij mensen met de ZvP: Een nieuw bootcamp-programma

Mensen met de ZvP krijgen het advies om lichamelijk actief te zijn. Sporten door bijvoorbeeld deel te nemen aan parkinson specifieke trainingsprogramma's is een goede optie om dit te bereiken. [35]. Omdat er vele verschillende opties op het gebied van trainingsprogramma's beschikbaar zijn voor mensen met de ZvP, kunnen deze mensen moeite hebben om te beslissen welke training ze willen doen. Het organiseren van een bootcamp waarin mensen kennis kunnen maken met verschillende opties zou een manier kunnen zijn om hierin te ondersteunen. [36, 37]. Hier is echter nog weinig onderzoek naar gedaan.

In hoofdstuk 7 beoordeelden we de meerwaarde, het gebruik (of deelnemers de kennis gebruiken en een – andere- training kiezen),de veiligheid en de tevredenheid van deelnemers aan een bootcamp waarin met verschillende groepstrainingen werd kennis gemaakt. De deelnemers namen deel aan een vierdaags programma bestaande uit oefensessies, workshops en sociale activiteiten. We verzamelden demografische gegevens en trainingsvoorkeuren vóór het programma. Direct na de bootcamp beoordeelden we de tevredenheid en voorkeuren na deelname. Bij de follow-up na één maand beoordeelden de deelnemers de meerwaarde van de bootcamp en de eventuele veranderingen in trainingsgewoontes . Acht personen met de ZvP, met een gemiddelde leeftijd van 59,5 ± 6,8 jaar, namen deel. Alle deelnemers vonden de bootcamp nuttig. Zeven van de acht deelnemers gaven aan dat ze een maand later veranderingen hadden aangebracht in hun training. De deelnemers meldden een hoge mate van tevredenheid, en er waren geen ernstige incidenten of complicaties. Gezien de voordelen van voortdurende lichaamsbeweging bij de ZvP en het aantal huidige opties, kan een dergelijk programma erg zinvol zijn. [38, 39].

Deel V - Discussie en samenvattingen

In de hoofdstukken 8, 9 & 10 zijn de belangrijkste bevindingen van dit proefschrift besproken en samengevat. Ik ging in op terugkerende vragen met betrekking tot het vergroten van expertise, verwijzingen, implementatiemethoden van groepstrainingsprogramma's en de begeleiding van mensen met de ZvP. Verder werden uitdagingen en mogelijke oplossingen voor toekomstig onderzoeks- en zorginitiatieven besproken.

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Appendices

List of publications
PhD Portfolio
Acknowledgments
Curriculum Vitae Summary
Research Data Management
Dissertation of the Donders of
Movement Research Group, Nijmegen

List of Publications

International peer reviewed journals

First Author:

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Poster/Abstracts

International

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Domingos, J.; Godinho, Catarina; John Dean; Katarzyna Smilowska; Melo, Filipe. "Acceptability of a novel trampoline intervention in rehabilitation for Parkinson's disease. Perceived barriers and facilitators (Abstract)". *Journal of Parkinson's Disease* 9 s1 (2019): 134. Poster presented in *5th World Parkinson Congress*, 2019.

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National

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Godinho, Catarina; **Domingos, J**.. "Satisfaction and perceived usefulness of a Boxing group exercise class at the Parkinson Patient Association". Poster presented in *Reunião Anual da Sociedade Portuguesa de Doenças do Movimento*, 2019.

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Godinho, Catarina; Melo, F.; Conde, Monserrat; **Domingos, J.M..** "Hand Motor Slowness in Parkinson Disease Patients performing Fitts Task". Paper presented in *3º International Congress of CiiEM. Research and Innovation in Human & Health Sciences.*, 2018.

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Martins, Inês B.; **Domingos, J**.M.; Godinho, Catarina. "The effect of assistive devices on gait patterns in Parkinson's disease: a pilot study.". Poster presented in *Translational Research and Innovation in Human and Health Sciences. 2nd International Congress of CiiEM.*, 2017.

