THE IMPACT OF A COMMUNITY BASED EXERCISE PROGRAMME FOR PEOPLE WITH PARKINSON DISEASE

(Spine title: Community based exercise programme)

(Thesis format: Monograph)

by

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Graduate Program

in

Public Health

A thesis submitted in partial fulfilment

of the requirements for the degree of

Master of Public Health

Faculty of Graduate Studies

Lakehead University

Thunder Bay, Ontario, Canada

Your file Votre référence
ISBN: 978-0-494-31198-1
Our file Notre référence
ISBN: 978-0-494-31198-1

Abstract

Objective: To develop and evaluate the impact of an 8-week community based exercise programme delivered by a community fitness facilitator upon performance and self-report measures in participants with Parkinson disease.

Design: Prospective, single group pre/post test

Setting: Older Adults Community Centre in Northwestern Ontario

Participants: Eleven participants (6 men, 5 women; mean age, 70.45 ± 1.98; mean length of disease, 3.27 years) with Idiopathic Parkinson disease, Hoehn & Yahr stages 1.0 to 2.5 and stable medication use.

Intervention: An 8 week exercise programme, developed by physiotherapists and delivered in the community by a community fitness facilitator trained through a competency based approach.

Outcome measures: The Unified Parkinson Disease Rating Scale motor subsection score (UPDRSm), the Berg Balance Scale (BBS), the Timed Up and Go Test (TUG), the Parkinson Disease Questionnaire-39 (PDQ-39), and the Activities-specific Balance Confidence Scale (ABC scale) were assessed at baseline and after the 8 week exercise programme. Attendance rates and the occurrence of any adverse events were recorded throughout the 8-week exercise programme by the fitness facilitator.

Results: Analysis of the outcome measures resulted in the removal of one participant outlier. Subsequent analysis of the remaining 10 participants resulted in a statistically significant decrease in the UPDRSm from baseline to 8 weeks (7.70, $p = 0.001$), and a statistically significant increase in TUG scores (2.03, $p = 0.005$). Although no statistical significance was demonstrated in the other outcome measures, significant effect size was demonstrated for all outcome measures. All eleven participants completed the study with an adherence rate of 90.8% attendance in the exercise programme. There were no adverse events reported. Conclusion: A community based exercise programme, developed by physiotherapists and delivered by a community fitness facilitator, can be provided safely to a group of people with Parkinson Disease. The exercise programme also appears to have demonstrated sufficient intensity to elicit changes in motor function, as measured by the UPDRSm, and there is potential for changes in all outcome measures with a larger sample population. It is hoped that this unique process of identifying and addressing the needs of a particular client population in Northwestern Ontario will help to facilitate the ongoing development of physiotherapy initiatives which address the changing reality of healthcare.

Keywords: Parkinson disease; exercise; physiotherapy; community based

Dedication

To my husband, children and parents – without whose support this would not have been possible.

Thank you Bryan, Emma, Connor and Fiona for supporting me through this last year and for understanding my need to do this project.

Thank you Mom and Dad for coming to our rescue.

And thank you to my better half (in research), Kirsti Reinikka, for your enthusiasm in this research project and for the innumerable long hours we have spent working on this together.

Acknowledgments

Thank you to the members of the Northwestern Ontario District of the Parkinson Society for their active role in advocacy and their enthusiastic participation in this project.

Thank you to St. Joseph's Care Group, Thunder Bay, Ontario for providing the support and financial assistance to make this research project a reality.

Thank you to the 55+ Centre, City of Thunder Bay for demonstrating an interest in this community based project and for providing space for the exercise programme and funding to the fitness facilitator.

Thank you to Doug Charters, our community fitness facilitator who eagerly took on the role of facilitating the class and leading the participants through the 8 weeks of exercise.

Thank you to the numerous volunteers who acted as subjects for videotaping and photographs of the exercise programme.

Thank you to the Neuro Day Rehabilitation Team at St. Joseph's Care Group, who undertook the delivery of the education component of this study.

Thank you to Dr. Mandar Jog for enthusiastically supporting this project and for his active participation in participant recruitment and screening.

Finally, thank you to Michel Johnson and Michel Bedard for their direction and advice in supervising this research project and thesis.

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Introduction

Parkinson Disease (PD) is a progressive, neurodegenerative disorder characterized by bradykinesia, resting tremor, rigidity, and postural instability. The Parkinson Society of Canada estimates that approximately 100,000 Canadians have PD, and that one percent of the population over 65 and two percent over age 70 are currently affected. There is a substantial burden of illness and cost to society with PD. Recent studies have estimated an increased rate of mortality, increased physician and hospital costs, and an increasing prevalence of PD seen with an aging population (Guttman, Kish & Furukawa, 2003). Although medical treatment is the most effective means of reducing motor symptoms of PD, rehabilitation has been shown to be an important adjunct (de Goede, Keus, Kwakkel & Wagenaar, 2001). Rehabilitation focuses on reducing the burden of illness by treating motor symptoms and helping to improve quality of life.

Parkinson Disease

Parkinson Disease is a disorder of the basal ganglia. It is characterized by a loss of dopaminergic cells in the substantia nigra pars compacta and the presence of Lewy bodies in all affected brain-stem regions (Lang & Lozano, 1998). Progressive loss of dopaminergic cells occurs with normal aging but this process seems to be accelerated in PD. The most common form of PD is Idiopathic Parkinson Disease (IPD) which tends to present itself between the ages of 50 and 79 years. There is no known cause of damage to the dopaminergic nigrostriatal pathway in IPD; however both genetics and the environment are thought to be important factors (Protas, Stanley& Jankovich, 1997).

The basal ganglia is involved in movement control, motor learning, memory, planning, and motivation (Marsden & Obeso, 1994; Parent & Hazrati, 1995). The motor disturbance resulting from a loss of dopaminergic cells in the basal ganglia is a combination of impaired movement initiation (akinesia), slowed movement (bradykinesia), and reduction in movement range (hypokinesia) (Reuter, Engelhardt, Freiwaldt & Bass, 1999). Symptoms occur when there is greater than 80% loss of the dopaminergic cells (Lang & Lozano, 1998). This deficiency in dopamine accounts for the clinical motor features of PD - tremor, bradykinesia, rigidity, and postural instability. Motor symptoms affect many aspects of movement – posture, gait, righting reflexes, speech, and facial expression. Changes in movement can result in impaired activities of daily living, such as, difficulties with handwriting, difficulty turning in or rising from bed, difficulty rising from a chair, and difficulties with self care (Protas et al., 1997). The changes in motor control and their effect on movement all contribute to the variety of functional problems seen in people with PD.

Acute Exercise Response

There is considerable intra and inter-individual variability in the symptoms of PD. Symptoms may fluctuate from hour to hour, day to day, week to week and person to person (Guttman et al., 2003). Consequently, people living with PD experience significant variability in their physiological responses to exercise. As discussed by Protas et al. in the ACSM textbook on Exercise Management for Persons with Chronic Diseases and Disabilities, the effects of PD on exercise response may be classified into direct, indirect and composite effects. Direct effects are the effects of the symptoms of PD themselves, such as tremor or rigidity. Indirect effects are those which occur along with the disease process, such as aerobic deconditioning, musculoskeletal changes and loss of range of motion from inactivity. Composite effects are a result of direct and indirect effects such as direct nervous system changes and indirect musculoskeletal changes which result in problems with balance and mobility. Research has demonstrated that people with PD have altered motor planning and motor memory (Canning, Alison, Allen & Groeller, 1997; Morris, Iansek & Matyas, 1996) as well as dysfunction of the Autonomic Nervous System (ANS). ANS dysfunction can result in impairments of the cardiovascular system, bowel and bladder dysfunction, impaired thermoregulation, and drooling (Magerkurth, Schnitzer & Braune, 2005). Impairments of the cardiovascular system include orthostatic hypotension and significant variability in heart rate and blood pressure changes with exercise (Mastrocola et al., 1999; Reuter et al., 1999). During exercise there is an increase in heart rate, respiratory rate and systolic blood pressure but not to the same level as people without PD (Mastorcola et al., 1999). This might indicate a better response to exercise in people with PD but there is a concomitant decrease in the peak VO2, increase in sub maximal heart rate and increase in oxygen consumption during exercise, indicating decreased exercise efficiency (Canning et al., 1997; Stanley, Protas & Jankovic, 1999). Exercise interventions may be most effectively directed at the indirect and composite effects of musculoskeletal and cardiopulmonary changes (Protas et al., 1997).

Chronic Exercise Response

Due to the progressive nature of Parkinson Disease and its associated decline in function and mobility, the link between physical activity and its effect on PD has been investigated to a large extent. Although it has been acknowledged that only a few studies have been methodologically sound (Deane et al., 2001), a recent meta- analysis supported the view that physical therapy is “an important adjunct to pharmacological treatment” (p.512), and it is generally recommended that clients with PD participate in regular physical activity (de Goede et al., 2001). The majority of studies evaluating the effect of exercise on PD have examined short-term hospital based rehabilitation programmes. These studies have demonstrated positive effects on strength, balance, gait parameters, and quality of life measures, and have generally involved physiotherapists directly leading clients through an exercise programme (Hirsche, Toole, Maitland & Rider, 2003; Trend, Kaye, Gage, Owen & Wade, 2002). Acknowledging the issues of both cost and attendance, a smaller number of studies have examined the effectiveness of home-exercise programmes. The results suggest that home exercise programmes delivered and reinforced by a physiotherapist are equally as effective as hospital-based programmes on improving motor symptoms of clients with PD (Lun, Pullan, Labelle, Adams & Suchowersky, 2005). Finally, a number of studies have also examined the effect of physiotherapy-led group exercise in people with PD. These demonstrated significant improvements in mobility and activities of daily living (Ellis, de Goede, Feldman, Wolters & Wagenaar, 2005); while group day programmes indicated improvements in quality of life measures as well (Trend et al., 2002).

Problem Statement

Health care delivery and service needs are unique for people in Thunder Bay and the surrounding communities of North Western Ontario (N.W.O.). The St. Joseph's Care Group Rehabilitation Network Survey Report, June 2005, indicated a number of obstacles to receiving rehabilitation services in communities across N.W.O. The primary barriers identified were lack of services, lack of funding for services, services not available when needed, specific expertise required but not available, and lack of continuity and follow-up. The need for alternative forms of service and programme delivery was apparent when considering these obstacles to care.

Through informal meetings and communications over the last several years, St. Joseph's Care Group (SJCG) and the local Parkinson Society have identified an absence of and a need for an ongoing, physical activity programme for clients with PD. A community based exercise programme delivered in, and by community partners was hypothesized to be one viable solution to meet the ongoing needs of this client population.

Design of Exercise Programme

Following the principles of Competency-Based Education Training (CBET), a community fitness facilitator was trained in the necessary competencies to safely and effectively deliver an exercise programme for people with PD. The CBET approach to training has been used in public and private corporations, human resources and professional development programmes (Cioffi, Lichtveld, Thielen & Miner, 2003). A need has been identified across various disciplines in health, education and business to define and utilize competencies as a basis for training. Because of a demand for health care that is clinically and cost effective, practice guidelines and evidence-based approaches to treatment have been developed (Hoge, Tondor & Marrelli, 2005). The use of a CBET approach to deliver a community based exercise programme is driven by the need to identify the knowledge, skills and attitudes needed to safely and effectively deliver the programme in the community.

The Canadian National Coaching Certification Programme (NCCP) has adopted a competency based education and training programme for their coaches (Bagnell et al., 1998). The experience of the NCCP over the last ten years has led to the development of various platforms designed to meet the needs of coaches across Canada. One such approach is the use of a computer based asynchronous learning environment containing multimedia, text, and quizzing components. This module-based computer platform approach was used as the basis for the development of the community exercise programme for PD.

Competencies are statements that link content to a level of performance. Competencies focus on "knowing how" rather than on "knowing that", and they include knowledge, skills and attitudes. A core belief of CBET is that competencies can be identified, individuals can be educated and trained to develop competencies, and that these competencies can be assessed. Assessment needs to be formative and summative, with opportunities for self-assessment and performance in the real world. Progression is learner centred with the mastery of specific knowledge and skills as the unit of progression. The approach to CBET should include the following: the identification of competencies; the identification of criteria for achievement and the conditions for achievement; learning guides and checklists for self progression; and an assessment process that takes into account knowledge and attitudes but that requires actual performance of the competencies as a source of evidence of attaining competency level (Kaslow et al., 2004).

