

Implementation of a Community-Based Exercise Program for Parkinson Patients: Using Boxing as an Example

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ABSTRACT

Background

Persons with Parkinson's Disease (PD) benefit from continuous exercise, but compliance remains a critical challenge. One possible solution to promote adherence to exercise is through participation in community-based exercise programs. However, community programs often lack PD-specific knowledge needed to provide safe and adequately dosed exercise programs.

Objective

To evaluate the acceptability of a PD-specific boxing program in the community.

Setting

Community.

Methods

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

Results

Twenty-six persons with PD (62% men) and 10 boxing instructors participated in the workshop. 81% of patients and 80% of instructors were very satisfied with the workshop. Instructors found the educational materials "very helpful" (60%) or "helpful" (40%). Patients expressed a clear interest (54%) or possible interest (46%) in the boxing program. We initiated classes with 10 participants. At 18-months follow-up, the program consisted of four boxing sessions/week, led by three instructors, with an average 40 participants (mean frequency 2 times/week). Seventeen patients (out of 40 participating weekly) responded to the questionnaire at

follow-up. Participants were “very satisfied” (9/17), “satisfied” (6/17) and neither satisfied nor unsatisfied (2/17) with the program. Adverse effects were mild (e.g. muscle aches). Transportation and physical disability were the main barriers for participation.

Conclusions

The community-based boxing program was well-received, with increasing numbers of participants at 18 months. The educational resources can support boxing instructors in future trials to further study the merits of PD-specific boxing classes in the community.

INTRODUCTION

Parkinson’s Disease (PD) is a progressive neurodegenerative movement disorder that has a tremendous impact on activities of daily life 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 a sustained adherence to exercise is through participation in community-based exercise programs. Evidence supporting community-based exercise in persons with PD is growing, e.g. on dance [6,7], boxing [8,9], Nordic walking [10,11], tai chi [12,13], qigong [14] and aquatic exercise [15,16]. Despite these positive effects, implementation of community-based exercise programs is often hampered by limited information about the exact intervention, the delivery mode and lack of specific knowledge about PD that is needed to provide safe and adequately dosed exercise programs tailored to the specific abilities of patients [3,17,18]. Therefore, the extent to which generic exercises in the community can be translated into sustained and safe PD-specific programs remains unclear. As community programs spread globally, fundamental questions arise on how community programs for persons with PD should be implemented.

Boxing is a promising new intervention, shown to be safe and feasible [8] and more effective than conventional group exercise in improving gait velocity and endurance [9]. Recently, a study by [19] showed improvement in quality of life and mobility in 10 older adults with PD with a community-based exercise program (Rock steady boxing) for 11 weeks. Here,

we present the development and implementation of a PD-specific, community-based boxing program and evaluate its acceptability at baseline and 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: development of educational resources, organizing an educational workshop, and 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 [20]; (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 (APPENDIX 1); (2) example of the structure of a PD-specific boxing class (APPENDIX 2); and (3) exercise videos. The Outline consisted of recommendations in the following key areas: (1) in- and exclusion criteria; (2) assessments; (3) boxing goals; (4) general principles 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 for future instructors (certified boxing trainers) and for patients recruited by the local Parkinson Patient Association. The workshop was delivered by an expert physiotherapist with boxing training. Details of the educational sessions for the instructors and patients are shown in (Table 1).

Importantly, care partners and other family members were also invited to participate in both the workshop and the training program to provide support, encouragement and enhance adherence [21].

For the practical boxing session, participants completed an informed consent form and completed two physical tests (Sit to

Stand and Timed-up-and-Go) as a rapid screening of fall risks. The Timed up and go Test [22] provides detailed information on walking speed during functional mobility. A high fall risk is defined, based on the time it takes to perform the test, with a cut-off set at ≥ 13.5 seconds. The Five times Sit to Stand Test [23] is a test that measures the time needed to rise from a 43-centimetre chair. It is used to assess balance when performing transfers. Risk of falling is defined as ≥ 16 seconds. These tests were repeated at the end of the workshop for motivational purposes, but we also report differences scores here, noting that this is only exploratory, as it is unlikely that a single boxing session would lead to very marked changes in outcomes.

At the end of the workshop, patients 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 or 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 [24,25]. Instructors were also asked to rate their level of satisfaction with the workshop (1 = Very

satisfied; 2= Satisfied; 3= Neither satisfied or 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 guarantee personalized support to people at risk of falling. Instructors could contact an expert physiotherapist at any time for clarifications or on any issues related to the program via email or Skype calls (clinical mentorship). After 18 months, we first assessed how many patients started the program and how many were still following the program after 18 months. Second, we studied the acceptability by patients by giving out a questionnaire on: (1) the types of problems that arose during boxing training; (2) satisfaction at 18 months; and (3) the perceived barriers and facilitators for participating in a community boxing program. Finally, we evaluated the number of questions that the instructors asked the expert physiotherapist during the 18 months and their difficulties reported.