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PhD portfolio

Name PhD candidate: Josefa Domingos
Graduate School: Donders Graduate School
Supervisors: Prof. dr Bastiaan Bloem, and Prof. Dr. Joaquim Ferreira
Co-supervisor: dr. Nienke de Vries

Courses & Workshops

Course	Organizer	Hours
ParkinsonNet Skills lab. 6-7 Nijmegen, The Netherlands (2018)	ParkinsonNet	14
How to write a scientific paper (2018)	Radboud University	8
Career development workshop "The next step in my career" (2018)	Radboud University	7
Course "Métodos de intervenção neuropsicológica mediada por sistema computorizado: COGWEB®" (2018)	Neuroinova	7
Course "Clinical examination of people with Parkinson's" (2019)	Sociedade Portuguesa Doencas do Movimento	5
MDS-ES Gait Disturbances in PD: What PTs Have To Know. Online (2020)	The International Parkinson and Movement Disorder Society	1
MDS-ES: "Tips and Tricks" in Advanced Deep Brain Stimulation. Online (2020)	The International Parkinson and Movement Disorder Society	1
MDS-AOS Gait and Balance. Online (2021)	The International Parkinson and Movement Disorder Society	1
MDS-ES: The Non Motor Vital Three of Parkinson's Disease. Online (2021)	The International Parkinson and Movement Disorder Society	1
MDS-ES Movement Disorders Emergencies: A Practical Approach. Online (2021)	The International Parkinson and Movement Disorder Society	1
Assessment and Management of Swallowing Difficulty in Parkinson's Disease. Online (2023)	The International Parkinson and Movement Disorder Society	1
MDS-AOS Interdisciplinary Teams and Rehabilitation in Parkinson's Disease and Movement Disorders – Education. Online (2022)	The International Parkinson and Movement Disorder Society	14
A Comprehensive Review of Movement Disorders for the Clinical Practitioner Virtual Aspen Course (2021)	The International Parkinson and Movement Disorder Society	27
Telemedicine for Movement Disorders During the COVID-19. Online (2020)	The International Parkinson and Movement Disorder Society	1
Medication adherence in Parkinson's Disease. Online (2023)	The International Parkinson and Movement Disorder Society	1
MDS Evaluation and Management of Postural Instability and Gait online course (2023)	The International Parkinson and Movement Disorder Society	1
Improving Hospital Stays For Patients with Parkinson's Disease. Online (2023)	The International Parkinson and Movement Disorder Society	1

Conferences & Summer schools

Conference	Location
4th Annual MDS Allied Health Professional Summer School for Physiotherapists (2017)	Newcastle upon Tyne, United Kingdom
1st MDS-ES Summer School for Nurses (2017)	Torres Vedras, Portugal
Freezing of Gait Conference (2018)	Leuven, Belgium
MDS-ES 2nd School for Nurses Involved with PD (2018)	Wales, Great Britain
Insight Summit on World Parkinson's Day. Online(2019)	https://pdwarrior.com/insight/
World Parkinson Congress WPC (2019)	Kyoto, Japan
MDS-ES: Movement Disorders in Neurological and Systemic. Online (2020)	The International Parkinson and Movement Disorder Society.
MDS Virtual Congress of Parkinson's Disease and Movement Disorders (2020)	The International Parkinson and Movement Disorder Society.
Seminar "Until There's a Cure: Living Your Best Life with Parkinson's" Online (2021)	Inova Parkinson and Movement Disorder Center.
MDS Virtual Congress of Parkinson's Disease and Movement Disorders (2021)	The International Parkinson and Movement Disorder Society.
MDS 1st Movement Disorders Clinical Practice Conference – Education. Online (2021)	The International Parkinson and Movement Disorder Society.
When You Care for Someone With Parkinson's. Online (2021)	Inova Parkinson and Movement Disorders Center Conference
Seminar Until There's a Cure: Living Your Best Life with Parkinson's. Online (2021)	Inova Parkinson and Movement Disorder Center
MDS International Congress of Parkinson's Disease and Movement Disorders (Sept 2022)	Madrid, Spain
Conference This Journey We Call Parkinson's. Online (2022)	Inova Parkinson and Movement Disorder Center
Congesso Sociedade Doencas do Movimento (2023)	Lisbon, Portugal
Sunflower Rev It Up for Parkinson's Symposium (2023)	Ohio, USA
6th World Parkinson Congress.	Barcelona, Portugal
MDS International Congress of Parkinson's Disease and Movement Disorders (2023)	Copenhagen, Denmark
Neuroconnect AbbVie Meeting (2023)	Lisbon, Portugal
PD Bial Summit (2023)	Lisbon, Portugal

