Title: A pilot study of a minimally supervised home exercise and walking program for people with Parkinson's disease in Jordan

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Abstract

Purpose: This study aimed to evaluate the feasibility and cultural considerations of a minimally-supervised, home-based exercise program in Jordan.

Methods: Quantitative and qualitative approaches were used. Thirty participants were randomly allocated to either an 8 week intervention group (n=16), or a standard care group (n=14). The intervention incorporated the home use of an exercise DVD, walking program, and initial instructional sessions and weekly phone calls provided by a physiotherapist. Interviews were used to explore feasibility. Unified Parkinson's disease Rating Scale (UPDRS-III); balance and walking speed were assessed.

Results: The retention rate was 86.7% and mean adherence rate was 77%. Personal and socio-cultural barriers of adherence to the exercise program were identified. UPDRS-III at follow up was lower in the intervention group.

Conclusions: A home exercise program was feasible. Socio-cultural barriers specific to Arabic culture may affect the uptake of such an intervention in PD in these countries.

Key words: Parkinson's disease, DVD, social support, adherence
INTRODUCTION

The benefits of physiotherapy in Parkinson's disease (PD) are well documented [1, 2], and studies have shown that intervention can improve motor symptoms, particularly mobility and balance [1]. The vast majority of these studies, however, have been supervised intervention programs [1, 2]. While these programs might be desirable, they come with some shortfalls. For example, attending these programs regularly can be time-consuming and difficult, especially for patients with significant mobility limitations as per PD [3]. In developing countries, the multiple cultural, financial, and environmental constraints add to the complexity of patient adherence to clinic-based physiotherapy programs. In Jordan, as in other developing countries, rehabilitation centres are often located in urban areas. The long-distance travelling coupled with inadequate public transport system makes clinic-based programs inaccessible to many rural area residences[4].

Home-based exercises have emerged as being feasible and beneficial for patients with PD[5-7][8], with potentially minimal financial requirements. A recent study, however, has suggested that home exercise may be the least effective approach in delivering exercise to people with PD, compared to supervised individual and group exercise[9]. In this study, the home programs were completely unsupervised; this lack of supervision as well as the non-progression of exercises were two factors that likely contributed to lack of improvement in the home exercise group [9, 10]. For people with complex neurologic diseases such as PD, at least some degree of supervision would seem to be important to facilitate uptake and adherence.

Many barriers may prevent people with PD from participating in these programs [3, 11, 12]. These include low self-efficacy, fear of falls, low outcome expectations, and lack of time. It should be noted, however, that the available evidence regarding barriers to exercise is largely based on information obtained from developed countries. There is very limited
reported literature about people with PD in the developing countries and the provision of physiotherapy services. In developing countries such as Jordan, many cultural factors including value of dependence versus interdependence on family members, religious, financial and social factors, and differences in healthcare and social systems impose a further challenge on the delivery of exercise interventions for people with chronic neurological conditions [13]. Thus, finding low-cost and broad reaching approaches to facilitate patients’ adherence to independent exercise programs is needed.

Exercise training utilizing a DVD may be one approach to achieve this goal. Evidence suggests that the use of an exercise DVD has a positive effect on increasing adherence to self-supervised exercise programs in the elderly [14, 15]. In addition, promoting community walking can be another low-cost approach to achieve this target. Though people with PD are known to have walking challenges [16], studies have shown they can benefit from participating in a regular community walking program [17, 18]. Community walking is an important enabler to participation in community activities and a range of societal, work, and leisure roles, and research evaluating the effectiveness of implementing such programs is needed [18].

This pilot study used both quantitative and qualitative approaches to evaluate the feasibility, acceptability, and cultural considerations of a walking program and a minimally-supervised home-based exercise augmented with the use of an exercise DVD in people with PD in Jordan. Particularly, cultural specifications, challenges, and enablers in participation in home-based exercise program, in Arab ethnicity who live in Jordan, were explored.
METHOD

Study design and setting

This pilot intervention study was undertaken in community dwelling people with PD who live in Jordan. We compared two groups: an intervention group who completed 8 week of home based exercise and walking program and a standard care group (i.e. routine care). In Jordan, usual care for patients with PD does not include any specific physiotherapy related interventions (i.e., physiotherapy is not yet routinely prescribed) [13]. Participants were randomly allocated to one of the two groups after baseline assessment. Participants in the control group were asked to continue as normal (usual care) and they were asked not to change their routine in terms of exercise and physical activity during the period of the study. Participants in the control group were offered the intervention at the end of the study.