A CBET training approach builds competencies and confidence because participants know what level of performance is expected, how knowledge and skills will be evaluated, that progression through training is self-paced and that there are opportunities for practice until mastery of competencies is achieved.

There is an inherent complexity in facilitating an exercise class for people with a specific (or a set of) disease process(es). This complexity can be attributed to many variables, including different levels of health and fitness of the individual participants as well as contextual situations that are continuously changing. Variables must be processed at a given point in time within a specific situation. Exercise facilitation involves ongoing interactions with a variety of people with a variety of individual needs. Direction and facilitation must adhere to certain values and goals inherent to the specific disease process and to the goal of the specific programme. This complexity requires the fitness facilitator to both integrate and transfer knowledge to the specific situation. The ability to deal with individuals and with situations within a clearly defined framework is the fundamental element of competent practice (Cioffi et al., 2003).

The exercise programme and experience of the participants is facilitator driven and must be supported by a system which values the need to plan, organize and support exercise programmes within the framework of the health care system as a whole. Thus, the vision, mission and programme outcomes for the support system, should guide the development of the CBET approach. Understanding the roles and needs of the participant, fitness facilitator and the support system is essential to the development of a comprehensive Competency Based Education Training model. The exercise programme and the specific approach to CBET delivery was undertaken as part of this research project.

The creation and validation of the content and materials for the CBET approach followed Lynn's (1986) two-stage process for content validation. The exercise program for PD was created using best practice guidelines (de Goede et al., 2001), during the developmental stage. The specific competencies needed to effectively deliver this programme in a community based environment by community exercise leaders, were identified and the necessary material created. (Appendices A,B,C,D respectively – Competency background, Participant Summary, Task Analysis, Exercise Cheat Sheet) A committee of experts in adult education and in CBET design were consulted to ensure the use of appropriate levels of language and competencies. The quantification stage involved a panel of content experts to review the programme and validate the relevance of the exercises to the domain of content. Qualitative suggestions were also used to improve the exercise programme.

It was hoped that this unique process of identifying and addressing the needs of a particular client population in North Western Ontario would help to facilitate the ongoing development of physiotherapy initiatives which address the changing reality of health care. The use of CBET to train the trainer was a novel approach in health care, which better addressed adult learning needs and helped to ensure the safe and effective delivery of an exercise programme.

Research Question

The goal of this research project was to develop and evaluate the impact of an 8-week community based exercise programme delivered by a community fitness facilitator upon performance and self-report measures in participants with Parkinson disease.

Hypothesis

The community-based exercise program will result in improvements of both performance and self-report measures.

Methods

Participants

Participants were recruited through the assistance of the Northwestern Ontario Chapter of the Parkinson Society of Canada, the Neurology Day Clinic at St. Josephs Care Group (SJCG), and the Movement Disorder Clinic (MDC) held at SJCG in Thunder Bay. Initial letters were sent out to potential participants and interested parties were contacted by telephone to review eligibility criteria. The eligibility criteria were as follows:
Inclusion criteria included (1) Idiopathic Parkinson Disease (IPD), modified Hoehn and Yahr stage 1.0 to 2.5 in an "on" stage of medication (the time of day when participants reported feeling their best – usually within an hour of taking their medications), (2) a stable PD medication regimen throughout the 20 week study period, and (3) aged 55 years and older Exclusion criteria included (1) presence of an unstable medical condition, (2) presence of other disorders that may affect balance (head injury, stroke, vestibular dysfunction, or peripheral neuropathy), (3) current regular exercise (more than two sessions/ week with more than 30 minutes/session of continuous aerobic training and/or strength training), (4) any musculoskeletal contraindications to exercise, and (5) presence of dementia.

If the criteria were met, participants were screened by a neurologist at the MDC to confirm the diagnosis of IPD and the modified Hoehn & Yahr Stage of 1.0 to 2.5 during the self-reported "on" stage of medication. Eligible participants then signed a consent form, which described the purpose, side effects and benefits of the study. Participants were assigned a participant number to ensure anonymity of research data.

The study was reviewed and approved by the Senate Research Ethics Board at Lakehead University and the Board Ethics Committee at St. Josephs Care Group in Thunder Bay.

Study Design

This research project was originally designed to evaluate the impact of an 8-week community based exercise programme versus an education programme, on performance and self-report quality of life measures in a 2-group crossover design. This design was chosen in order to provide all participants with a potentially beneficial intervention, while ensuring the presence of a control group. Participants meeting the criteria for participation in the study were to be stratified by gender, age, and modified Hoehn and Yahr staging. Participants were then to be randomly assigned to one of two groups; group A or group B. Participants were to receive identical interventions occurring over two different time periods.

- Both groups were to complete an 8-week community based exercise programme.
- Both groups were to receive a multi-disciplinary education intervention delivered by health care professionals at SJCG.

The two groups were to crossover following their initial 8-week intervention. The crossover research design was chosen to ensure that all participants received the exercise intervention. The education component was chosen to reflect a programme currently in place in the city of Thunder Bay and to help account for any bias resulting from the benefits from attention and interaction found in a group setting. Performance and self-report measures were to be assessed in both groups at three points in time: before any intervention, after the initial 8-week intervention, and following the second 8-week intervention.

	First 8 weeks	Second 8 weeks
Exercise	Group A	Group B
Education	Group B	Group A

Due to a limited pool of participants available, the study was modified to a single group pre-test/post- test design which evaluated the impact of an 8 week exercise programme on performance and self-report measures. Because the potential participants had been invited to participate in a research project which included both an exercise and an education component, the participants did receive both components from the original study design. Performance and self-report measures were assessed at two points in time: at baseline and following the 8 week exercise intervention.

	First 8 weeks	Second 8 weeks
Exercise	Group A	
Education		Group A

Measures

Outcome measures were performed using standardized techniques, at baseline and following the 8-week exercise program. To minimize the effects of medications on the participants' physical performance, the time of day of testing remained constant throughout the study, and testing was performed during the "on" stage of medication.

During the 8-week exercise program adherence and safety were recorded by the fitness facilitator. Adherence was evaluated by rate of attendance and safety was evaluated by the absence of any adverse events such as falls, musculoskeletal injuries, cardiovascular events or worsening of disease state.

The Unified Parkinson Disease Rating Scale motor subsection (UPDRSm), the Berg Balance Scale (BBS), and the Timed Up and Go test (TUG) were selected as outcome measures because motor function has been reported to be relatively stable in PD patients and these types of measurements have been found to be reliable over time (Morris & Iansek, 2001; Shenkeman et al., 1998). These standardized performance-based measures test a participant's actual performance of an activity in a given environment at a given point in time. Clinicians can easily administer these tests with minimal equipment found in most settings and clinicians are increasingly using the tests to screen clients, determine the need for intervention and to classify people according to functional status (Brusse, Zimdars, Zalewski & Steffen, 2005). The most frequently used clinical scale for PD is the UPDRS, and most clinical trials rely on the motor examination as the primary outcome measure (Goetz & Stebbins, 2004). The motor examination section of the UPDRS (UPDRSm) quantifies the type, number and severity of extrapyramidal signs, and is used to monitor the severity of motor aspects of Parkinson's disease. The UPDRSm is a clinician-rated structured interview and examination tool which assesses speech, facial expression, tremor at rest (face and each limb), action or postural tremor (upper limbs), rigidity (limbs and trunk), finger tapping (taps of thumb with index finger), hand movements (rapid opening and closing), rapid alternating movements (pronation and supination), leg agility (rapid heel tapping), getting up from a chair, posture, gait, postural stability, body bradykinesia/hypokinesia. A five step severity gradation is used for each motor sign, with 0 representing absence and 4 representing maximum severity of that sign. A total of 108 points is possible, with 108 representing maximal disability and 0 representing no disability. The UPDRSm has been shown to have adequate reliability and validity, high inter-rater reliability (ICC = .90) and intra-rater reliability (ICC = .90), and is widely used in both clinical practice and research (Metman et al., 2004). The BBS is a performance measure designed to measure change in functional standing balance over time. The scale consists of 14 tasks common in everyday life. The items test the participants' ability to maintain positions or movements of increasing difficulty by diminishing the base of support from sitting, standing, to single leg stance. The ability to change positions is also assessed. The 14 item scale rates each function from 0 (worst) to 4 (best) with total scores indicating overall balance abilities: 0 to 20, wheelchair bound; 21 to 40, walking with assistance; 41 to 56, independent (Berg, Wood-Dauphinee, Williams & Maki, 1992). It is widely used, clinically and in research, in both the elderly and PD populations (Finch, Brooks, Stratford & Mayo, 2002). The BBS demonstrates moderate to good validity (Qutubuddin et al., 2005; Brusse et al., 2005) with high inter-rater (ICC=0.74) and intra-rater (ICC=0.87) reliability (Lim et al., 2005). The TUG is a performance measure designed to evaluate mobility, balance, and loco motor performance in the elderly population with balance difficulties. The timed "Up & Go" test measures, in seconds, the time taken by an individual to stand up from a standard arm chair (approximate seat height of 46 cm, arm height 65 cm), walk a distance of 3 meters, turn, walk back to the chair, and sit down again. Although there is significant variability in individual measures, normative values for the TUG have been established in people living with PD. These values range from 13.72 ± 3.9 seconds (Morris et al., 2001) to 14.8 ± 5.8 seconds (Brusse et al., 2005) with a minimal detectable change of 1.63 seconds (Lim et al., 2005). This measure is widely used in clinical and research applications in PD and has demonstrated high inter-rater (ICC = .87) and intra-rater (ICC = .88) reliability (Finch et al., 2002; Morris et al., 2001). These three performance measures comprehensively reflect performance in balance, walking and mobility tasks in people living with PD. The TUG has demonstrated significant correlation with the UPDRSm ($r = .50$, $p < .05$) and the BBS ($r =$

.78, $p < 0.001$). The BBS has also been found to correlate with UPDRSm ($r = 0.69$, $p < .05$) (Brusse et al., 2005).

The Parkinson Disease Questionnaire-39 (PDQ-39) and the Activities-specific Balance Confidence Scale (ABC Scale) are outcome measures selected to address health related quality of life issues and participants' own perception of balance confidence respectively. PDQ-39 is a quality of life scale designed for and validated with clients with PD (Peto, Jenkinson, Fitzpatrick & Greenhall, 1995). It covers mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communication and bodily discomfort. It results in a 100 point score, with lower scores indicating better-perceived health. A number of studies have suggested that it is sensitive to changes in health status (Jenkinson et al., 1997; Peto, Jenkinson & Fitzpatrick, 1998). The ABC Scale is designed to detect loss of balance confidence in individuals of differing functional levels. The scale includes both walking and reaching oriented activities that challenge postural control and activities that are performed both indoors and outdoors. The scale requires participants to rate the degree of confidence they have for completing 16 activities of daily living without falling, with results ranging from 0% (no confidence) to 100% (complete confidence). A score of 67% has been shown to be a reliable means or predicting future falls in elderly individuals without PD (Lajoie & Gallagher, 2004). Although the ABC Scale has not been validated for use in PD, low balance confidence on the ABC scale has been shown to reflect an increase fear of falling in clients with PD (Adkins, Frank & Jog, 2002; Lajoie & Gallagher, 2004). Restoring client confidence in their ability to perform activities of daily living could be essential to avoid the negative consequences of activity restriction and reduced quality of life (Lachman et al., 1998; Shrag, Jahanshahi & Quinn, 2000).