Teaching activities

Teaching activity	Study program	Duration
Lecturer on "The role of physiotherapy - what a nurse needs to now?" (2017)	1st MDS-ES Summer School for Nurses	1
Lecturer on "The Role of the European Guidelines. Supervising practical workshops. (2017)	4th Annual MDS Allied Health Professional Summer School for Physiotherapists	1
Course director and lecturer: Continuing Education Courses on "Dual cognitive and motor task training in Parkinson's for the interdisciplinary team' in the USA: Las Vegas, NV, Wilkes-Barre, PA Wichita, KS, New York (2019)	Dual-task for Parkinson's Education programs	32
Course director and lecturer: The practicalities of community-based exercise programs in Neurology (2019)	Neurological Congress Brasil	16
Lecturer on "Physiotherapy in Parkinson's disease: clinical implications of current and emerging evidence" (2019)	Movement Disorder Society (MDS) Salvador, Brazil	7
Lecturer on "Practicalities in implementing community-based rehabilitation and exercise programs" REHPA, Knowledge Center for Rehabilitation and Palliation. (2019)	Research Seminar rehabilitation and Parkinson's disease. Nyborg, Denmark	3
Lecturer on "Practicalities of Dual-task training. What when how? "Online (2019)	Insight Summit on World Parkinson's Day	2
Lecturer on "Essential Components of a PD-Specific Exercise Program" Online (2020)	Online INSIGHT Parkinson Conference	1
Lecturer on "Unmet needs for Parkinson's disease" and co-chair of the Symposium - Changing the course of Parkinson's disease: the potential of disease-modifying therapies. Online (2020)	AAT-AD/PD™ Focus Meeting Alzheimer's Disease and Parkinson's Disease conference	4
Course director and lecturer on the 2-day course on "Physiotherapy in Parkinson's." Online (2020)	Malta Parkinson's Disease Association, and Ministry for Health.	16
Lecturer on "How lifestyle choices like exercise, therapy, and eating well make a difference" Online Conference - When You Care for Someone with Parkinson's. (2021)	Inova Parkinson and Movement Disorders Center Conference	1
Lecturer on "Bespoke Exercise for Parkinson's" Online (2021)	Parkinson Foundation of Western Pennsylvania	1
Lecturer on "Dual-task Exercise for Parkinson's" Online Seminar Until There's a Cure: Living Your Best Life with Parkinson's. (2021)	Inova Parkinson and Movement Disorders Center Seminar	1
Lecturer on "Dual-task exercise that combines Movement, Voice, and Cognition". Online (2022)	Michigan Parkinson's Foundation.	1
Lecturer on "The Big Picture of Parkinson's Webinar" Online (2022)	Parkinson Foundation of Western Pennsylvania	1

Teaching activities

Teaching activity	Study program	Duration
Lecturer on "Non-medical treatments: exercise, diet and more" Online (2022)	Inova Parkinson and Movement Disorders Center conference	1
Lecturer on course "Physiotherapy for Parkinson's disease" (2022)	Escola Superior de Saude de Leiria	5
Course director and lecturer at "Specialized Physiotherapy in Parkinson's Course" Porto (2023)	Young Parkies Portugal National Course	16
Lecturer on "Your Plan of Action for diet & exercise" Online (2023)	Inova Parkinson and Movement Disorders Center conference	1
Juri of the opposition for 4th-year students' Projects - Licenciatura em Fisioterapia da Escola Superior de Saúde do Instituto Politécnico de Setúbal (2023)	Instituto Politécnico de Setúbal	4
Lecturer on "Delivering exercise in an online world" (2023)	6th World Parkinson Congress	32
Lecturer on "Stand, Walk, Freeze: Tips to Improve Gait" Online (2023)	Parkinson Foundation of Western Pennsylvania	1
Lecturer on "Setting healthy goals and choices in Parkinson's" Online (2023)	Parkinson Foundation of Western Pennsylvania	1
Lecturer "Dance, Boxing & Other Exercise" Online (2023)	Parkinson Foundation of Western Pennsylvania	1
Lecturer on "Physiotherapy for Parkinson's throughout the world" (2023)	XXI Colóquios de Neurologia Garcia de Orta	1
Lecturer of the topic: Terapêutica não-farmacológica in Parkinson's disease. Online (2023)	Bial Moving On Academy e-learning course of Introduction to Movement Disorders – Parkinson's	4