Recruitment

Participants were recruited from two hospitals in Jordan: King Abdulla University Hospital (KAUH) and Princess Basma Hospital (PBH). Sequential PD patients attending routine neurology clinic appointments at these two hospitals between November 2013 and March 2015 were screened for eligibility by a neurology consultant. Eligible subjects were invited to participate in the study. Inclusion criteria were 1) diagnosis of idiopathic PD, confirmed by neurologist examination, 2) capacity to give informed consent, 3) modified Hoehn and Yahr Stage 1 to 4 during the on stage of medication, and 4) maintaining a stable medical regime for 3 weeks prior to initiation of study. Exclusion criteria were 1) presence of an unstable medical condition, 2) presence of other disorders that may affect balance (e.g. head injury and stroke), and 3) any medical or musculoskeletal condition that would interfere with the safe conduct of the exercise intervention. All participants gave a written informed consent approved from the Institutional Research Committees of Jordan.
Outcome assessments

All participants in the intervention group who completed the study were interviewed to determine acceptability of the intervention and in particular to identify cultural barriers and enablers to participate in the program (Appendix 1). All interviews were audio recorded and were transcribed by one researcher. The transcripts were coded into categories using a content thematic analysis approach [19] by two independent researchers. Team discussion between the two researchers verified these thematic categories (peer checking) [20]. Finally, codes were sent back to all participants asking them to read and validate the identified themes (member checking) [20]. Transcripts were prepared in Arabic, illustrative quotes for the purposes of this paper were translated into English.

Feasibility was determined by recruitment, retention and adherence rates. Recruitment rate was calculated as the percentage of subjects who completed the baseline assessment relative to those who were eligible to participate in the study. Retention rate was calculated as the percentage of participants who completed the follow-up assessment relative to those who completed the baseline assessment. Adherence rate was determined as the percentage of completed exercise sessions. Adherence to home-based exercise sessions was obtained from the exercise diaries and was also cross-checked during the weekly phone calls. Safety of the intervention was monitored during the supervised sessions and during the weekly phone calls and was assessed using standard procedures whereby events were classified into serious, related and unrelated [21].

Additionally, participants were assessed by a blinded assessor at baseline and 8 weeks later on a range of outcome measures that were chosen to reflect the range of impairments and activity limitations seen in people with PD and also due to their high test re-test reliability in
this population [22]. All outcome measures apart from the Movement Disorders Society-Unified Parkinson's Disease Rating scale (MDS-UPDRS)-Part III were conducted by one physiotherapist who received training on conducting the assessments as per standard operating procedure. The MDS-UPDRS-Part III[23]was assessed by a neurologist who was also blinded to group allocations. Other outcomes included measures of walking speed, balance, fear of falls and function. The 10- Meter Walk Test (10-MWT)[22, 24]was used to record comfortable walking speed. The 6- Minute Walk Test (6-MWT)[22, 25] provided a measure of functional capacity of participants while the 30-second chair stand test (30CST)[26, 27] assessed functional lower extremity strength. The Mini-Best Test[28] was used to assess balance. The falls efficacy scale (FES) [29-31] provided a measure of participants' perception of balance and fear of falls. The physical performance test (PPT)[32] was used as a measure of function. All tests were administered in a standardized manner; order of tests was kept the same within individuals for baseline and follow-up assessments. All assessment sessions were conducted in the morning during the peak effect L-dopa medication to avoid problems related to ”on-off” statements that can be seen in patients with PD.

**Randomisation:**

Randomisation was performed by an investigator who was not involved in recruitment or assessments to ensure allocation concealment. Randomization was performed using a minimization procedure [33, 34] to ensure balance between the groups for confounding variables including age and disease severity as measured using the Movement Disorder Society-Unified Parkinson's Disease Rating Scale (MDS-UPDRS)-motor score [23]. These two factors were treated equally (i.e. both age and disease severity were given the same weighting during the minimization procedure). Age was classified into six categories as follows: 1) less than 30; 2) between 30 and 39; 3) between 40 and 49; 4) between 50 and 59;
5) between 60 and 69; 6) more than 69. Similarly, the MDS-UPDRS motor score [23] was classified into three categories: 1) MDS-UPDRS scores correspond to mild stage (0-35); 2) MDS-UPDRS scores correspond to moderate stage (36-58); 3) MDS-UPDRS correspond to severe stage (>59).