Exercise Program

The exercise program was based on best-practice evidence (de Goede et al., 2001) and on the recommendations of the Parkinson Society of Canada (2003). It was delivered at an Older Adults Community Centre (55+ Centre) by a community fitness facilitator educated through a competency based education training (CBET) approach (Cioffi, Lichtveld, Thielen &Miner, 2003; Hoge,Tondor & Marrelli, 2005). The 8-week community based exercise program was focused upon the physical impairments and functional limitations common to those living with PD. Significant weakness of the respiratory muscles has been demonstrated in those with mild to moderate PD, and can affect individuals during exercise (Haas, Trew & Castle, 2004). Rigidity results in decreased axial and extremity flexibility. Stretching exercises have been shown to improve both flexibility and physical performance in individuals with PD (Schenkman et al., 1998). Strength deficits have also been demonstrated in this population - primarily in the lower extremities. This results in increased fall risk, and difficulties in rising from sitting to standing, as well as changes in parameters of gait (Inkster, Eng, MacIntyre & Stoessl, 2003; Paasuke et al., 2004). In keeping with the literature, the exercise programme was held twice weekly with each session being approximately one hour in length (Lun et al., 2005; Reuter et al., 1999). The exercise programme consisted of the following: warm up exercises which included postural, breathing and aerobic exercises; stretching exercises performed in both standing and sitting positions, with a focus on postural and lower extremity muscle groups; strengthening exercises which also included standing and sitting exercises (closed and open-chain exercises) emphasizing lower-extremity strength; and cool-down exercises which included breathing and aerobic exercises. A complete list of the exercises can be found in Table 1.

Table 1. *Exercise Program*

1-WARM UP 1 Posture in standing (3reps) 2 Diaphragmatic Breathing (5reps) 3 Deep Breathing Exercise (5reps) 4 Cardio Marching on the spot (3-5min)	4-STRETCHING EXCERCISES IN SITTING Hold time 10 seconds 3-5 repetitions 1 Turtle Tuck 2 Forward Stretch in Chair 3 Backward Stretch in Chair 4 Side Stretch in Chair 5 Upper back rotation in chair 6 Arm Raises in Chair 7 Hamstring stretch in chair 8 Ankle Circles 9 Shoulder Blade Squeeze
2-STRETCHING EXERCISES IN STANDING Hold time 10 seconds 3-5 repetitions 1 Posture at Wall 2 Wall Stretch 3 Stretch Tall 4 Stretch arms behind back 5 Calf Stretch	5-COOL DOWN 1 Moderate stepping (3mins) 2 Diaphragmatic Breathing (5 reps)
3- STRENGTHENING EXCERCISES Hold time 5 seconds 5-10 repetitions 1 Weight Shift 2 Backward Leg Swing 3 Heel Raises 4 Toe Lifts 5 Mini Squats behind chair 6 Posture in sitting 7 Knee Extensions 8 Chair Sit to Stand 9 Triceps Strengthening 10 Arm Raises to the side	

Analysis

The changes in outcome measures were descriptively analyzed and 95% confidence intervals were then used to evaluate the measures. A paired Student's t-test was used to assess the statistical significance of the change in outcome measures between baseline and 8 weeks. Only within group comparisons were made and prior to testing, significance levels were established at $p < 0.05$. Effect size for each outcome measure was established using Cohen's d, which was calculated by taking the difference between the means from baseline to 8-weeks divided by the pooled standard deviation. The correlation between the change in outcome measures from baseline to 8-weeks ($_{pre-post}$) and baseline measure ($_{pre}$) was also calculated ($_{pre-post/pre}$) using a paired Student's t-test with a level of significance set at $p < 0.05$.

Results

Baseline characteristics of the participants are presented in Table 2. All participants participated in the pre and post testing as well as the exercise component of the study (11/11). Adherence was evaluated by attendance records completed by the community fitness facilitator during the exercise programme. Participants completed an average of 14.5 (± 0 .4) of 16 exercise classes during the 8-week exercise period (80.9% adherence). No adverse events were reported during the exercise programme. There were no reported changes in PD medication, dose or timing during the study period.

Table 2. *Baseline characteristics of participants*

Participants (n)	11
Male/Female	6/5
Age, yr (mean ± SD)	70.45 (1.98)
Modified Hoehn & Yahr stage (mean)	2.0
Length of disease, yr (mean)	3.27

The mean and standard deviation for each outcome measure at baseline (pre-test) and at eight weeks (post-test) are presented in Table 3. There was a statistically significant improvement in the UPDRSm with a decrease of 8.18 ($p < 0.001$). The change in scores for the ABC Scale, the Berg Balance Scale, the PDQ-39, and the Timed Up and Go were not statistically different ($p > 0.05$). Effect size is presented in Table 3 for each of the outcome measures. Using Cohen's definition of effect sizes as "small, $d = .2$", "medium, $d = .5$", and "large, $d = .8$", the ABC Scale did not demonstrate any effect size in its measurement ($d = 0.006$), the PDQ-39 demonstrated small to medium effect ($d = 0.387$), and a large effect size was demonstrated by the TUG ($d = 1.268$), BBS ($d = 1.591$), and the UPDRSm ($d = 3.619$). Table 3 also contains data on the correlation between the change in outcome measures baseline to 8-weeks ($_{\text{pre-post}}$) and baseline measures ($_{\text{pre}}$) for each outcome measurement ($_{\text{pre-}}$

$_{post/pre}$). Figures 1 to 5 represent the scatter diagrams of these relationships and the lines of best fit, for the ABC scale, PDQ-39, TUG, BBS and UPDRSm respectively. There is no correlation between the changes in outcome measures and the baseline measure for the ABC scale ($r = 0.009$, $p = 0.977$) and a negligible line of best fit. Positive correlations are demonstrated for the remaining four scales by the line of best fit on each graph and by correlation coefficients of $r = 0.740$, $p = 0.009$ for the PDQ-39; $r = 0.690$, $p = 0.019$ for the TUG; $r = 0.672$, $p = 0.024$ for the BBS; and $r = 0.894$, $p < 0.001$ for the UPDRSm.

Table 3. *Changes in outcome measurements in people with Parkinson's disease following eight weeks of training*

Outcome Measure	Baseline	8 weeks
ABC Scale	74.88 ± 4.14	74.85 ± 5.25
Mean baseline to 8-week difference	0.03	
95% CI	-7.28 to 7.33	
p value	p = 0.993	
Cohen's d	d = 0.006	
$\Delta ABC/ABC_{pre}$	r = 0.009	
P value	p = 0.977	
PDQ-39	23.61 ± 4.64	22.07 ± 3.19
Mean baseline to 8-week difference	1.54	
95% CI	-4.63 to 7.71	
p value	p = 0.590	
Cohen's d	d = 0.387	
$\Delta PDQ/PDQ_{pre}$	r = 0.740	
P value	p = 0.009	
Timed Up and Go (TUG)	13.16 ± 1.08	14.37 ± 0.81
Mean baseline to 8-week difference	-1.21	
95% CI	-3.35 to 0.94	
p value	p = 0.238	
Cohen's d	d = 1.268	
$\Delta TUG/TUG_{pre}$	r = 0.690	
P value	p = 0.019	
Berg Balance Scale (BBS)	51.09 ± 1.28	52.91 ± 0.99
Mean baseline to 8-week difference	-1.82	
95% CI	-4.39 to 0.69	
p value	p = 0.138	
Cohen's d	d = 1.591	
$\Delta BBS/BBS_{pre}$	r = 0.672	
P value	p = 0.024	
UPDRSm	28.18 ± 2.79	20.00 ± 1.56
Mean baseline to 8-week difference	8.18	
95% CI	4.68 to 11.68	
p value	p < 0.001*	
Cohen's d	d = 3.619	
$\Delta UPDRSm/UPDRSm_{pre}$	r = 0.894	
P value	p < 0.001	

*statistically significant change. ABC Scale, Activities-specific Balance Confidence Scale; PDQ-39, Parkinson Disease Questionnaire-39; UPDRSm, Unified Parkinson Disease Rating Scale motor subsection; CI, Confidence Interval; Cohen's d represents Effect Size; r represents the Correlation Coefficient. Values are expressed as mean ± Standard Deviation.

Figure 1. Scatter diagram and line of best fit for the ABC scale.

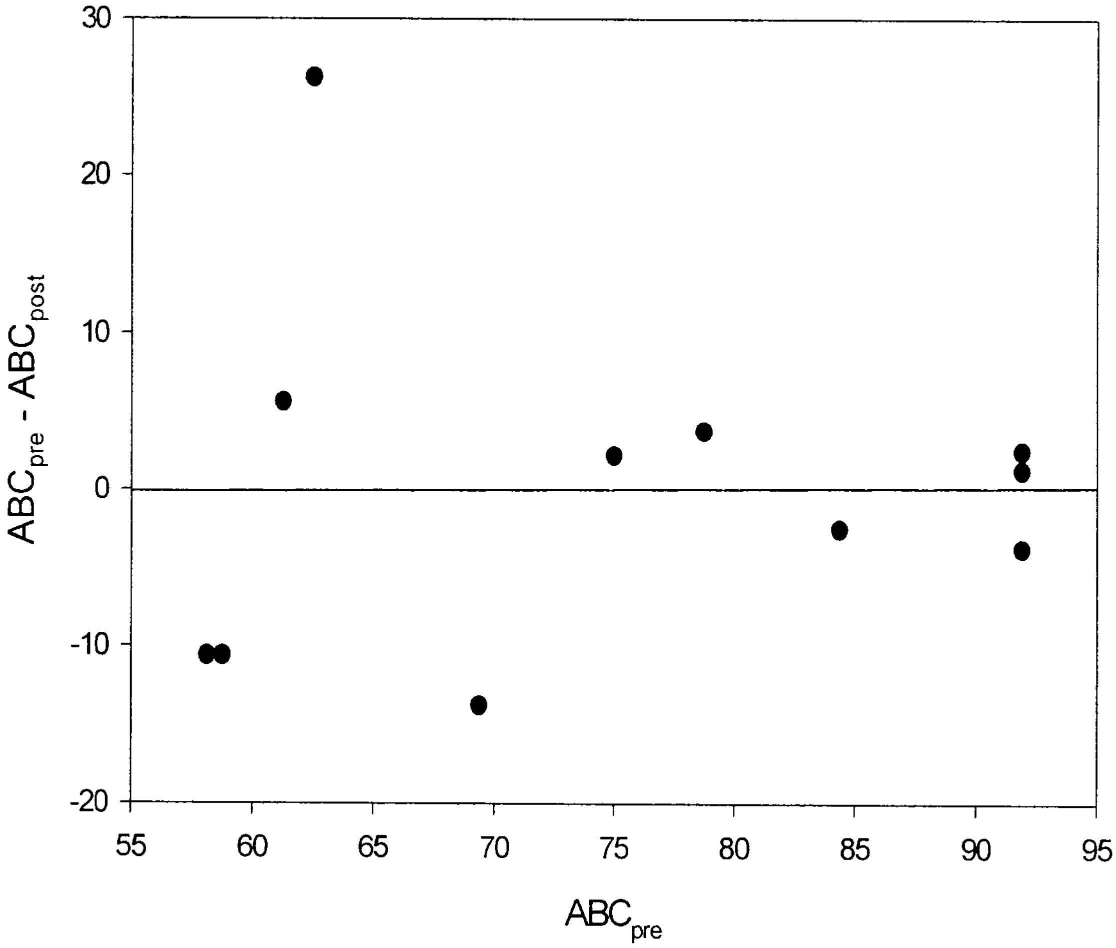


Figure 2. Scatter diagram and line of best fit for PDQ-39.

