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Motor Performance and Quality of Life in a Community Exercise Program for Parkinson Disease

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We investigated the effect of a comprehensive community program composed of exercise, mindfulness practice, and education on motor function and quality of life in individuals with Parkinson disease (PD). Thirty-six participants completed physical and quality-of-life assessments independently at baseline and 12 months. Physical assessments showed stability or improvement in functional mobility, integrated strength, and walking ability over the 1-year interval. PDQ-39 measures showed improvement in 6 of 8 indices: mobility, activities of daily living, emotional well-being, stigma reduction, social support, and bodily discomfort. Our results demonstrate the effectiveness of exercise, mindfulness, and education in community and group settings.
Key words: community program, exercise, mindfulness, Parkinson disease

Parkinson disease (PD) is a progressive neurodegenerative disorder, affecting an estimated 1 million people in the United States, including 1% of persons older than 60 years and 3% of persons 80 years and older.[1] PD is characterized and diagnosed by motor symptoms and signs such as tremor, rigidity, akinesia, and postural instability, with tremor more common in older patients.[2] The breadth, frequency, and importance of nonmotor symptoms such as depression, dementia, autonomic disturbances, sleep disorders, and fatigue in PD have increasingly been recognized.[3] As PD progresses, motor performance declines and quality of life for both the person with PD and his or her care partner can be adversely affected. Stigma resulting from PD can lead to social withdrawal and worsening of health-related symptoms[4]; the social isolation that results can be detrimental to patients' quality of life.[5]

While there is no cure, a growing body of evidence suggests that physical exercise, mindfulness interventions, and education can slow the progression of PD symptoms, improve quality of life,[6,7] and ease burden on care partners.[8] Other studies suggest that programs based in community settings may support participation and long-term retention,[9,10] resulting in better outcomes for those participants. Unfortunately, many of these studies have been conducted over a shorter time span, typically no longer than 12 weeks, a small sample period in the setting of a chronic disease such as PD, whose course is measured over multiple years. However, these findings do indicate that community-based wellness programs may be a critical tool in ensuring quality of life and "health before care" in people who are affected by PD. With the number of people diagnosed with PD in the United States expected to grow to 1.2 million by 2040,[11] and a shortage of US physical therapists forecasted by 2030,[12] research into treatment delivery and outcomes of community-based approaches is both timely and relevant. More cost-effective, longer-term approaches will become increasingly important. To address this gap, the primary aim of this study was to demonstrate the effectiveness of a community-based, integrated program by evaluating 2 goals: (1) preservation of motor performance and (2) the facilitation of a high quality of life for people with PD, over the span of a full year.

METHODS

Study setting

Since 2015, InMotion has delivered evidence-based exercise, mindfulness, education, support, and arts programs and services to people with PD and their care partners in Northeast Ohio free of charge. Currently serving 1200 clients and care partners, the community center of InMotion welcomes, on average, 1 new client per day. The center has a 3-year participant retention rate of 73% and coach/instructor retention rate of 100%. Since opening its doors, the organization has been committed to a rigorous, standards-based data collection and analysis program. An earlier study conducted at InMotion for program participants indicated that motor performance was stable or improved over a 6-month period (unpublished data). The primary purpose of the current study is to present updated results of participants' performance assessments over a 12-month period.

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Program overview

InMotion currently offers 30 to 33 hours of programs and services per week, including a proprietary comprehensive exercise program named Better Every Day, (TM) boxing, mindfulness, yoga, cycling, dance, singing, voice enhancement, handwriting, tai chi, support groups, and education. Programs are centered around helping clients acquire the tools to cope positively and constructively with the changes that PD presents. Classes are taught by certified instructors and trained volunteer assistants, and a maximum 10:1 client to coach ratio is maintained in each class. Classes are group-based but tailored to meet the individual needs of participants, accomplished through small class sizes and by grouping clients into classes according to their mobility levels and needs.