**Intervention**

The intervention focused on the home use of an exercise DVD that was specifically developed for people with movement disorders including people with Parkinson's disease (PD) and Huntington's Disease (HD) and available in Arabic. Details of the exercise DVD and its content are published elsewhere[35]. In brief, this DVD focuses on the main components of fitness introduced by an acting lady and a gentleman in five main sections. The first section is focused on warm up and flexibility activities; the second, third and fourth sections focus on strength, flexibility, balance and endurance exercises specifically tailored for people with PD, and training on performing functional tasks of sit to stand, stepping up onto stairs, and getting on and off the floor; and the fifth section focuses on relaxation, stretching and breathing techniques. In addition to these main three sections, the DVD includes a list of precautions, equipment required and postural instructions.

During the study period, the intervention group were instructed to perform the exercises three times a week using the exercise DVD and **one walking session weekly** over a period of 8 weeks (Figure 1). During the first 4 weeks, participants received eight instructional sessions in the clinic from a physiotherapist (HK) (i.e. for the first four weeks, two weekly sessions performed with the therapist and one weekly session performed independently by participants at home). This means that in total 25% of the prescribed sessions (eight out of 32 sessions) were supervised. In these sessions participants were introduced to all exercises in the exercise DVD; the therapist observed the participant while performing the exercises and provided feedback whenever was needed. In addition, potential
benefits and risks of performing the exercises were discussed. During these instructional
sessions, participants were also instructed how to progress their exercises by gradually
increasing the number of repetitions while decreasing the number and length of rest breaks
and increasing the level of exercise progression. For the remaining four weeks, participants
were asked to perform the three exercise sessions independently at home. Each participant
received a weekly phone call from the therapist to ask about the frequency, difficulties, and
concerns of performing the exercises.

In addition to the exercise DVD, participants were asked to follow a walking program
once a week for 45 minutes. They were instructed in use of the Borg CR10 Rating of
Perceived Exertion (RPE) scale[36] for self-monitoring of walking intensity. Participants
were encouraged to progress their weekly walks by decreasing the number of breaks and
increasing the intensity toward a moderate (i.e. 3-4) level using the Borg CR10 RPE scale.
Participants in the intervention group were asked to keep an exercise diary (Appendix 2).

**Statistical analysis**

As a pilot study, formal sample size calculations were not made. We aimed to recruit
30 participants. **Changes in outcomes at the follow-up scores for between group
differences were computed using analysis of covariance (ANCOVA) controlling for
baseline differences. Results are summarized using regression coefficients and 95%
confidence intervals (95% CI). Effect sizes of all outcomes were also computed based on
the difference in the change score from base line to follow up. Confidence intervals and
effect sizes for each outcome were used to provide an indication of benefit.**

To aid data interpretation, scatter plots of individual responses, scores at baseline and
the change scores were plotted for the primary outcome (MDS-UPDRS-motor
score). **Qualitative data** from those in the intervention group who had a change score larger
than the minimal detectable change (MDC) (i.e. those who responded to the intervention) on
the primary outcome were explored (MDC on UPDRS motor score is -11) [22].

**RESULTS**

**Study Feasibility:**

Of the 108 consecutive individuals screened for potential recruitment for the study, 28
(25.9%) did not meet inclusion criteria, 35 (43.8%) declined participation, and 15 (13.8%)
could not be reached by the research team as their phone numbers were not in service. Thirty
participants were recruited into the study with a recruitment rate of 37.5% (i.e. recruits from
eligible participants) (Figure 2).

![Insert Figure 2 here]

Sixteen participants were allocated to the intervention group and 14 to the control
group (Figure 2). Fifteen participants in the intervention and 11 in the control group
completed the study (retention rate of 86.7%). The mean adherence rate (SD) to the exercise
program in the intervention group was 77% (23.2) of the total 32 prescribed sessions.

No serious adverse events were recorded during the study; however, six of the 15
participants in the intervention group reported that they experienced some pain that had lasted
for more than 24 hours during the first weeks of the program. This included transient neck
pain or low back pain related to existing cervical or lumbar disk and knee pain due to
osteoarthritis. In all cases, the pain was resolved by modifying the exercise and no further
intervention for pain management was required. Increased dystonia on exercise initiation was
reported by one participant. This increase in dystonia limited the subject from performing
certain exercises. It also triggered shoulder, hip and knee pain. Pain in this case resolved by
modifying some of the exercises and by using over-counter pain killers.

Characteristics of the participants are shown in Table 1. At the follow up assessment,
scores on the MDS-UPDRS-motor score (mean difference -13.5; 95% CI -25.3 to -1.7) and
the falls efficacy scale (mean difference -11.7; 95% CI -19.8 to 0.3) were improved for those in the intervention group in comparison to the control group (Table 2).