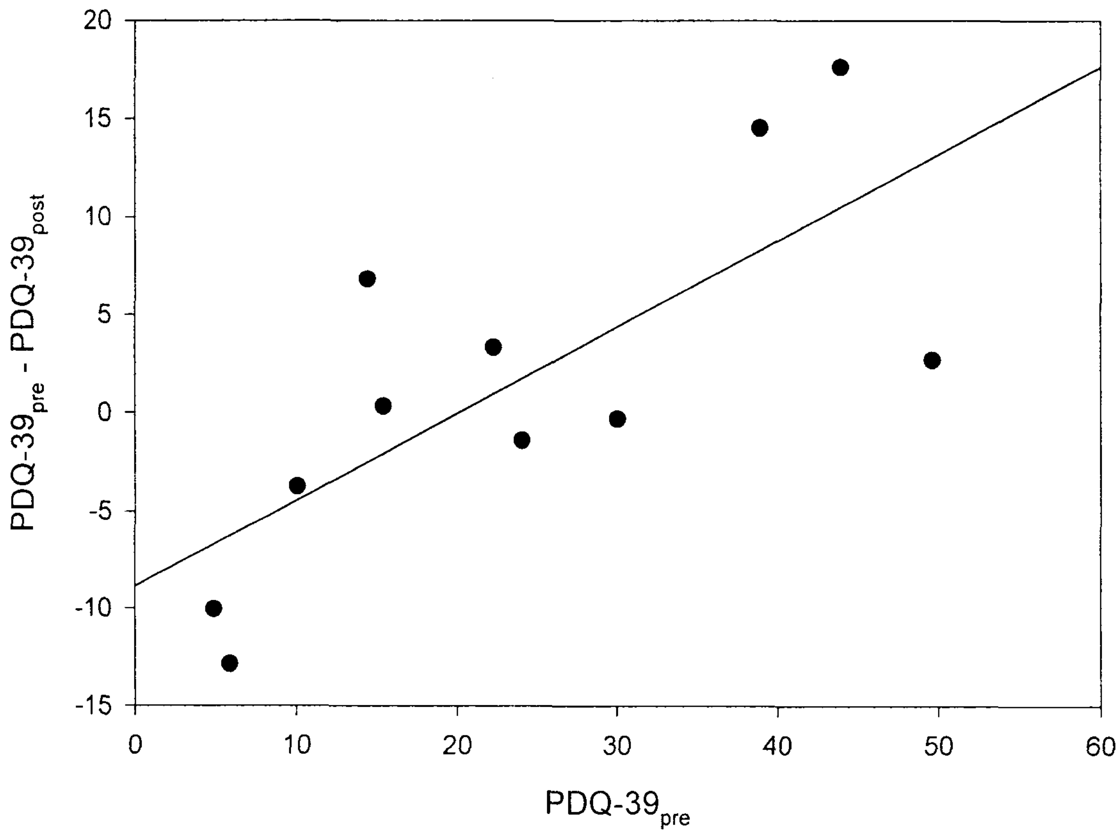


Figure 3. Scatter diagram and line of best fit for the TUG.

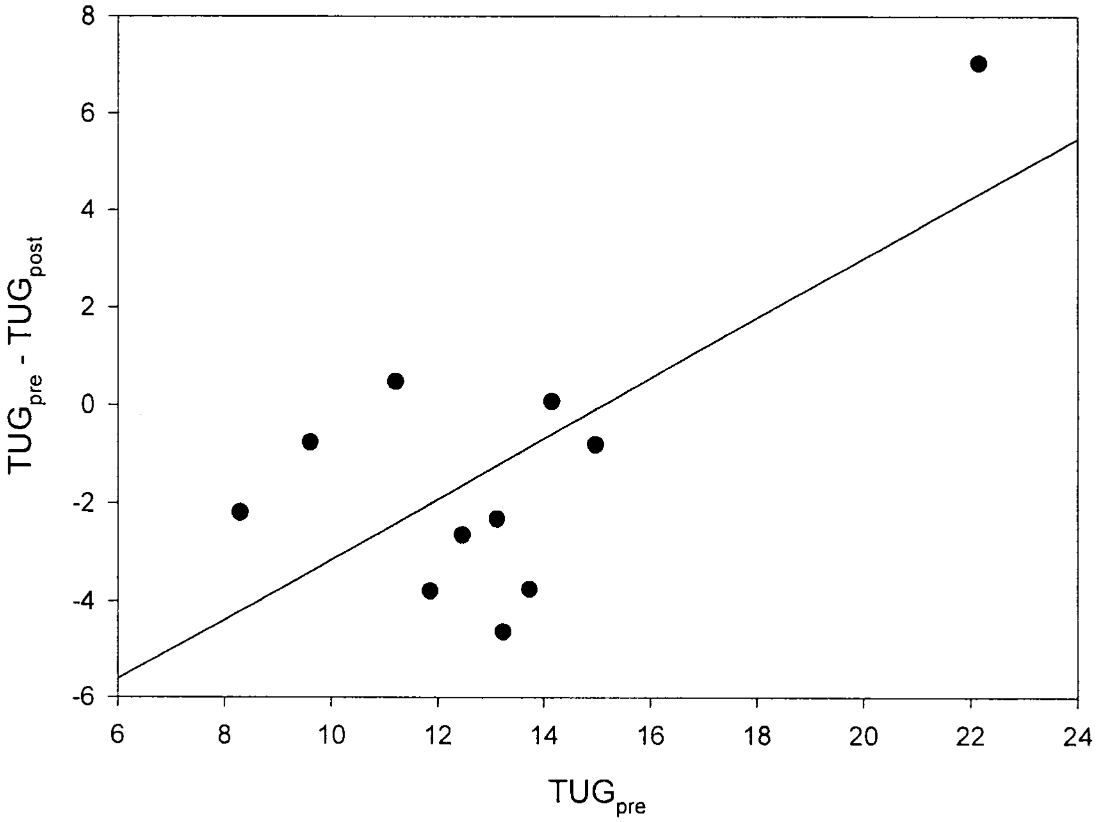


Figure 4. Scatter diagram and line of best fit for the BBS.

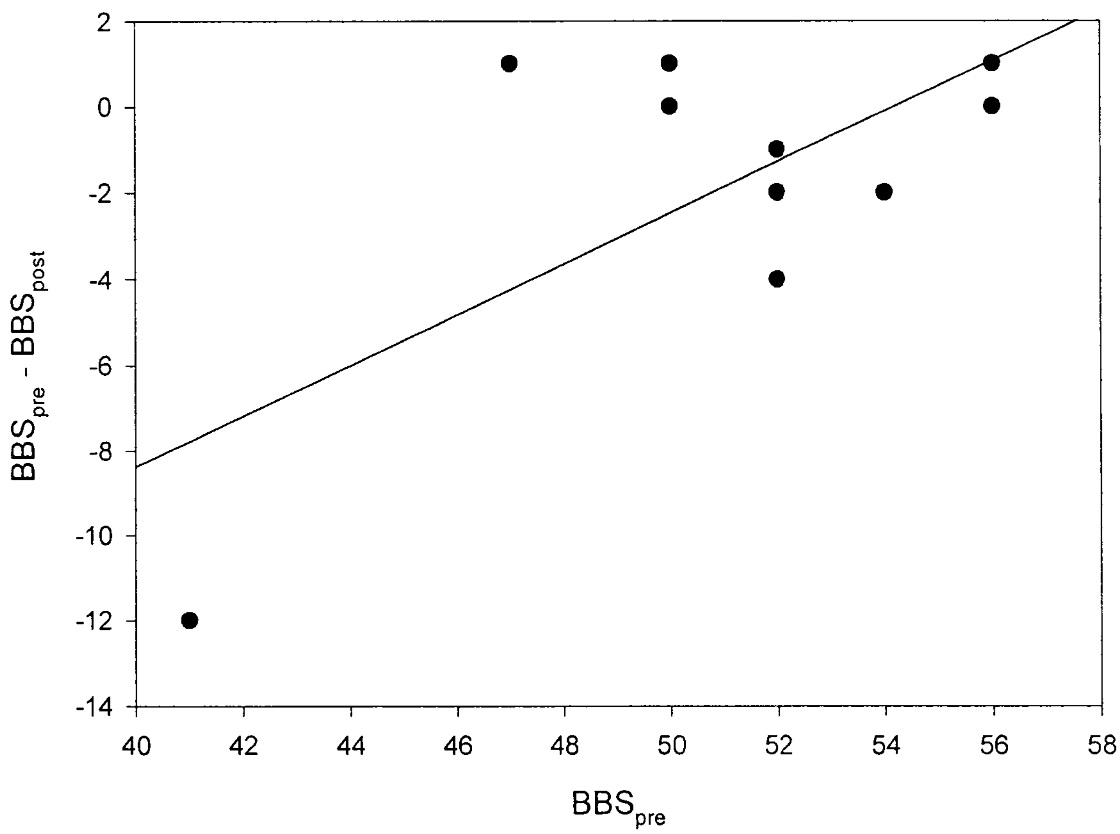
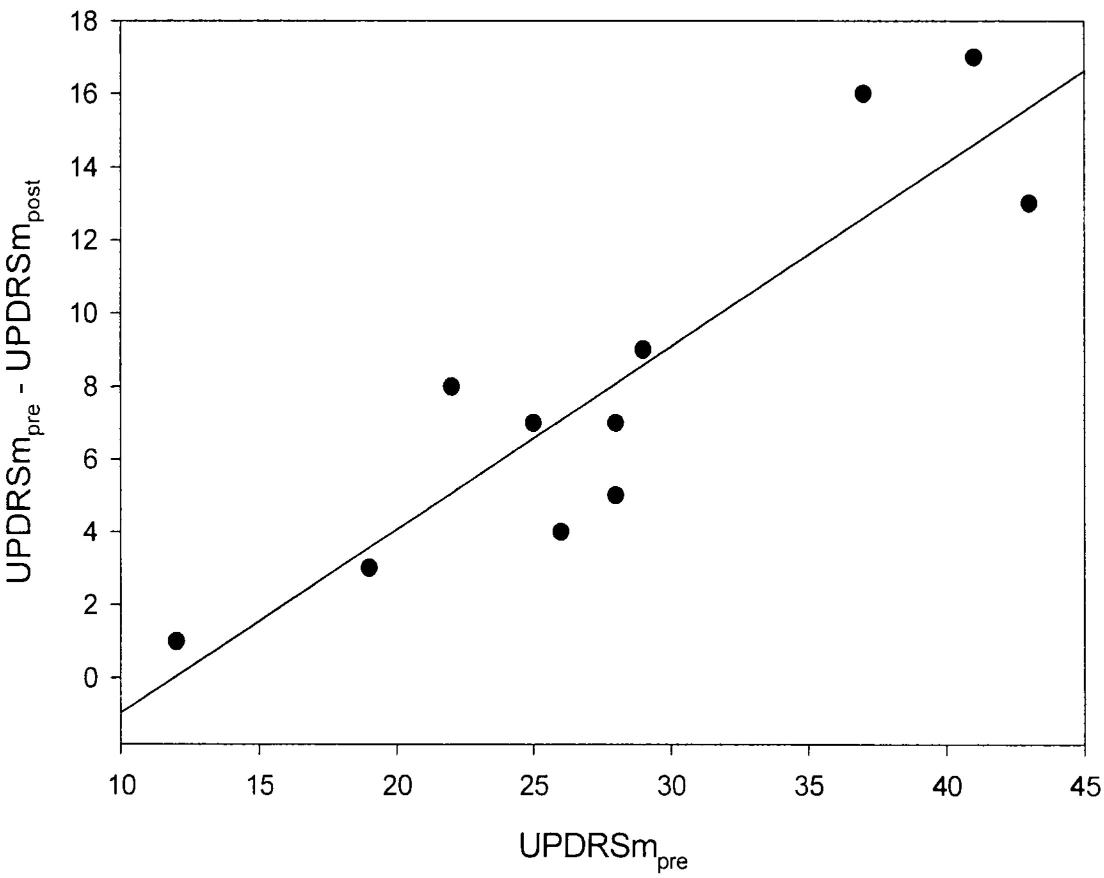


Figure 5. Scatter diagram and line of best fit for UPDRSm.



The scatter diagrams in Figures 1, 3 and 4 demonstrate a picture of heterogeneity with one score scattered far from the other 10 scores. Inspection of the raw data demonstrated that baseline measurements for one participant were all greater than 3 standard deviations from the mean. Although the participant met the criteria for the study, some differences in baseline characteristics were also demonstrated, in that the participant was the only person to use an assistive device (a cane, walker and sometimes a scooter for long distances), the participant was the only person to be clinically assessed at the upper limits of 2.5 on the modified Hoehn and Yahr staging score (group mean of 2), and the participant had the longest disease duration at 11 years (group mean of 3.27). This participant can thus be considered an outlier, with their results having a potentially significant effect on the analysis of the rest of the outcome measures. The data set was therefore, re-analyzed with the removal of this one participant's results. Table 4 presents the baseline characteristics for the remaining 10 participants.