Committees

Member of the Scientific Committee of the Portuguese Gerontology Society (2012 – Present)

Board member of European Parkinson's Disease Association (2020-Present)

Member of the Davis Phinney Foundation Scientific Board (2021-2023)

Member of Parkinson's Europe Scientific Committee (2019-2023)

Member of the MDS Wellness Task Force (2022-Present)

Board Member & Co-founder of Young Parkies Portugal (2021-Present)

President Parkinson's Europe (2023-Present)

Outreach & Societal impact

Activity	Location
ExerciseCast EPDA European Parkinson Disease Association. Covid exercise response (2020)	https://www.epda.eu.com/exercisecast/
Pos-covid socializing & exercise initiative: Ping-pong exercise program in Parkinson’s (2021)	Lisbon, Portugal
Recently Diagnosed for Parkinson’s. Educational programs Inova Movement Disorder Centre (2021-ongoing)	https://ipmdc.org/recently-diagnosed/
Carepatrtner Tips & Tricks Program. Educational programs Inova Movement Disorder Centre (2021-ongoing)	https://ipmdc.org/care-partner-tips/
Writing content for Young Parkies Portugal (2021-2023)	www.youngparkiesportugal.org
Exercise and Care Partner Parkinson Program – Keep it On Bial (2021-2022)	https://bial-keepiton.pt/
Implement project trampoline training for people with Parkinson’s (Projeto BounceBack). Award Pémio BPI La Caixa Séniores (2022)	Lisbon, Portugal
Implement climbing for young onset Parkinson’s disease (Project ClimbON) Award Roche (2023)	Lisbon, Portugal
Implementation of Exercise Online for Young Onset Parkinson for Young Parkinson Portugal (YPP) (2022-present)	https://www.youngparkiesportugal.org

CV Summary

Josefa Domingos is a Physiotherapist specializing in Parkinson's with almost 20 years of working exclusively with people with Parkinson's & other movement disorders. Josefa's career has focused on creating and implementing specialized care for people living with Parkinson's. In 2005, she played a pivotal role in introducing Parkinson's disease specialized Health Services in Portugal and has since founded numerous specialized services for people with Parkinson's across the country. Her expertise and commitment have significantly impacted the lives of countless individuals within the Parkinson's community.

Josefa Domingos currently holds the position of National Health Coordinator at the Portuguese Parkinson Patient Association (APDPk). Furthermore, she is a co-founder of Young Parkies Portugal (YPP). As an educator, clinician, and researcher, she is currently finishing her Ph.D. on the Practicalities of Community-based exercise in PD at Radboud University Centre (The Netherlands) under the supervision of Prof. Dr. Bas Bloem and Prod. Dr. Joaquim Ferreira.

On an international scale, she has been serving as a board member of Parkinson's Europe (PE) since 2019 and is currently the President of PE. Josefa also contributes her expertise as a member of the scientific committee of the Davis Phinney Foundation and actively participates in the Wellness Group of the Movement Disorder Society (MDS). Her involvement in these esteemed organizations highlights her dedication to advancing Parkinson's research, advocacy, and support both nationally and internationally.