<Insert Table 1 here>

<Insert Table 2 here>

Figure 3 shows the baseline scores for each participant plotted against the change scores, categorized by group allocation, for the MDS-UPDRS- motor score. The participants in the intervention group who demonstrated a change score larger than the MDC [22] were identified (n=9).

<Insert Figure 3 here>

**Acceptability:**

Adherence details for each participant are provided in Table 3. An over-riding theme that emerged was the overall satisfaction of those who adhered with the exercise program. Most of the participants felt that the exercise sessions were the right length and the right frequency (73.3%). Participants expressed strong desire to continue exercises at home in the future (86.5%). Data revealed enablers and challenges to engaging in the exercise program. Enablers included the use of the exercise DVD itself, perceived improvement, continuous monitoring, social interaction and relation with the therapist, and family support. The challenges fell into two main categories: personal and socio-cultural factors. Personal factors included co-morbidities, disease-specific factors including fatigue and depression, lack of time, lack of outcome expectations and denial of PD diagnosis. Socio-cultural factors included stigma. The results from the thematic analysis of the interviews with description of the categorical codes and illustrative quotes are provided in Table 4 below.

<Insert Table 3 here>

<Insert Table 4 here>
Overall, the MDS-UPDRS decreased by >11 points in 64.3% of the participants in the intervention group (i.e. 9 participants in the intervention group had a change score in MDS-UPDRS that was larger than MDS) (see Figure 2). Qualitative feedback indicated that most of these responders performed exercises in frequencies that were even higher to that originally prescribed (average adherence rate was 96%). For example, in some cases participants reported daily walking for at least 30 minutes after being introduced to the intervention. Additionally, in one case, the participant reported returning back to his favourite sport, Karate. In contrast, the participants who achieved <11 points improvement in the MDS-UPDRS motor score (i.e. the none-responders (n=4/5)), reported <75% adherence rate on average.

**DISCUSSION**

The DVD-home-based exercise program utilized in this study was feasible and engaging, with high recruitment, retention and compliance rates and low adverse events. The intervention was generally well-tolerated with participants who had a high adherence rate reporting high satisfaction levels with all aspects of the program. Additionally, MDS-UPDRS-motor score and the falls efficacy scale improved in the intervention versus the control groups. Given its low-cost, the results suggest the program broad usability for people with PD in developing countries including the Arabic-speaking countries and for Arabic speakers living in non-Arabic speaking countries.

Although most participants managed to adhere to the intervention, a number of challenges that could impact adherence to the home-based program were reported. Generally, lack of adherence was common among participants who were at early stage of the disease. The lack of adherence in these cases was mainly due to some socio-cultural issues related to the disease and exercising stigmatization. Firstly, some patients
were worried to be stigmatized for being diagnosed with PD, even by family members. Family members of two participants didn’t know about the PD diagnosis. Thus, these participants didn’t exercise at home as they did not want to attract attention and to explain about their performance of the exercises at home. One participant believed that exercising was not suitable for “older” individuals. It should be noted that these issues might be particularly important in countries with a gap in knowledge about the known role of exercise in managing PD symptoms [13]. Additionally the lack of “habitual” exercise and physical activity, which might be considered a socio-cultural phenomenon that also affects the general population could contribute to this stigmatization in PD [37]. Overall, this data indicate that the location of the exercise is an important consideration when recommending exercise to people with PD. While home-based exercise program may be appropriate for some people with PD, center-based exercise program may still be preferable for others who have such barriers that would limit their adherence to home exercises. Additionally, it might be important to educate patients and family members about exercise benefits, particularly in the early stages, to enhance exercise adherence [38].

Conversely, participants generally viewed the DVD format as an enabler, reinforcing the individual’s capability to engage in unsupervised exercises at home. Additionally, participants’ feedback suggests that initial supervised instructional sessions, the routine support calls, and the DVD itself were all factors that helped in minimizing attrition. Additionally, these care-provider contributions might have mitigated the adverse events associated with exercise, mainly pain and fear of falling, thus enhancing engagement. These elements of the intervention seemed to target known barriers to exercise in the PD population, including low self-efficacy [11, 12]. This close monitoring at initial stages of a home-based exercise program may be even more needed for PD patients from Arab ethnicity
who live in developing countries as they would usually lack informational support about exercise and lack of past "habit" of being active [39].

Future studies in this area should consider the dose and intensity of the exercise program. Qualitative feedback indicated that the improvement in the responders (i.e. those who had a change score on the MDS-UPDRS that was larger than MDS) can be partly explained by their adherence to the intervention. Most of the responders performed exercises in frequencies that were even higher to originally prescribed to them while the non-responders reported <75% adherence rate on average. These observations suggest that people with PD may need to be encouraged to supplement the DVD activities with additional exercises including walking, thus achieve optimal benefits. Overall, due to the small sample size in this study, this observation should be interpreted with some caution.