Table 4. *Baseline characteristics of participants with outlier removed*

Participants (n)	10
Male/Female	5/5
Age, yr (mean ± SD)	71.0 (2.11)
Modified Hoehn & Yahr stage (mean)	2.0
Length of disease, yr (mean)	2.5

The mean and standard deviation for each outcome measure at baseline (pre-test) and at eight weeks (post-test) are presented in Table 5 for the remaining 10 participants. There was a statistically significant improvement in the UPDRSm as demonstrated by a decrease of 7.70 ($p = 0.001$). There was a statistically significant increase in the TUG scores of 2.03 ($p = 0.005$), which represents an unexpected finding of a potential worsening of mobility scores. The change in scores for the ABC Scale, the Berg Balance Scale, and the PDQ-39 were not statistically different ($p > 0.05$). Effect size is presented in Table 5 for each of the outcome measures. Using Cohen's definition of effect sizes as "small, d = .2", "medium, d = .5", and "large, d = .8", a medium to large effect size was demonstrated in the ABC Scale (d = 0.624) and in the PDQ-39 (d = 0.419). A large effect size was demonstrated by the TUG (d = 2.519), BBS (d =0.808), and the UPDRSm (d = 3.695). Table 5 also contains data on the correlation between the change in outcome measures baseline to 8-weeks ($_{pre\text{-}post}$) and baseline measures ($_{pre}$) for each outcome measurement ($_{pre\text{-}post/pre}$). Figures 6 to 10 represent the scatter diagrams and lines of best fit of these relationships for the ABC scale, PDQ-39, TUG, BBS and UPDRSm respectively. These scatter diagrams reveal a more homogenous picture amongst the participants as well as a significant correlation between pre and post relationships for the UPDRSm ($r = 0.906$, $p < 0.001$) and the PDQ-39 ($r = 0.866$, $p = 0.001$). There is a lack of correlation between pre and post relationships for the ABC scale ($r = 0.435$, $p = 0.209$), the TUG ($r = 0.086$, $p = 0.813$), and the BBS ($r = 0.148$, $p = 0.684$).

Table 5. *Changes in outcome measurements in people with Parkinson's disease following eight weeks of training (N = 10)*

Outcome Measure	Baseline	8 weeks
ABC Scale	76.13 ± 4.36	78.72 ± 3.94
Mean baseline to 8-week difference	-2.59	
95% CI	-7.52 to 2.33	
p value	p = 0.264	
Cohen's d	d = 0.624	
$\Delta ABC/ABC_{pre}$	r = 0.435	
P value	p = 0.209	
PDQ-39	21.00 ± 4.25	19.58 ± 2.21
Mean baseline to 8-week difference	1.42	
95% CI	-5.49 to 8.34	
p value	p = 0.653	
Cohen's d	d = 0.419	
$\Delta PDQ/PDQ_{pre}$	r = 0.866	
P value	p = 0.001	
Timed Up and Go	12.26 ± 0.66	14.29 ± 0.89
Mean baseline to 8-week difference	-2.03	
95% CI	-3.28 to -0.79	
p value	p = 0.005*	
Cohen's d	d = 2.591	
$\Delta TUG/TUG_{pre}$	r = -0.086	
P value	p = 0.813	
Berg Balance Scale	52.1 ± 0.88	52.90 ± 1.09
Mean baseline to 8-week difference	-0.80	
95% CI	-2.00 to 0.41	
p value	p = 0.168	
Cohen's d	d = 0.808	
$\Delta BBS/BBS_{pre}$	r = -0.148	
P value	p = 0.684	
UPDRSm	26.7 ± 2.63	19.00 ± 1.33
Mean baseline to 8-week difference	7.70	
95% CI	3.96 to 11.44	
p value	p = 0.001*	
Cohen's d	d = 3.695	
$\Delta UPDRSm/UPDRSm_{pre}$	r = 0.906	
P value	p < 0.001	

*statistically significant change. ABC Scale, Activities-specific Balance Confidence Scale; PDQ-39, Parkinson Disease Questionnaire-39; UPDRSm, Unified Parkinson Disease Rating Scale motor subsection; CI, Confidence Interval; Cohen's d represents Effect Size; r represents the Correlation Coefficient. Values are expressed as mean ± Standard Deviation.

Figure 6. Scatter diagram and line of best fit for ABC (n=10).

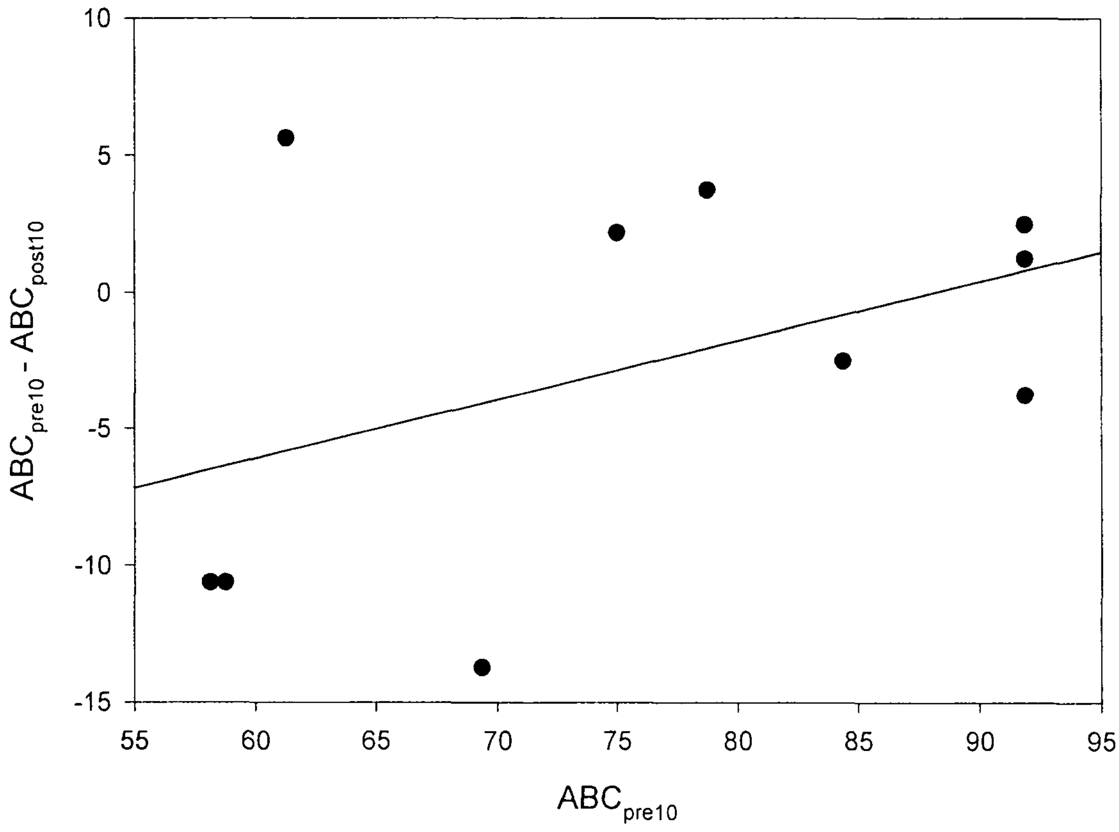


Figure 7. Scatter diagram and line of best fit for PDQ-39 (n=10).

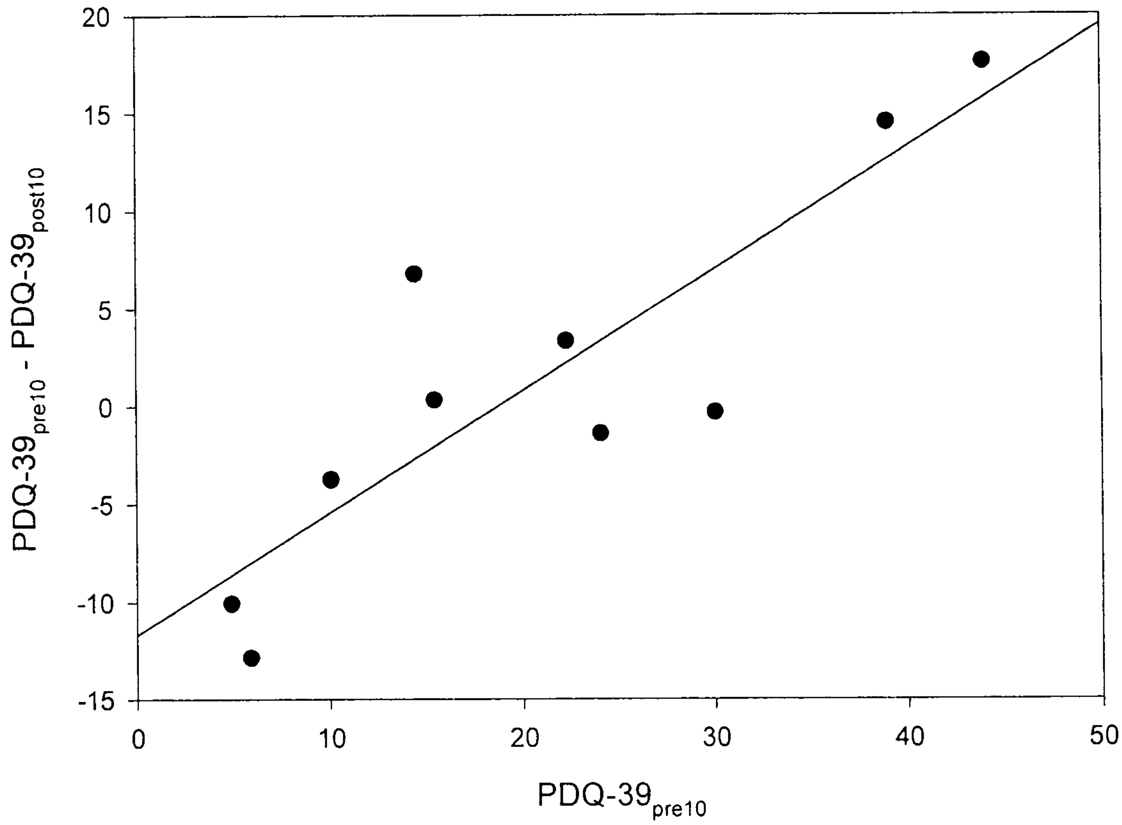


Figure 8. Scatter diagram and line of best fit for TUG (n=10).

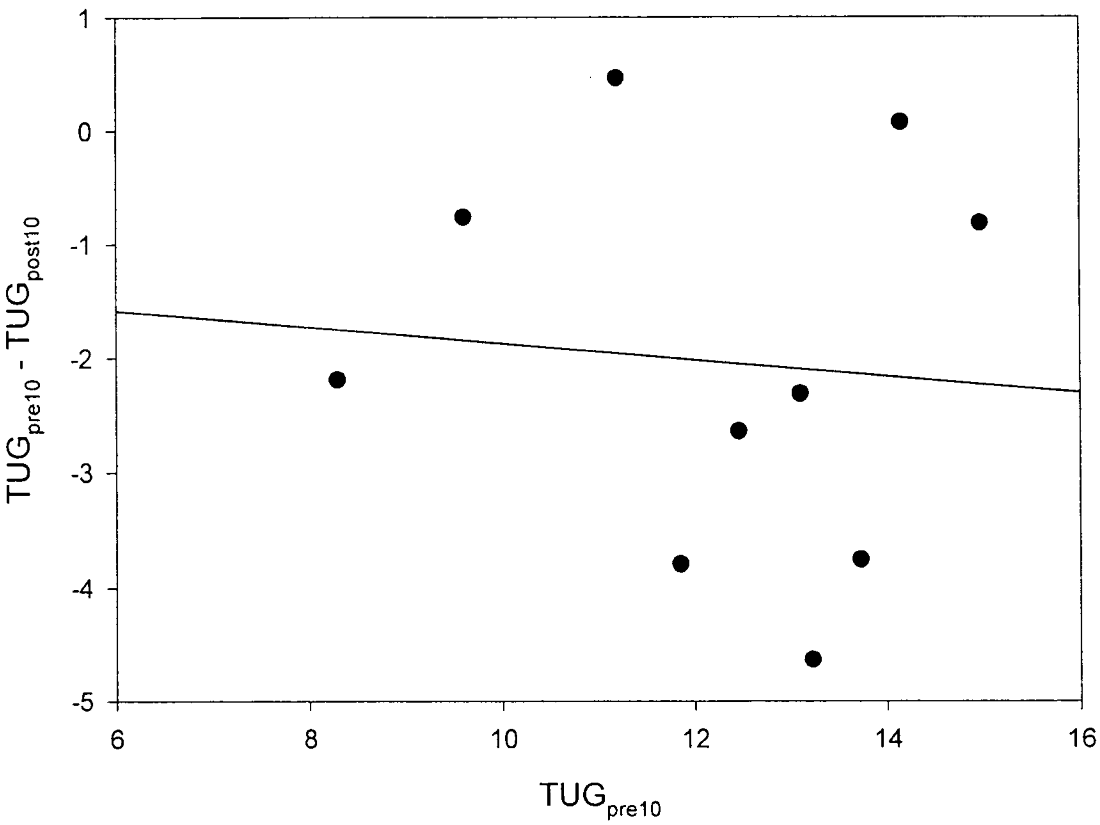


Figure 9. Scatter diagram and line of best fit for BBS (n=10).