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

Educational workshop		
	For boxing Instructors	For people with PD
Main Aim	To deliver effective and safe application of boxing training in PD.	To allow patients to experience the beneficial effects of exercising with boxing and to receive social support from fellow patients.
Actions	(1) A 5-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 patients.	(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 trainings. (2) An 1 hour boxing session led by physiotherapist with support from boxing instructors.
Safety Notes	Assessing fall risk and preventing falls was strongly reinforced and instructors were taught to identify patients at risk with a brief assessment using: history of falls in the past 12 months and the Timed Up & Go test (TUG) [3].	Before the boxing session, patients gave informed consent for participation, were asked if they had fallen in the last 12 months and completed the TUG test for a quick screening of fall risk. Patients identified at risk of falling were provided with additional support by boxing instructors, care partners or volunteers (60+ aged non-PD boxing training participants).

RESULTS

Educational workshop

Twenty-six persons with PD (62% men) and 10 boxing instructors participated in the workshop. Three sessions with patients were organized (3 groups with ≤ 10 patients). All

participants ambulated independently, however, 3 (3/26; 12%) patients had an increased risk of falling based on the fall screening (Table 2). To reduce the fall risk during the workshop, each of these patients was supported by a volunteer.

Table 2: 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)	Sit-to-stand post	TUG pre (risk if) score ≥ 13.5 seconds	TUG post
1	0	10.82	8.22	6.02	4.54
2	0	6.8	5.52	6.3	4.78
3	0	8.37	7.55	6.5	Missing
4	0	12.63	8.4	8.05	7.45
5	0	13.33	9.2	9.43	Missing
6	0	11.43	10.53	7.88	6.69
7	1	12.1	9.71	14.26	8
8	0	7.61	5.28	5.86	5.63
9	0	15.21	12.31	9.15	8.41
10	0	13.06	11.2	9.23	7.55
11	0	13.43	Missing	9.65	8.33
12	0	6.73	6.19	7.48	6.75
13	1	15.86	8.26	13.53	8.21
14	0	7.6	6.1	7.26	5.38
15	0	10.61	8.96	9.09	7.18
16	0	8.56	6.8	6.35	5.66
17	0	9.35	8.45	7.38	6.81
18	0	7.91	6.45	6.78	5.4
19	0	9.38	6.15	6.36	5.1
20	0	6.76	5.7	4.48	5.03
21	0	11.28	11.3	6.34	7.98
22	0	12.05	10.11	9.87	10.91
23	0	6.43	5.81	6.38	5
24	1	11.41	9.16	13.92	7.58
25	0	6.91	7.3	6.08	6
26	0	6.3	7.6	5.81	7
		Mean = 10.07 (SD+/-2.86)"	Mean = 8.10 (SD+/-2.09)"	Mean = 8.05 (SD+/-2.57)	Mean = 6.75 (SD+/-1.49)

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

without any serious adverse events, except for one patient experiencing anxiety while coming down 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 general sense of safety.

Eight instructors were (8/10; 80%) "very satisfied" with the workshop and two were "satisfied" (2/2-; 10%). Instructors found the educational resources either "helpful" (4/10; 40%) or "very helpful" (6/10; 60%). They also identified some concerns regarding their lack of PD-specific expertise and on

how to help patients navigate through difficult environments, such as the stairs.

18-month follow-up assessment

The boxing program (Narva Boxningsklubb) initiated twice weekly PD boxing classes one week after the workshop with 10 out of the 26 patients participating in the workshop (38%). At 18-month follow-up, the program consisted of four boxing sessions per week with an average of 40 patients per week (mean frequency of 2 times per week per participant). Eight of the 10 patients that initially participated in the workshop, still followed the boxing classes (80%). Three out of the 10 trained instructors (30%) led the local classes; the others had meanwhile begun to participate in 13 other boxing classes across Sweden, serving up to 250 PD patients.

Seventeen participants (out of 40 participating) and all

instructors responded to the follow-up questionnaires. Participants indicated that they were very satisfied (9/17), satisfied (6/17) and neither satisfied nor unsatisfied (2/17). None of the participants were unsatisfied. Self-reported problems, facilitators and barriers are presented in (Table 3). Transportation and physical disability were the most common barriers and facilitators reported. During the 18 months, the expert physiotherapist was consulted twice by instructors regarding training intensity and potential new activities. At follow-up, instructors reported that (a) no major problems were encountered during the sessions; (b) patients needed to be monitored continuously (especially in transition to exercise stations), and (c) some participants needed more assistance and time for learning than others.