Responders to intervention in this study may have been more empowered and motivated to engage in exercise. As per the qualitative feedback, participants in the intervention group and in particular the responders expressed that for the first time they felt that "someone is taking care of them". This was perceived as one of the main motivators to adhere to the program. This might appear as a potential Hawthorne effect (i.e. increased adherence due to extra attention and human interaction) [40]. However, it also indicates that social support provided by healthcare professionals is important for the initial adoption and maintenance of self-supervised exercise programs in this population. This may be of particular consideration for people with PD who live in a developing country as lack of support provided by health-care professionals and organisations was recognised by patients themselves as one of the unmet needs [13].

This work is not without limitation. For example, aspects related to phone calls and time spent with therapists was not controlled for in the current study. Future studies
controlling for these factors to minimize the possibility of Hawthorne effect is warranted. Also no retrospective blinding check was performed. However, every possible effort was made during the conduct of the study to ensure its concealment. The intervention has multiple components (i.e. DVD exercise and walking program) so it is difficult to differentiate their effects. Additionally, the intervention was of short duration (8 weeks) with no longer periods of follow-up. Given the challenges usually associated with long-term exercise interventions; future studies are needed to examine the sustainability of adherence and benefits beyond the program period and during longer interventions. Future studies also are important to understand barriers, facilitators and cultural considerations that affect exercise participation in the long term in this population.

Summary points:

- A community walking program and a minimally supervised home-based exercise augmented with the DVD use was perceived to be suitable and feasible in people with PD.

- Specific socio-cultural barriers, may affect the uptake of such intervention in Arabic culture in developing countries.

- There is a need to identify socio-cultural barriers when prescribing these programs to people with PD in the developing countries.

- The home-based intervention used in this study may increase accessibility to exercise interventions by addressing major barriers to exercise in people with PD in developing countries, including cost and mobility restrictions.

- Future studies are needed to examine the sustainability of adherence and benefits beyond the program period and during longer interventions.
Future studies also are important to understand barriers, facilitators and cultural considerations that affect exercise participation in the long term in this population.

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Conflict of interest and source of funding: This study has received funding support from Jordan University of Science and Technology. Authors have nothing to declare in relation to the submitted work.
Figure 1: The distribution of the prescribed sessions of the intervention (n=32) over 8 weeks

1st set
(first four weeks)

2 exercise sessions per week using the DVD with a therapist

One exercise session using the DVD per week performed at home independently

One walking session per week

2nd set
(remaining 4 weeks)

3 exercise session using the DVD per week performed at home independently

One walking session per week
Figure 2: Flow chart of the study

Assessed for eligibility (n=108)

* Eligible subjects who were approached by neurologist but could not be approached by research team as phone number was not in service (n=15)
* Declined to participate (n=35)

* Not meeting inclusion criteria (n=28)
  * Bed or wheelchair bound (n=23)
  * Severe cognitive or behavioural deficits (n=3)
  * Severe hearing problems (n=2)

Consented and completed baseline assessment (n=30)

Randomized (n=30)

Allocated to intervention group (n=16)
Received allocated intervention (n=16)

Allocated to control group (n=14)
8 weeks of no intervention

Lost to follow-up at 8 week assessment (n=1)
Reasons: Did not provide reason

Lost to follow-up at 8 week assessment (n=3)
Reasons: Change in health (n=1); need to travel for long distance (n=2)

Analysed (n=15)

Analysis

Intervention offered to control group when they completed the follow-up assessment

Follow up

Analysed (n=11)
Figure 3: Distribution plot for MDS-UPDRS motor score at baseline against change score, categorized by group allocation. Change score is the difference between baseline and follow-up score (follow-up score – baseline score). Zero line indicates no difference (i.e. no change from baseline to follow-up). A negative change (i.e. change below zero) indicates improvement in MDS-UPDRS motor score at follow-up. The -11 line indicates the MDC for the MDS-UPDRS motor score. Cases below this line has a change score that exceeds the MDC.
<table>
<thead>
<tr>
<th>Table 1: Baseline characteristics of intervention and control groups</th>
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<tbody>
<tr>
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<tr>
<td>------</td>
</tr>
<tr>
<td>Gender (M/F)</td>
</tr>
<tr>
<td>Age (years)</td>
</tr>
<tr>
<td>Duration of disease (years)</td>
</tr>
<tr>
<td>HY</td>
</tr>
<tr>
<td>MDS-UPRS motor</td>
</tr>
</tbody>
</table>