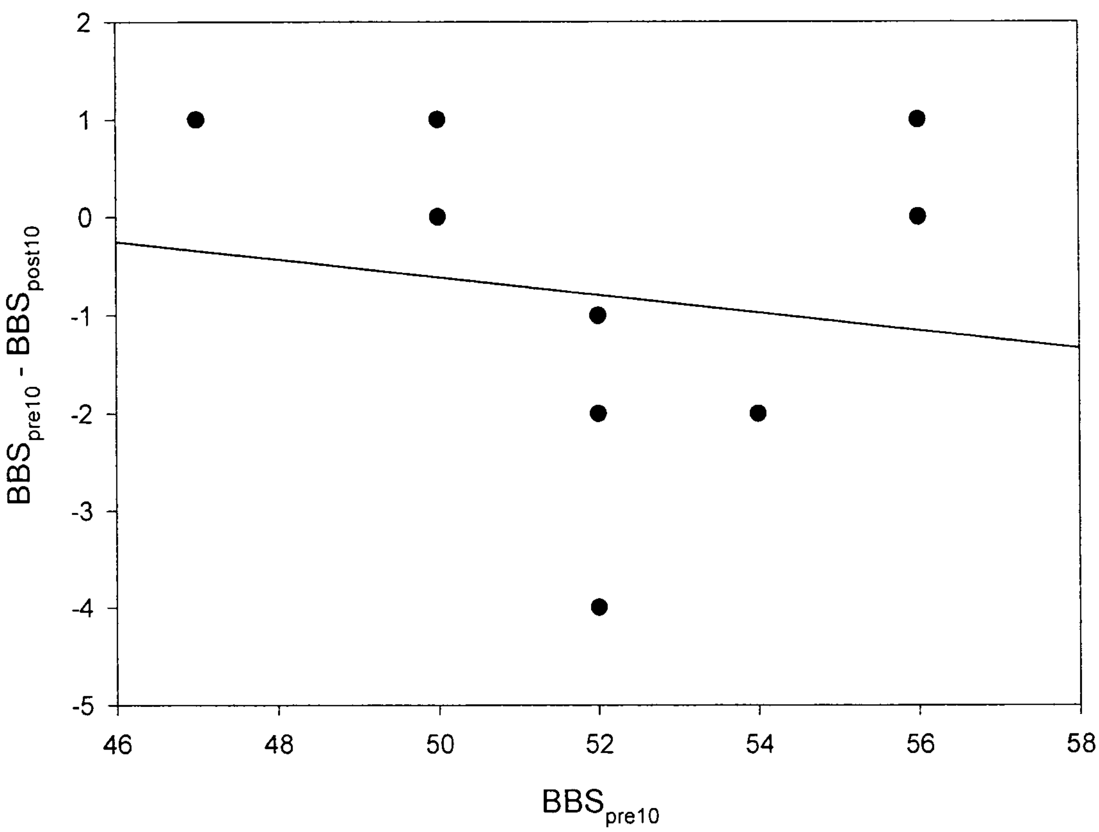
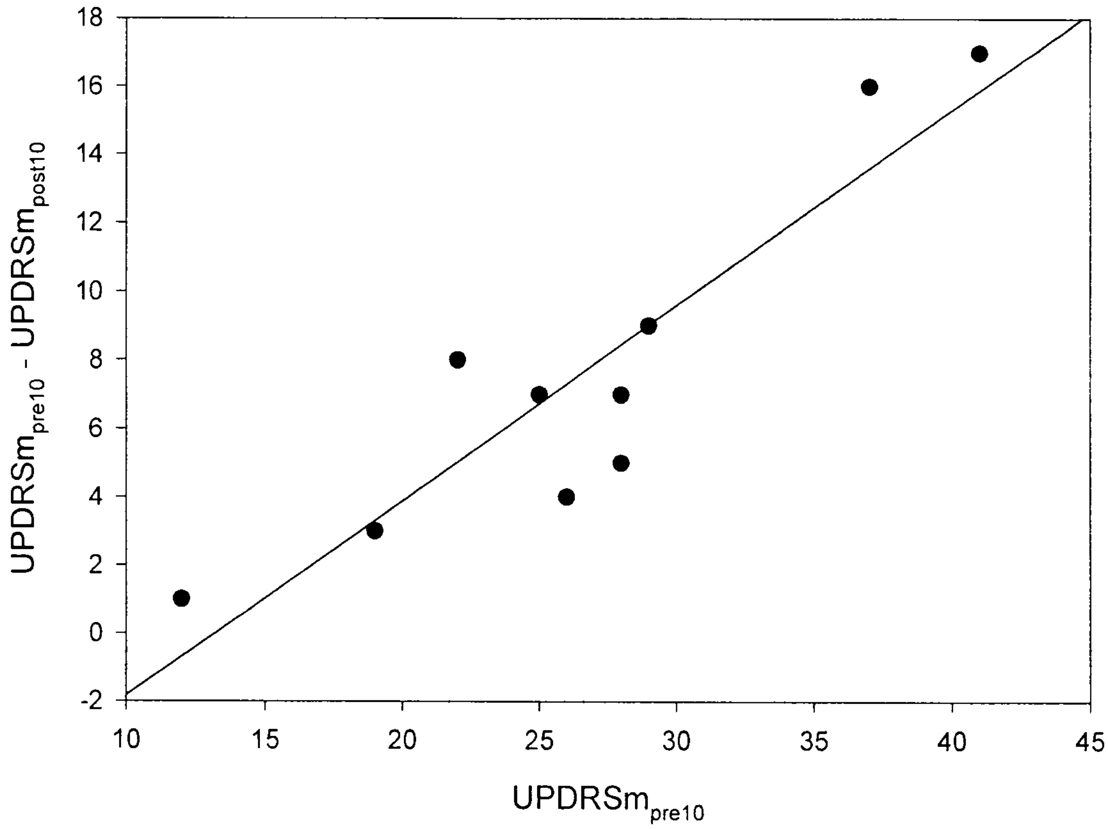


Figure 10. Scatter diagram and line of best fit for UPDRSm (n=10



Discussion

This study was designed to evaluate the impact of an 8-week community based exercise programme developed by physiotherapists and delivered by a community fitness facilitator upon performance and self-report measures in participants with Parkinson disease. There were four main findings: (1) the results showed an improvement in motor symptoms as measured by the UPDRSm, (2) in contrast to typical clinical and research findings a significant increase in the TUG scores was demonstrated, (3) although no significant changes were calculated for the ABC scale, PDQ-39 or BBS, medium to large size effects were demonstrated for all outcome measures indicating sufficient intensity of the exercise programme, and (4) the importance of classification systems for ensuring sample homogeneity is illustrated by the identification and removal of one set of outlying data.

Sample Homogeneity

Initial analysis of outcome measures demonstrated little of statistical significance and an overall picture of participant heterogeneity. Correlation coefficients, scatter diagrams, and lines of best fit representing the change in outcome measures at baseline to 8-weeks as compared to baseline measures, revealed the presence of a set of outlying measures. Upon examination of raw data, it was determined that the outcome measures for one participant were all greater than 3SD from the mean at baseline. The removal of this participant outlier and re-analysis of the outcome measures for the remaining ten participants, revealed statistically stronger results for the outcome measures. The presence of one participant who met the inclusion and exclusion criteria for the study but whose individual outcome measure data varied significantly from the rest of the participants, had a potentially significant statistical effect upon the results. The initial 2-group crossover design included the stratification of participants by gender, age, and Hoehn and Yahr staging. There is considerable intra and inter-individual variability in the symptoms of PD and in the functional abilities of people living with PD (Guttman et al., 2003). Given this inherent variability and the potential for variability within an identified sample population, future research should include the stratification and identification of participants based not only on the inclusion criteria but also on baseline outcome measures. The use of matched sample pairs based on these criteria will help to ensure sample homogeneity.

Impact of Exercise Programme on Motor Symptoms

The community-based exercise programme was found to result in an improvement of motor symptoms as measured by a statistically significant improvement in UPDRSm scores. There was a decrease in the score of 8.18 ($p < 0.001$, n of 11) or 7.70 ($p = 0.001$, n of 10) from baseline to 8 weeks. This finding is consistent with the literature on exercise and PD which has also demonstrated improvement in motor symptoms with exercise (Lun et al., 2005; Reuter et al., 1999).

Previous studies examining the effect of supervised exercise programmes and home exercise programmes on motor symptoms have demonstrated a beneficial effect (Comella, Stebbins, Brown-Toms & Goetz, 1994; Lun et al., 2005; Reuter et al., 1999). Improvements in strength, balance, mobility, activities of daily living and quality of life are also reported (Ellis et al., 2005; Hirsch et al., 2003; Trend et al., 2002). The present study, which evaluated a community based exercise programme delivered by a community fitness facilitator who has received training from a physiotherapist, also demonstrated an improvement in motor symptoms. This exercise programme, designed as a maintenance programme to be used as an adjunct to rehabilitation health care services already in place, has demonstrated clinical value in maintaining and improving motor function.

Both Lun (2005) and Comella (1994) reported a decrease in the UPDRSm score, however as Lun reports in his study "no published studies could be found to indicate what absolute change in the Motor subsection score of the UPDRS is considered clinically significant." (p.974) In this study, independent of the one participant outlier, the UPDRSm demonstrated a statistically significant change as well as a very large size effect ($d = 3.695$) and a significant positive correlation between the change in measures and baseline measurement ($r = 0.906$, $p < 0.001$). This data suggests that sufficient intensity was achieved in the exercise programme to demonstrate significant clinical change. Further studies comparing changes in the UPDRSm with changes in performance and self-report measures are needed to determine the smallest level of detectable change to help identify what magnitude of change is clinically significant and functionally relevant. Motor function has been shown to be relatively stable over time with a trend towards decreasing function as the disease progresses (Schenkman et al., 1997). The improvement in UPDRSm scores demonstrated over an 8 week period during this study, likely reflect improvements in the indirect effects of PD which are those effects that occur along with the disease process, such as aerobic deconditioning, musculoskeletal changes and loss of range of motion from inactivity (Protas et al., 1997). A community based maintenance exercise programme appears to help address these indirect effects of PD by providing a programme focused upon the physical impairments and functional limitations common to those living with PD.

Unexpected Finding

One unexpected change in outcome measures in our study was the statistically significant increase in TUG scores from baseline to the 8 week measurement (2.03, p = 0.005, n of 10). Although individual participant times remained within the normal values established for similar populations of people with PD (Morris et al., 2001; Brusse et al., 2005), almost all participants (9/11) demonstrated increased times for the TUG scores at eight weeks. Clinically, the responsiveness of the TUG as an outcome measure in people living with PD has been established at 1.63 seconds minimal detectable difference (Lim et al., 2005). The raw data for nine out of eleven participants' revealed increases of greater than 1.63 seconds following the exercise programme. The one participant outlier removed from the results was the only participant for whom timed scores decreased (expected direction of change) instead of increased.