Josefa Domingos is not only an accomplished professional but also the author of several research publications. She is a co-author of the European Guideline for Physiotherapy in Parkinson's Disease (2010-2013). This significant publication was organized by esteemed organizations, including the Royal Dutch Society for Physical Therapy (KNGF), the Association of Physiotherapy in Parkinson’s Disease Europe, and the Movement Disorders Society. Josefa's commitment to staying at the forefront of knowledge and expertise is evident through her consistent pursuit of additional education in specialized Parkinson's courses. Some of these include the Allied Team Training for Parkinson's Disease; LSVT BIG® program; Parkinson Wellness Recovery® training; Mark Morris Dance Group's Dance for PD® Method; Ronnie Gardner

Method®; Boxmaster® training; Boxercise®; Ageing, Physical Activity and Functional Independence graduate course; Aquatic NeuroRehabilitation Halliwick graduate course; Madrid Cognitive Rehabilitation Course and internship; Zumba Fitness and Gold®; MDS DBS Specializing Course; Strong by Zumba®; and Pound Drumming®. Additionally, she has been developing and researching dual-task cognitive and motor exercise programs for PD, adapting this concept to different exercise modalities (in-person & online https://dualtaskforparkinsons.com/). Furthermore, for over 12 years, she has been developing, organizing, and facilitating national and international rehab retreats/boot camps specifically designed for individuals with Parkinson's in Portugal, the UK, Sweden, and the USA.

Internationally, she has participated in several European projects regarding People with Parkinson's, such as Prk Treatment Eurostars Program project: Exercise System for Parkinson continuous treatment and rehabilitation (http://www.parkinsontreatment.eu/); Parkinson Disease Physiotherapy European Guidelines with Royal Dutch Society for Physical Therapy; REMPARK project (Personal Health Device for the Remote Management of Parkinson's Disease). Project funded under the EU Seventh Framework Programme. http://www.rempark.eu/); FP7 funded project SENSE-PARK (2012---2015): Supporting and Empowering Parkinson patients in their home environment using a Novel Sensory information system that monitors daily life- -relevant parameters of Parkinson's disease and their change (www.sense-park.eu); Physiotherapy outcomes multi-center research project in Huntington's disease. European Huntington Disease Network (EHDN); ExerciseCast EPDA (https://www.epda.eu.com/exercisecast/) and keep it On (https://bial-keepiton.com/).

Josefa's commitment to continuous learning and her contributions to various initiatives demonstrate her unwavering dedication to improving the lives of people living with Parkinson's disease.

Acknowledgments

I want to sincerely thank all the people who have been instrumental in supporting and contributing to the successful completion of my PhD journey. First, I am deeply grateful to my PhD supervisors, Prof. dr Bas Bloem and Prof. dr Joaquim Ferreira, for their unwavering guidance, mentorship, and invaluable support throughout this research endeavor. Their expertise and scholarly input have significantly enriched the content and rigor of my study.

I would also like to extend my utmost gratitude to my co supervisor, Prof dr. Nienke de Vries, for her insightful feedback, valuable suggestions, and critical evaluation of my research. Her expertise, encouragement, and constructive feedback have been instrumental in shaping the direction and quality of my work. But above all, this achievement would not have been possible without her kindness, patience, and friendship.

Additionally, I extend my gratitude to my colleagues, friends, family members, and loving husband for their continuous encouragement, understanding, and motivation during the challenging phases of my doctoral journey. Their unwavering support and belief in me have been truly inspiring. Finally, I am thankful to the institution, funding agencies, and research facilities that provided resources, grants, and access to necessary data and equipment for my research.

Lastly, I want to thank all the individuals with Parkinson's who have contributed, regardless of the extent, to my knowledge, friendship, and the support they have shown. Their generosity has been instrumental in helping me successfully complete my Ph.D. journey.

Research Data Management

Ethics, data collection, and storage

Chapters 5, 6, and 7 in this thesis contain experimental data which were conducted in compliance with the Ethical Principles for Medical Research Involving Human Subjects, as defined in the Declaration of Helsinki. Informed consent was obtained from research participants.

For study 5, no randomization was performed, and data were collected during regular care/ practice, so no ethical approval was obtained. Paper (hardcopy) data is stored in cabinets in the department at Egas Moniz - Cooperativa de Ensino Superior, C.R.L, and limited people have access to it. After five years, the data will be destroyed.