Table 3: 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 trainings	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 helps'	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

DISCUSSION

PD-specific community exercise programs have recently gained considerable attention as a means 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 at baseline and at 18-month 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 that is gaining popularity within the PD community [8,9]. Apart from being satisfied with the workshop, 38% of patients started the program immediately after the workshop, and 40 patients took part in the program at 18 months follow-up. These results are in agreement with other studies showing a desire to participate in PD-specific community exercise programs [26]. Together with already published preliminary evidence on the safety, feasibility and effectiveness of boxing to improve balance, mobility and endurance, boxing is consistently highly appreciated by participants in all these studies [8,9]. Additionally, boxing might also improve cognition through its aerobic and cognitively demanding components (for example, memorizing the boxing combinations) [27,28]. Given the importance of cognitive processes in maintaining balance and reducing falls, boxing programs such as community program tested here may be useful in managing these problems in PD [29,30].

Second, we believe that the collaboration between physiotherapist/clinicians and boxing instructors played a significant role in the success of this program. Instructors initially highlighted concerns about their lack of knowledge about PD and were keen to learn. The workshop allowed them to learn about the typical signs and symptoms of PD. We believe that just as for physiotherapists [25,31,32], PD-specific expertise among boxing instructors will improve the benefits and safety of the exercise program. This expertise also enables them to recognize limitations and warrant adequate referral to

appropriate healthcare professionals when necessary [3,33]. We believe that involving boxing instructors, physiotherapists and patients in developing educational resources enhanced their usability.

Third, providing a workshop for patients may have positively contributed to motivate them to participate in the program [34,35]. This session was designed to inform participants about the benefits of boxing as 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 were able to perform the exercises and tasks, increasing self-efficacy [36,37]. Participants were assessed for fall risk to guarantee additional support to those at risk of falling during the workshop (a strategy that was reinforced to boxing instructors to use for future inclusion and safety issues). Even though we did not aim to study effectiveness, reassessments of the Timed-up-and-Go and sit to stand were performed at the end of the workshop. All participants showed improvement after the workshop (Table 2). This is in line with other studies showing that people with PD have the potential for short-term motor skill adaptation. For example, the study by [38] where walking patterns were recorded pre and post dual task training and which showed positive improvements on the recorded gait variables. The involvement of care partners was perceived to be helpful and was even suggested by patients to improve future attendance. Also, the disease-specific and boxing knowledge of the leading physiotherapist allowed for adequate replies to all questions, adaptation of the exercises to the groups' needs and quick action on problems that arose. All of these environmental aspects may have contributed to overall patient satisfaction and motivation for future adherence. Similarly, in a study on dancing, persons with Parkinson disease perceived teaching methods and environmental factors as the most relevant facilitating factors when undertaking a dance class [39]. Implementing the program was 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 [35,40]. At 18 months follow-up, several barriers and facilitators for participation were identified, mainly related to transportation, class time, physical disabilities, and the content of the program

(e.g. not being personalized enough). This is in line with previous research on barriers and facilitators for exercise in PD [35,40,41]. 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 ability to drive, further complicating the problem. Travel support (possibly via volunteer initiatives) could help reduce this barrier. Also smaller group sizes with the opportunity for more personalized approaches and adjustment of scheduled class times that are more appropriate for patients who are still working may further improve the program. Additionally, we included participants that self-enrolled through the Parkinson Association, possibly creating a bias in the types of patients that participated. Referrals from other sources (e.g. physicians, physiotherapist, and advocacy institutions) can be guided by specific referral criteria that promote integration of patients subgroups that may better benefit [33]. Notably, even though 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 guaranteed safety to individuals with risk of falling and this strategy could also be applicable to people with cognitive impairment. This might constitute an important future line of research. Further research remains needed to test the (cost-) effectiveness of this program in a randomized controlled trial. Finally, a detailed process analysis may help to better understand the reasons for not attending, who to include, when the patients start getting better, what ongoing teaching methods to use and how to assess the continuous educational needs of instructors. These assessments are not only relevant to assess the program implementation and to provide feedback to participants, but also to show a benefit to those providing funding for such programs.

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Bastiaan R. Bloem currently serves as Associate Editor for the Journal of Parkinson's disease, has received honoraria from serving on the scientific advisory board for Zambon and

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