Data are presented in mean (SD).  
MDS-UPDRS: The Movement Disorders Society Unified Parkinson’s Disease Rating Scale/Range 0 to 132 with a lower score indicates a better performance.  
HY: Hoehn and Yahr Staging Scale/Range 0 to 5 with a lower score indicates a better performance.
Table 2: Measurements at baseline and follow for all participants who completed the study

<table>
<thead>
<tr>
<th>Outcome measure</th>
<th>Baseline</th>
<th></th>
<th>Follow up</th>
<th></th>
<th>Differences between groups at follow up adjusted for baseline measures</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intervention</td>
<td>Control</td>
<td>Intervention</td>
<td>Control</td>
<td>Mean difference (95% confidence interval of difference)</td>
</tr>
<tr>
<td>MDS-UPDRS motor</td>
<td>52.6 (16.8)</td>
<td>45.7 (19.8)</td>
<td>41.4 (18.0)</td>
<td>49.8 (16.2)</td>
<td>-13.5 (-25.3 to -1.7)</td>
</tr>
<tr>
<td>TenMWT (m/s)</td>
<td>0.76 (0.24)</td>
<td>0.82 (0.32)</td>
<td>0.97 (0.32)</td>
<td>0.82 (0.3)</td>
<td>0.19 (-0.07 to 0.45)</td>
</tr>
<tr>
<td>Mini-Best</td>
<td>17.7 (5.5)</td>
<td>17.7 (7.3)</td>
<td>19.6 (5.6)</td>
<td>19.2 (6.3)</td>
<td>0.42 (-3.3 to 4.1)</td>
</tr>
<tr>
<td>CSTS</td>
<td>7.1 (4.5)</td>
<td>7.5 (4.7)</td>
<td>9.3 (3.9)</td>
<td>7.9 (3.4)</td>
<td>1.7 (-0.25 to 3.6)</td>
</tr>
<tr>
<td>FES</td>
<td>34.9 (14.6)</td>
<td>32.4 (17.7)</td>
<td>31.4 (14.1)</td>
<td>41.5 (14.7)</td>
<td>-11.7 (-19.8 to 0.3)</td>
</tr>
<tr>
<td>PPT</td>
<td>14.3 (5.6)</td>
<td>14.0 (6.1)</td>
<td>17.1 (5.9)</td>
<td>14.5 (6.1)</td>
<td>2.4 (-0.8 to 5.8)</td>
</tr>
<tr>
<td>SixMWT (m)</td>
<td>251.8 (130.8)</td>
<td>252.6 (123.6)</td>
<td>285 (115.1)</td>
<td>227.7 (111.3)</td>
<td>57.6 (-5.2 to 120.3)</td>
</tr>
</tbody>
</table>