Both exercise classes and physical assessments focus on functional mobility, particularly walking. Functional mobility is "a person's physiological ability to move independently and safely … to accomplish functional activities or tasks and to participate in the activities of daily living…."[13(p122)] Walking, a complex activity that is important for activities of daily living, is a common area of difficulty for people with PD due to impaired lower-extremity function, freezing of gait, fatigue, prolonged PD duration, fear of falling, and many other factors.[14] The InMotion program targets both cognitive and motor functions to maintain or relearn motor behavior and develop learning and compensatory strategies to master skills and movements that were previously unconscious and automatic.[15,16]

Assessment overview

Participants have been (and continue to be) enrolled in this study on an ongoing basis from the InMotion clientele with PD. Subjects were considered eligible for this report only if they had completed physical assessments independently at baseline and 6 and 12 months. Although data were collected individually, assessments were conducted in a group setting, consistent with the usual format of InMotion classes; this allowed for encouragement from others and created a supportive environment. The battery of assessments (Table 1) was selected from an assortment of previously published studies on the effects of physical activity on PD to emphasize the principle of functional mobility described earlier. The assessment data collections were performed by trained instructors and volunteers.

In addition to the physical assessments listed in Table 1, we assessed quality of life with a validated self-administered questionnaire, the 39-item Parkinson's Disease Questionnaire (PDQ-39).[17] The 39 questions are grouped into 8 "dimensions," with each dimension scored on a 100-point scale. Higher scores indicate that the respondent is experiencing more difficulties. We report aggregate cohort results for each dimension of the PDQ-39.

Statistics were analyzed using paired *t* tests to compare client assessments on the mobility and balance tests listed in Table 1 and on the PDQ-39, at baseline and after clients had attended InMotion programs for 12 months.

RESULTS

A total of 36 subjects completed baseline and 12-month assessment batteries. Table 2 lists the mean aggregated

TABLE 1 Assessment Measures

Measure	Description
Two-Minute Walk Test	A measure of the distance a person can walk as fast as possible, but safely, in 2 min. Walking aids may be used as needed. The test is conducted indoors on turf and timed with a stopwatch.
Sit-to-stand test	The number of times a person can stand from a sitting position in 60 s. Participants sit on a bench or chair with arms crossed over the chest and feet flat on the floor. Participants rise to a full standing position and then sit back down again.
Single-leg stance	Participants are asked to stand with arms crossed over the chest. One foot is raised off the ground and held for 30 s. The number of times the elevated foot touches the floor to restore balance is measured. The exercise is repeated on the other side.
Lateral stepping	How quickly and often a client can cross a hurdle moving laterally. Participants step across a low hurdle and back continuously for 60 s. The number of steps is counted.
Single-arm clean and press	Participants lift a small weight (2.72 kg for men, 1.36 kg for women) vertically from the ground to overhead and then put it back down. The number of repetitions completed in 30 s with each hand is measured.
Extended Timed Up and Go	The time required for a person to stand, walk around a hurdle, and return. Participants rise from chair 1, walk forward for 10 yards, circle chair 2, and return to sit in chair 1. Participants' completion time is measured in seconds.
Rotational body turn	Participants stand with back to a wall holding a small ball in both hands in front of them. They rotate to the right, tap the ball on the wall, and return to the neutral forward position. The number of rotational wall taps in 30 s is counted. The exercise is then repeated to the left.

TABLE 2 Motor Performance Assessment Scores (N = 36)

Assessment	Baseline (mean)	1 Year (mean)	% Who Improved
2-Minute Walk Test	222.3 m	233.1 m	56
Sit-to-stand	31.1 reps	35.4 reps[a]	74
Single-leg stance	8.6 touches	8.9 touches	39
Lateral stepping	54.4 reps	58.3 reps	39
Single-arm press	28.8 reps	32.6 reps[a]	72
Extended Timed Up and Go	10.5 s	10.3 s	67
Body turns	45.1 reps	49.9 reps[a]	64

Abbreviation: reps, repetitions.
[a]$P \leq .05$ in a positive direction.

baseline and 12-month results for each assessment. Subjects showed statistically significant improvement on 3 of 8 tasks over that span: sit-to-stand, single-arm press, and body turns. All other motor tests showed stability from baseline to 12 months; none of the tasks showed evidence of deterioration over the 1-year period. Table 2 also provides data for the proportion of individuals who improved their scores for each task during the 12-month interval between assessments.