For study 6, the study protocol was evaluated by the local Commission Human Research (CMO) Arnhem/Nijmegen (dossier number: 2019-5658). Technical and organizational measures were followed to safeguard the data's availability, integrity, and confidentiality (these measures include independent monitoring, pseudonymization, access authorization, and secure data storage). Data for Chapter 6 was collected through electronic Case Report Forms using CASTOR EDC. From Castor EDC, data was exported to SPSS for analysis. Paper (hardcopy) data is stored in cabinets in the department. The data will be archived for 15 years after termination of the study. Reusing the data for future research is only possible after renewed permission from the participants. The anonymous datasets used for analysis are available from the corresponding author upon reasonable request.

For study 7**,** the study protocol was evaluated by the Institutional Ethics Committee of Egas Moniz Higher School of Health (ID 948; Date: 25/03/2021). Data were collected using online surveys for eight weeks, after which the data were downloaded to a secure location, and the online versions were deleted. The server data was analyzed using Microsoft Excel. Essential documents were archived in a restricted access locked file at Egas Moniz - Cooperativa de Ensino Superior, C.R.L. in a way that ensures that they are readily available, upon request, to the competent authorities. The data will be kept in the file cabinet for a period of five years, after which it will be disposed of. All data is securely locked, and subject information is kept anonymous to maintain confidentiality.

Availability of data

All 3 studies are published with open access. Participants are not named or identified in the publications.

Dissertation of the Donders of Movement Research Group, Nijmegen

616. Van Bentum, G. (2023)
On the localization and segregation of two sounds

615. Shao, S. (2023)
Neuronal and network mechanisms for the emergence of neural computations

614. Zhang, Y. (2023)
Top-down regulation of adaptive sensorimotor control

613. Tosato, T. (2023)
Quantifying and testing for phase-locking in behavioral reports

612. Vreeken, D. (2023)
Obesity and the brain. Improving the brain by losing weight?

611. Afanasyeva, T. (2023)
LCA5- and PCARE-associated retinal disease: from molecular mechanism towards therapeutic intervention

610. Sutter, K. (2023)
Motor planning, control and learning in health and disease

609. Houwen, S. (2023)
Duchenne muscular dystrophy:
Future perspectives

608. Sievers, M. (2023)
Large-scale connectomics in mouse barrel cortex

607. Kausch, B. (2023)

606. Widomska, J. (2023)
Molecular mechanisms underlying Tourette's disorder and obsessive-compulsive disorder: insights from animal and human studies

605. Wang, S. (2023)
Modeling the pathogenesis of neurodevelopmental disorders using human induced pluripotent stem cells: From genetics to cellular phenotypes

604. Braunsdorf, M. (2023)
The temporal lobe and medial wall in social cognition: computations and organisation

603. Tang, Z. (2023)
Deconstructing the Sense of Touch: The Role of Monoamines in Sensorimotor Control

602. Ferreira, J. (2023)
Inflectional encoding in language production: Inhibition and the basal ganglia

601. Ma, F. (2023)
Neural coding of active sensing

600. Algermissen, J. (2023)
On the Origin and Control over Pavlovian Biases in Learning and Decision Making

599. Zach, H. (2023)
Parkinson's tremor: effects of dopamine and cognitive load

598. Stelten, B. (2023)
Cerebrotendinous Xanthomatosis. A treatable inborn error of metabolism

597. Dirven, B. (2023)
The Neurobiological Signature of Susceptibility to Traumatic Stress

596. Lustenhouwer, R. (2023)
Recovery in Neuralgic Amyotrophy: an interplay between peripheral nerve damage, motor dysfunction, and the brain

595. Ras, G. (2023)
Perspectives on Explainable Deep Learning

594. Langwerden, R.C. (2023)
The normalcy of individual differences: Investigating dimensional and hierarchical psychopathology using the MMPI-2-RF

593. de Jong, L. (2023)
Effects of lower limb orthotic devices in people with neurological disorders

592. Gonzales Damatac, C. (2023)
White matter microstructural development in the course of ADHD

591. Meijer, M. (2023)
Epigenetics in externalizing behaviours: linking the environment and genome through epigenetics as a key to understanding externalizing behaviours

590. Conte, F. (2023)
Phosphoglucomutase 1 deficiency: from clinical presentation to sugar metabolism in cell models

589. Rutar, D. (2023)
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