Data are presented in mean (SD). MDS-UPDRS; The Movement Disorders Society Unified Parkinson’s Disease Rating Scale/Range 0 to 132 with a lower score indicates a better performance. CSTS; Chair Sit To Stand test/ Higher score indicates a better performance. TenMWT; Ten Meter Walk Test/ Lower score indicates a better performance. SixMWT; Six Minute Walk Test/Higher score indicates a better performance. PPT; Physical Performance Test/Higher score indicates a better performance. FES, Fall Efficacy Scale/ Range 16 to 64 with a lower score indicates a better performance.
<table>
<thead>
<tr>
<th></th>
<th>% of performed sessions with therapist</th>
<th>% of performed independent sessions</th>
<th>% of walks</th>
<th>% of adherence (without walks)</th>
<th>% of adherence (with walks)</th>
<th>Reasons for lack of adherence</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>100</td>
<td>87.5</td>
<td>75</td>
<td>91.7</td>
<td>87.5</td>
<td>Participant was sick on one week.</td>
</tr>
<tr>
<td>2</td>
<td>100</td>
<td>50</td>
<td>75</td>
<td>66.7</td>
<td>68.8</td>
<td>1. Lack of time: participant felt that performing exercises twice a week rather than 3 times was more feasible to him. 2. Knee pain at one week prevented him from doing exercises at that week.</td>
</tr>
<tr>
<td>3</td>
<td>100</td>
<td>100</td>
<td>75</td>
<td>100</td>
<td>93.8</td>
<td>Fatigue and pain limited walking in the first 2 weeks.</td>
</tr>
<tr>
<td>4</td>
<td>100</td>
<td>75</td>
<td>100</td>
<td>83.3</td>
<td>87.5</td>
<td>Participant was sick for two weeks.</td>
</tr>
<tr>
<td>5</td>
<td>25</td>
<td>0</td>
<td>75</td>
<td>8.3</td>
<td>25</td>
<td>1. Participant was still in doubt of experiencing PD. 2. Secrecy of diagnosis.</td>
</tr>
<tr>
<td>6</td>
<td>12.5</td>
<td>25</td>
<td>100</td>
<td>20.8</td>
<td>40.6</td>
<td>1. Participant was still in doubt of experiencing PD. 2. Lack of family support. 3. Secrecy of diagnosis.</td>
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<tr>
<td>7</td>
<td>100</td>
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<tr>
<td>8</td>
<td>50</td>
<td>31.3</td>
<td>37.5</td>
<td>37.5</td>
<td>37.5</td>
<td>Participant was very depressed which affected his motivation to do things including exercises</td>
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<tr>
<td>9</td>
<td>100</td>
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<tr>
<td>10</td>
<td>100</td>
<td>75</td>
<td>100</td>
<td>83.3</td>
<td>87.5</td>
<td>Fatigue/pain and fear of falls limited walking in the first 2 weeks.</td>
</tr>
<tr>
<td>11</td>
<td>100</td>
<td>100</td>
<td>0</td>
<td>100</td>
<td>75</td>
<td>Family felt unsafe for participant to walk outside home.</td>
</tr>
<tr>
<td>12</td>
<td>87.5</td>
<td>100</td>
<td>100</td>
<td>95.8</td>
<td>96.9</td>
<td>Participant missed one session with the therapist due to work commitments.</td>
</tr>
<tr>
<td>13</td>
<td>100</td>
<td>75</td>
<td>100</td>
<td>83.3</td>
<td>87.5</td>
<td>Participant missed one session with therapist and 3 sessions at home in one week due to family commitments.</td>
</tr>
<tr>
<td>14</td>
<td>100</td>
<td>81.25</td>
<td>100</td>
<td>87.5</td>
<td>90.6</td>
<td>Participant was sick on one week</td>
</tr>
<tr>
<td>15</td>
<td>75</td>
<td>62.5</td>
<td>100</td>
<td>66.7</td>
<td>75</td>
<td>Participant felt stigmatized of doing exercises at home in the presence of family.</td>
</tr>
<tr>
<td>Themes</td>
<td>Categorical codes</td>
<td>Description</td>
<td>Illustrative quotes</td>
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<tr>
<td>Enablers</td>
<td>DVD and the exercise booklet</td>
<td>Participants reported that DVD was very clear, easy to follow and provided an important tool to continue performing the exercises independently at home (n=11).</td>
<td>&quot;The DVD was simple and easy to follow..its use at home was a strong motivator to continue doing the exercises”</td>
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<td></td>
<td>Perceived improvement</td>
<td>Some participants reported that recognizing the improvement in whether in physical or mental status was a key to motivate them to adhere to the exercise program (n=7).</td>
<td>&quot;The exercise program has affected me both mentally and physically..before I got to know you and was introduced to this program I used to lock myself away at home..fear of falling was a big issue.. I was therefore not moving…Now my mobility has improved dramatically…I feel as If I have regained big chunk of my life”</td>
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<td></td>
<td>Compensation for transportation</td>
<td>Participants reported that the financial aid in compensation for transportation helped in adherence to the program (n= 9).</td>
<td>&quot;As you know I come from a distance and my participation would have been impossible without covering the transportation costs..that was really important aspect”</td>
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<td></td>
<td>Continuous monitoring</td>
<td>Participants perceived the importance of initial instructional sessions and the weekly phone calls as important elements for initial adoption of the program and also for continuation; they were perceived as important aspects of the program to build self-efficacy (n=6).</td>
<td>&quot;I really prefer doing the exercises at home…the sessions with therapist were very important to know what I am supposed to do and to build confidence”</td>
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<td></td>
<td>Social interaction and relation with the therapist</td>
<td>Participants felt that the social interaction and relation with therapist during the instructional sessions and the weekly phone calls was a strong motivator to adhere to the program (n=7)</td>
<td>&quot;For the first time ever I felt that someone was truly taking care of me..that was the best piece of the intervention. It made me feel in turn that I should take care of myself by committing to the exercise program. The therapist was an excellent motivator”</td>
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<td></td>
<td>Family support</td>
<td>For early stage participants, encouragement provided by family members was perceived to be important for initial adoption and for continuation (n=2). For fairly affected patients (n=1), family involvement was very important for encouragement and for physical help in performing exercises. For female patients (n=1), family involvement was very important for encouragement and for providing means of transportation.</td>
<td>&quot;The family encouragement was very important for me to take this step and start the exercise program with you”</td>
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<tr>
<td>Themes</td>
<td>Categorical codes</td>
<td>Description</td>
<td>Illustrative quotes</td>
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<tr>
<td>Personal Challenges</td>
<td>Co-morbidities</td>
<td>Participants felt that co-morbidities such as knee or hip osteoarthritis, cervical or lumbar disk, limited but did not prevent them from engaging in the exercise program (n=6).</td>
<td>&quot;I have a chronic problem in my knee and some of the balance exercises were causing me more pain…this did not stop me from doing the exercise…the therapist helped me in modifying the exercise so that it became more tolerable&quot;</td>
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<td></td>
<td>Physical fatigue</td>
<td>Participants perceived that fatigue would limit but not prevent them from engaging in the exercise program (n=2).</td>
<td>&quot;I lacked the habit of past exercise…this is the first time I have been in a structured program. When I first started I used to feel tired even after performing only a few movements. This feeling however, ceased off after few weeks.&quot;</td>
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<td></td>
<td>Lack of time</td>
<td>Some participants reported that lack of time due to family and work commitments was a limiting factor to adhere to the program (n=3).</td>
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<td></td>
<td>Depression</td>
<td>One participant felt that depression affected motivation to do anything including getting engaged in the exercise program (n=1).</td>
<td>&quot;since I've been diagnosed with PD and I felt low…I became less motivated to do anything in life….even when you invited me to do the exercises I felt apathetic&quot;</td>
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<td></td>
<td>Lack of outcome expectations</td>
<td>One participant at early stage believed he was not necessarily in need for exercise as they were still physically fit (n=1).</td>
<td>&quot;I feel I am physically better than other people…and the nature of my work requires a lot of movements. I work as a plumber; hence I move all the time&quot;</td>
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<td></td>
<td>Denial of PD diagnosis</td>
<td>Participants at early stage were still in doubt of being diagnosed of PD (n=2). This has influenced their acceptance to any treatment to manage PD including the delivered exercise program.</td>
<td>&quot;I did not do the exercises because I am still not convinced I have PD…I have this dilemma…I am really not convinced that I have PD…..next week I will be seeing another neurologist to discuss my case&quot;</td>
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<tr>
<td>Cultural Challenges</td>
<td>Stigma</td>
<td>Culturally being active is not the norm particularly for old people</td>
<td>&quot;at home I have the fear that my sons will comment on this…I am trying to avoid this…I did though all the sessions with the therapist in the clinic but did not do the sessions at home&quot;</td>
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<td></td>
<td>Secrecy of the diagnosis</td>
<td>Some participants were unable to share diagnosis with family including spouse and children; performing exercises at home would be questionable (n=2).</td>
<td>&quot;PD is a big secret in my life..No one apart from one very close friend knows about it..even my wife..If I bring the DVD to home and start exercising they will start to ask the questions…basically it hurts but I still do not want them to know about it&quot;</td>
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</table>
Appendix 1: Semi-structured interview schedule