There is evidence to show that increased TUG scores relate to increased fatigue levels and increased disease severity (Garber & Friedman, 2003; Thompson & Medley, 1998). However, during the performance of the TUG test at the 8 week point, participants in our study reported subjective improvement in their ability to perform the task, especially the component of sit to stand. The clinical impression was that participants appeared to demonstrate improved control of the sit to stand components at the 8 week point, resulting in safer, but slower movement transitions. All participants chose to rise from and descend into the chair independently without making use of the arm rests. The TUG depends largely on the muscular strength of the quadriceps and hip extensors muscles to arise from a chair. Garber & Friedman studied fatigue and its' effect on physical activity and function in people with PD and they note that "sedentary habits result in reduced muscular strength, agility, balance, and lower cardio respiratory endurance, attributes that are important determinants of performance on the Up and Go Test" (p.1122, 2003). The community based exercise program focused on strengthening and functional exercises for the lower extremities, with an emphasis on chair sit to stand and mini-squats behind a chair. It seems that participants' TUG scores tended to increase at the eight week measure because of a specific focus on training the sit to stand component. Contrary to previous studies which demonstrate a correlation between increased TUG scores and decreased motor function (Thompson & Medley, 1998; Brusse et al., 2005), our participants demonstrated improved control and safety with the sit to stand component of the TUG. This unexpected increase in TUG scores challenges the clinical usefulness of this outcome measure in this particular study. A more specific outcome measure may have been the Expanded Timed Up & Go test (ETUG) (Wall, Bell & Campbell, 2000). This test measures the time it takes to stand, walk, turn around and return to sitting. The phases of the test which are timed and recorded include: sit to stand time, gait initiation time (2 meters), a 6 meter walking speed, time used to turn around, a deceleration speed, and a turn and sit down speed. The turn and sit down speed is a component added by Blackington et al., in their 2002 study on tertiary prevention in PD. The ETUG has potential as a clinical and research tool in that it addresses the component parts of the TUG allowing for more detailed analysis of a mobility measure and for improved targeting of rehabilitation strategies for retraining.

Intensity of the Exercise Programme

No statistically significant differences were observed in the BBS, PDQ-39 or the ABC Scale. This finding was not unexpected as baseline scores were high for the BBS and the ABC Scale, and low for the PDQ-39, not leaving much room for improvement in the scales. Our participants had mild to moderate disease activity (H&Y stage 1 to 2.5) and these outcome measures may not be sensitive enough to detect changes in mobility, balance or self-report measures for this population. Individuals in the early stages of PD have a wide variety of impairments and functional limitations making it difficult for outcome measures to estimate functional improvements when applied to a group of individuals (Schenkman et al., 2002). These performance and self-report measures may demonstrate a limited ability to measure change in motor function and quality of life, in people with mild to moderate PD. However, although no statistically significant results were measured, the effect size for each of these outcomes was significant when the outlier participant was removed. Effect size as measured by Cohen's d, was medium to large for the PDQ-39 ($d = 0.419$) and large for the ABC scale ($d = 0.624$) and the BBS ($d = 0.808$). The implication of the large effect sizes demonstrated within a small study population (n of 10), are twofold. This magnitude of effect size indicates that the intensity of the community based exercise programme was sufficient and that statistically significant changes in these outcome measures may be demonstrated in a larger population sample. The performance and self-report measures used in this study thus appear to be appropriate to this client population and sensitive enough to detect changes in participants with mild to moderate disease activity.

Despite the limited number of participants (11) in our research study, the absence of dropouts and the commitment to the research process is quite unique. The systematic review on rehabilitation for PD by Gage and Storey, reports a wide range of completing subjects from 7 to 84 with a mean of 28 in a series of 25 controlled trials (2004). A review of studies on physical therapy and exercise in PD demonstrates fluctuating adherence rates from as low as 46.7% (Blackington et al., 2002) to 90% (Lun et al., 2005). The present study is one component of a 20-week research project to which the participants consented to and to which all eleven people participated in and completed. This commitment and willingness to participate in research may perhaps be attributed to the advocacy role these participants assumed as active members of the local Parkinson Society Support Group. St. Joseph's Care Group (SJCG) and the local Parkinson Society identified a lack of and a need for an ongoing, physical activity programme for clients with PD. A community based exercise programme delivered in, and by community partners was hypothesized to be one viable solution to meet the ongoing needs of this client population. The Parkinson Support Group advocated the need for an exercise programme as well as for its location in an Older Adult Community Centre. The advocacy role and commitment to research of our participants will be investigated in a subsequent qualitative study.

The current pilot study has demonstrated that a community based exercise programme delivered by non-health care professionals can be provided safely to a group of people with Parkinson Disease. Safety was demonstrated by the absence of any adverse events throughout the 8-week exercise programme. People who have mild to moderate PD, who enjoy exercising in a group, are motivated to attend a community centre, and who have the time, funds and transportation to do so, are ideal candidates for a community based exercise programme. This type of programme also addresses issues identified in the regional rehabilitation health care provider's report which indicated a number of obstacles to receiving rehabilitation services in northern, rural communities. The goal of this programme was to provide support to people with Parkinson Disease through the provision of an appropriate community exercise class. It is also hoped that this unique process of identifying and addressing the needs of a particular client population in Northwestern Ontario will help to facilitate the ongoing development of physiotherapy initiatives which address the changing reality of healthcare.

Limitations and Delimitations

The primary limitation of the present study is the lack of a control group. While the original study was designed to evaluate the impact of an 8-week community based exercise programme versus an education programme, in a 2-group crossover design, the limited pool of participants available at the time of the current study, resulted in a single group pre-post test. Consequently, a pilot study was undertaken to develop and evaluate the impact of an 8-week exercise programme upon performance and self-report measures in people living with PD. An exercise programme has been developed by physiotherapists and delivered safely by a community fitness facilitator to a group of people with PD. A control group is needed to help determine the effectiveness of the exercise programme. A randomized clinical trial is needed to determine what effect a community based exercise programme has on motor function and quality of life in people with PD.

While treatment of Parkinson Disease is primarily aimed at improving motor function, quality of life (QOL) is increasingly being recognized as a critical measure in health care as it incorporates the client's own perspective of their health. The factor most closely associated with QOL in Parkinson Disease is the presence of depression, followed by disability, postural instability and cognitive impairment (Schrag, Jahanshahi & Quinn, 2000).

Numerous studies have demonstrated that depression accounts for 40% of the reduction in quality of life in clients with Parkinson Disease (Karlsen, Larsen, Tandberg, & Maeland, 1999; GPDS 2000). The presence of depression could potentially affect the effectiveness of therapy, if depressed clients are less compliant during exercise sessions.

Conversely, the exercise sessions may affect the depression itself. The clients' mood may improve due to the attention they receive during exercise, and by increased social contact. The Beck Depression Index is a 21 item, self-rated inventory covering a wide variety of cognitive, behavioural and somatic aspects of depression, is a highly validated and sensitive scale used to assess depression and has been used in a number of studies of clients with Parkinson Disease (Vanacore et al., 2004; Viinamaki et al., 2004).

Due to time constraints and a lack of available human resources we were unable to provide therapeutic assessment and treatment if subjects were to have scored at a positive risk level for depression. The BDI was thus dropped from the initial study design at the request of the clinical staff at SJCG.

Stage 1.0 to 2.5 on the modified Hoehn & Yahr scale was chosen as an inclusion criterion for the study. These stages identify the population of people with PD who are living and functioning independently in the community, and are thus the most appropriate population, for a community based exercise programme. Due to the relatively small population of people living with Parkinson Disease in Thunder Bay, and an unknown number of people with stage 1 to 2.5 on the Hoehn & Yahr scale for PD, the number of potential participants for the study was limited. As well, several potential participants were excluded on the basis of recent or anticipated medication changes. Finally, the potential pool of participants was also affected by the length of the study (20 weeks), the time of year (winter months), the need for independent transportation to the community centre and the minimal age requirement of the Older Adult Centre (55 years and older).

Given the limited pool of participants available, only eleven people were included as participants in the present study. As previously reported, the study was modified to a single group pre-test/post- test design which evaluated the effect of an 8 week exercise programme on performance and self-report measures. Because the potential participants had been invited to participate in a research project which included both an exercise and an education component, the eleven participants did receive both components from the original study design. Following the pre-test/post-test data analysis it was decided that there was insufficient change to justify repeating the outcome measures at the end of the 8-week education component. Human resources and physical space were limited and testing was impacting upon the provision of clinical care at SJCG. Given these factors the outcome measures were not repeated following the education component.

Future research

In order to determine the effectiveness of physiotherapy in PD and in particular the effectiveness of community based exercise programmes for people living with PD, it is necessary to develop greater consensus as to the most reliable outcome measures for people with PD who are living and functioning independently in the community. Research is needed to determine valid and reliable outcome measures which accurately assess physical performance and quality of life at all stages of the disease process. The UPDRSm has been shown to demonstrate significant changes in motor function with an exercise programme. Further studies comparing changes in the UPDRSm with changes in performance and self-report measures are needed to determine the smallest level of detectable change to help identify what magnitude of change is clinically significant and functionally relevant. As well, large randomized clinical trials are required to demonstrate the effectiveness of physiotherapy in PD. In particular, outcome measures which have clinical and functional meaning to physiotherapists and to clients should be used wherever possible.

Although this study had a limited number of participants, changes in motor symptoms were demonstrated on the UPDRSm. Further research is warranted with a larger study sample, to investigate longer- term effects of the 8-week exercise programme, as well as the effects of continued participation in a community-based exercise programme. In order to replicate the reality of services found in northern, remote communities, and apply the results of this study to smaller, rural communities, future studies should also include a control group, which receives no intervention for the first time period, and then exercise only for the second period. A 2-group crossover design study would allow for the evaluation of the true impact of this exercise programme. A randomized clinical trail is needed to determine what effect a community based exercise programme, delivered in and by the community, has on motor function and quality of life in people living with PD.

This pilot study has helped to establish a potential framework for future research projects on exercise and PD. Future studies may first help to answer whether there is any long-term effect of an ongoing community based exercise programme and secondly, what role an ongoing community based exercise programme plays in the health care system. A randomized clinical trial should ideally include follow-up, both of longer-tem effects of the 8-week exercise programme and of the effects of continued participation in a community based exercise programme. The potential long-term effects of a community based programme may include investigations into attainable levels of physical fitness in people living with PD and how improved fitness affects motor symptoms and functional impairments. Research into the specificity of the exercises in a maintenance programme may provide information on the effect of exercise on the pathophysiology of PD. This may also include the analysis of direct, indirect and composite effects of PD on exercise. Once the effect of a community exercise programme on performance and self-report measures in people living with PD and the long-term effects of a community programme are established, the role of the community programme within the health care system may be better defined. Future studies may be able to examine the role of an ongoing community exercise programme in relation to the frequency and use of the health care system. There is potential for ongoing participation in a community-based exercise programme to decrease the need for or frequency of, in-hospital rehabilitation treatment programmes. Community exercise programmes may also help to support the health care system through the coordination of planned short (2-4 week) intensive treatment courses provided in hospital by a rehabilitation therapist while participating in an ongoing community based exercise programme. Research into the roles of both community and hospital based programmes has the potential to develop future care plans which help to address the changing realities of health care.

Summary

The initial goals of the research project have been met. In response to the expressed needs of the Northwestern Ontario Parkinson Society Support Group, support has been provided to people living with Parkinson Disease, through the development and provision of a community exercise programme. The identification of a number of obstacles to receiving rehabilitation services in communities across N.W.O. resulted in the need for an alternative form of programme delivery. The use of CBET to train the trainer was a novel approach in health care, which better addressed adult learning needs and helped to ensure the safe delivery of an exercise programme in the community. The present pilot study has demonstrated that a community based exercise programme, developed by physiotherapists and delivered by non-health care professionals, can be provided safely to a group of people with Parkinson Disease. Despite the lack of a control group, the exercise programme also appears to have demonstrated sufficient intensity to elicit changes in motor function, as measured by the UPDRSm, and the potential for changes in all outcome measures with a larger sample population. This preliminary investigation provides a framework for future research in the area of Parkinson Disease and community based exercise programmes.

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Appendices A

Competency Background

Competencies are the knowledge, skills and attitudes needed to effectively perform a role or function (Kaslow et al., 2004). The following six (6) competencies represent the key components of facilitating a community based exercise programme, and reflect the primary goal of delivering a safe and effective exercise programme in the community (Bagnell et al., 1998). The six competencies will be applied to 4 areas: programme design, programme management, support to participants of an exercise class, and social support. The six competencies are:

Analysis: The ability to observe and assess the performance of participants and the conditions that exist within the exercise class. On completion of the training programme, you will be able to analyze and deal with the environment in a systematic way – to examine characteristics present in the situation and to derive meaning from evidence.