We were able to collect baseline and 12-month PDQ-39 data on 33 of the 36 participants; 3 subjects did not submit questionnaires for both time points. Table 3 shows the mean responses for each category at baseline and 12 months. Six of 8 PDQ-39 dimensions showed mean stability or improvement from baseline to 1 year; in the case of "mobility," the degree was statistically significant. "Cognition" and "communication" dimension scores had deteriorated at 12 months.

TABLE 3 PDQ-39 Dimension Scores (N = 33)

PDQ Dimension	Baseline	1 Year
Mobility	23.4	15.9[a]
Activities of daily living	19.4	15.3
Emotional well-being	18.9	16.9
Stigma	13.1	9.4
Social support	7.6	6.8
Cognition	19.1	25.5
Communication	10.7	18.6
Bodily discomfort	32.6	29.3

Abbreviation: PDQ, Parkinson's Disease Questionnaire.
[a]$P \leq .05$ in a positive direction.

To know whether gains were evenly distributed across groups, we performed additional analysis. First, we ran the *t* test again with just women. The results were overall stronger in this subgroup, with women performing statistically better on 6 of the assessments. Although we could not make a direct comparison with men since there were only 15 male participants (<20 may not be useful), by comparing the women's performance with overall performance, we can see some difference in that women are improving in more categories than the group as a whole.

We also calculated a percentage improvement rate for each assessment and then correlated the new improvement variables with the year that the client was diagnosed with PD. Findings show that diagnosis date was correlated with improvement on only one measure which was the 2-minute walk (the later the diagnosis, the greater the improvement). On the other assessments, findings were not significant. For our final follow-up test, we correlated all of the improvement scores with age and again found only one statistically significant relationship, which was with lateral balance. In all other tests, age was not correlated with improvements.

DISCUSSION

In a cohort of 36 subjects with PD, we demonstrated that participation in a community-based program of physical and mental activities was associated with stabilization or improvement of motor performance and quality of life over a 12-month period, as measured by an assortment of mobility and balance tests and the PDQ-39. The results presented here are consistent with an expanding body of literature demonstrating the beneficial aspects of exercise and mindfulness on physical performance, cognitive function, and well-being in persons with PD.[18-21] Our study indicates that such benefits are applicable in a field setting and can be extended over a 12-month period. The positive findings spanning a full year were especially gratifying, given the progressive nature of PD.

There are a number of potential limitations to our conclusions resulting from the research design we were able to execute. The tasks we used to assess motor performance do not represent a validated battery, but rather a group of tasks used in published research studies that we assembled for our study. It is possible that these tasks are not fully representative of motor performance as a whole in subjects with PD. We have not recruited sufficient numbers of participants to identify whether all elements of our program contribute to its success or whether certain activities are more effective than others. The low number of participants who have persisted in the project for a full year may represent the result of a form of selection bias. Finally, we cannot claim a direct intervention effect for our program, because we could not control for contributory factors that

may well be relevant, including changes in medication and outside levels of physical activity. However, other research has shown that people with PD who do not exercise show increased symptoms and medication levels.[22,23]

As noted earlier, enrollment in this study is ongoing. We expect the strength of our research design to improve with greater numbers of subjects and by incorporating data on attendance frequency and analysis of the effects of different scheduled activities. For example, we could examine what combinations of classes (eg, physical classes only vs a combination of physical and expressive classes such as singing) produce the strongest results. With larger numbers of participants, we may be able to focus on identifying subgroups of participants who benefit from specific activities. Finally, an experimental design with random selection into the experimental and control groups would be the strongest approach methodologically to guard against unknown biases and other factors that cannot be controlled. We expect the data we generate will drive innovation and continuous improvement in our program delivery.

Nevertheless, at the 1-year mark, our work to date already demonstrates the potential effectiveness of a community setting with group classes designed to retain or build functional mobility, integrated strength, and walking ability. Our findings support previous research regarding the beneficial aspects of exercise and other activities in people with PD, while doing so over a prolonged period. Our results suggest that the InMotion program delivery contributes to stabilization or improvement of the clinical course of participants and supports the practice of recommending physical activity as a therapeutic measure for persons with PD.

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