- Can you explain how much of the prescribed exercise session did you do?
- Did you do any other exercises or physical activities other than what was prescribed during the last 8 weeks?
- What do you think of the exercise program in general? What is the most and the least that you liked about the program?
- What do you think made it easier for you to engage in the exercise program?
- What are the challenges or the difficulties that you encountered that made it more difficult for you to do the exercises?
- Do you have any suggestions of how this program can be improved?
Appendix 2: Exercise diary

<table>
<thead>
<tr>
<th>Exercises Diary (week 1)</th>
<th>Week start date:</th>
<th>Week end date:</th>
</tr>
</thead>
<tbody>
<tr>
<td>1- Please check when exercise is completed (record the number of repetition for each exercise)</td>
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</table>

<p>| Session 1 | | | | |
|-----------| | | | |
| Session 2 | | | | |
| Session 3 | | | | |
| Session 1 | | | | |
| Session 2 | | | | |
| Session 3 | | | | |</p>
<table>
<thead>
<tr>
<th>Other physical activities</th>
<th>Number of times during the week</th>
<th>Number of minutes per time</th>
<th>Number of rests taken per time</th>
<th>Time of rest in minutes</th>
<th>Exertion scale- BORG 1-10</th>
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<tr>
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<tr>
<td>Did you miss any of the prescribed sessions or exercises for this week?</td>
<td>1. Yes</td>
<td>If yes, please mention the reasons.</td>
<td>1.</td>
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<td></td>
<td>2. No</td>
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</tbody>
</table>

29
References

Papers of special note have been highlighted as: * of interest; ** of considerable interest