Solution generation (problem solving): A multi-step process to identify appropriate solutions for the specific situation or challenges that may be faced.

Value-based decision-making (valuing): The selection of a solution(s) that is consistent with the notion of safe and effective practice, characterized by respect for participants, respect for the design of the exercise programme and the notion of maintaining ones integrity. This refers to your ability to reach decisions that contribute positively to participant involvement in the exercise programme.

Communication: The ability to exchange information in a manner that is clear and time efficient and with a level of language that is appropriate for the audience. It includes all forms of both verbal and non-verbal communication.

Implementation: The ability to translate one's decisions into actions that are consistent with the objectives of the exercise programme, grounded in the mission and vision of the programme and that will contribute to the positive solution of the situation or challenge.

Critical thinking: The ability to reflect critically on the processes used by one's self to analyze the situation, generate solutions, assess validity of solution and decide what to do next.

The competencies are interdependent, as all or some may be applied to deal with a particular situation or task within each of the four areas.

Degree of competence

You will be provided with a specific set of knowledge and skills. Competency will be demonstrated by your ability to reproduce standard answers, skills or behaviours that are associated with well-defined problems linked specifically to the exercise programme and its participants.

Knowledge is limited to the delivery of this exercise programme and to a basic level of understanding and application specifically geared towards Parkinson Disease.
Mastery of skills is determined based on evidence that fundamental elements of the standardized programme are present and respected. On completion of this training programme, it is intended that you will be able to communicate information that is applicable to the situation at hand and be able to establish a positive rapport in the specific setting. The competencies required will assure the safe and effective delivery of the community based exercise programme for people with Parkinson Disease.

How to evaluate competencies

The Task Analysis will be used for self-evaluation at the start of the training programme and again, once you have completed all the components of the programme. The evaluation of your ability to deliver the exercise programme will be assessed through the observation of a trial exercise class. Your ability to deliver the class in a fun, safe and effective manner will be evaluated in the following manner.

Process of evaluating competency in exercise programme delivery

- Observe trainer's delivery of exercise class to a small group of people
- Evaluate delivery of class based on objectives of programme and competencies with strong focus on safe and effective delivery of the exercises.
- Post-class discussion and review

Self-evaluation of competencies by trainer

- Which competencies were achieved (Task Analysis)
- Which ones require ongoing education or support

You will be given the opportunity to learn at your own pace, repeating knowledge sections and practical applications as needed.

Appendices B

Participant summary

People with Parkinson Disease

Physical Status: Parkinson Disease
No history of falls
No musculoskeletal contraindications to exercise
No disorders that affect balance
No unstable medical conditions
Mental Status: Absence of dementia

This is a community based exercise programme that centres on a high level of participation involving an exercise routine that emphasizes a positive experience that helps participants to progress to the best of their abilities and interest.
The programme is delivered by a community fitness facilitator at a level and intensity appropriate to the participants' abilities and needs.

Community based exercise programme - 8 weeks – 2x/week

Objectives

1) Provide a safe and effective maintenance exercise programme for people with Parkinson Disease
2) Focus on physical impairment and functional limitation common to Parkinson Disease
    a) Weakness of respiratory muscles -- deep breathing exercises and aerobic conditioning
    b) Rigidity and decreased flexibility -- stretching exercises
    c) Decreased muscle strength -- strengthening exercises
3) Focus on posture in all exercises
4) Focus on maintaining or improving participants quality of life
5) Create a sense of belonging/ meet other people
6) Be active – improve general fitness level

Fitness Facilitator

- ❑ Novice level – safe and effective delivery of a standardized programme

Appendices C

Task Analysis

People with Parkinson Disease

Competencies Involved

Community based exercise class

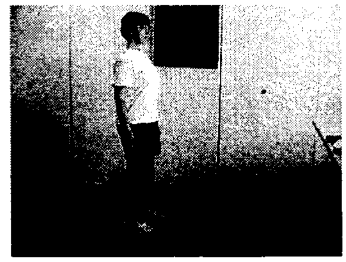
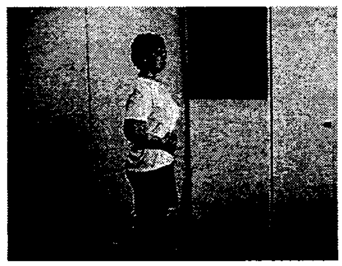
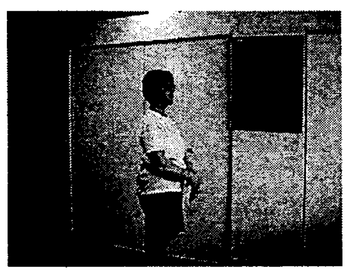
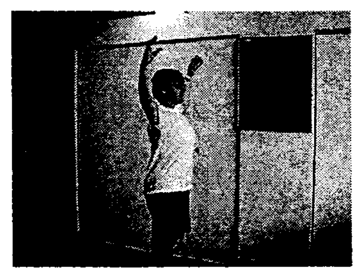
1 Analysis	4 communication
2 Problem solving	5 implementation
3 Valuing	6 critical thinking

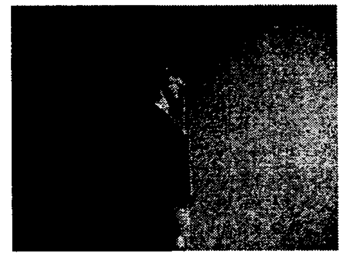
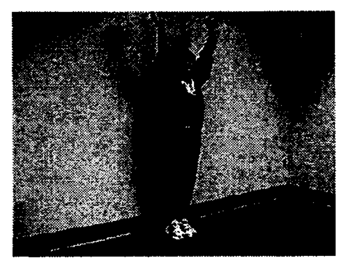
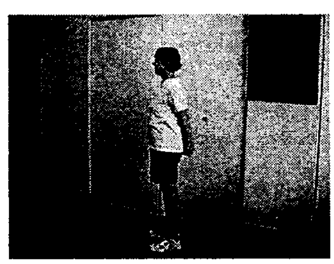
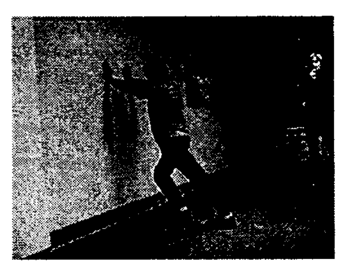
Programme Design: As a Fitness Facilitator I will…	**Importance**	**Time**	**Competencies**
Understand program vision and mission	medium	a little	3
Identify goals and objectives of exercise programme	great	a little	3,6
Demonstrate basic knowledge of Parkinson Disease	medium	a little	3,6
Identify difficulties with movement for people with PD	medium	a little	2,3,6
Understand importance of ensuring proper posture throughout exercise programme	medium	a little	1,3,6
Identify and assimilate the need for exercise in PD	medium	a little	3,6
Identify foundations of exercise programme	medium	a little	3, 6
Identify why, do's and don'ts, and how of each exercise foundation	medium	a little	1,3,6
Identify two methods for monitoring exercise intensity	medium	a little	3,6
Identify common errors and corrections for each exercise	great	a lot	1,3,6
Identify modifications and progressions to exercise	medium	a little	1,3,6
Understand sequence of exercise programme	medium	a little	3,6
Identify resources available for programme support	minimal	a little	3
Programme Management: As a Fitness Facilitator I will…	**Importance**	**Time**	**Competencies**
Identify facility needs	minimal	a little	3,6
Integrate contribution of support resources as needed	minimal	a little	3,6
Interact with facility administrators	minimal	a little	3,4
Follow facility policies and procedures	minimal	a little	3,4
Manage time in exercise class and in preparation	minimal	a little	3

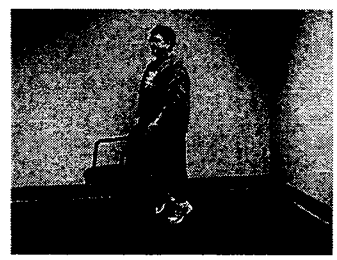
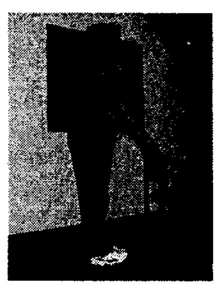
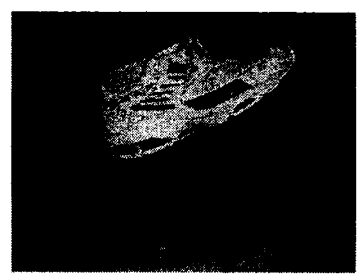
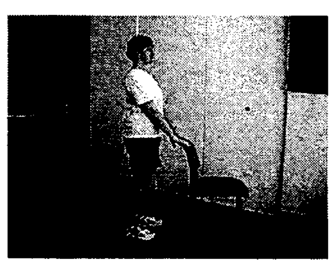
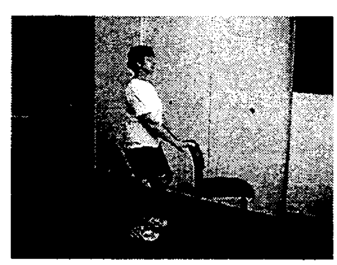
Support to participants of exercise class: As a Fitness Facilitator I will…	**Importance**	**Time**	**Competencies**
Direct/control intensity of activities	great	a lot	2,4,5
Direct/supervise warm-up activities	great	a lot	4
Conduct/supervise exercise programme	great	a lot	4
Direct/supervise cool-down activities	great	a lot	4
Demonstrate exercises	great	a lot	4, 6
Teach exercises	great	a lot	4,5
Observe participant performance	great	medium	1, 4,6
Recognize common errors	great	medium	1,6
Provide feedback to participants	great	medium	1,2,3,4,6
Teach corrected exercise patterns	great	medium	3,4,5
Adjust teaching methods to suit participant	great	a little	2,4,5,6
Teach the basics of good posture	great	a lot	4,5
Observe participant posture throughout exercise programme	great	a lot	1,4,6
Correct posture throughout exercise programme	great	a lot	3,4,5
Ensure environment is safe	medium	a little	1,2,6
Ensure facilities are safe	medium	a little	1,2,6
Ensure equipment is appropriate	medium	a little	1,2,5,6
Set up exercise environment	minimal	a little	1,2,5,6
Manage environmental factors	minimal	a little	1,2,3,4,5,6
Ensure participants exercise safely	great	a little	1,2,5,6
Adjust to unexpected situations	minimal	a little	1,2,5,6
Administer basic first aid	minimal	a little	5,6
Follow facility procedures in case of injury or emergencies	minimal	a little	5,6
Help participants set goals/objectives for exercise	medium	a little	4,5,6
Motivate participants to exercise	great	a little	4,5
Monitor participant progress	medium	a little	1,3,6
Social Support: As a Fitness Facilitator I will…	**Importance**	**Time**	**Competencies**
Promote a positive, constructive environment	great	a little	3,4
Make sure fun is a priority	minimal	a little	3,4
Ensure appropriate involvement of all participants	medium	a little	3,4,6
Provide appropriate attention to each participant	medium	medium	3,4,6
Promote and model supportive conduct	minimal	a little	3,4
Manage conflicts	minimal	a little	3,4,5
Motivate participants to learn	minimal	a little	3,4,5
Listen to participants	minimal	a little	3
Be aware of participant self-esteem	minimal	a little	3
Encourage and support aspects of self-esteem	minimal	a little	3,4,5
Promote group support for each other	minimal	a little	3,4,5
Influence group harmony positively	minimal	a little	3,4
Encourage participants to persevere	minimal	a little	3,4

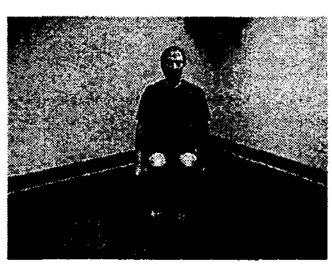
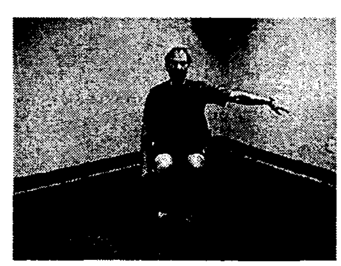
Appendices D

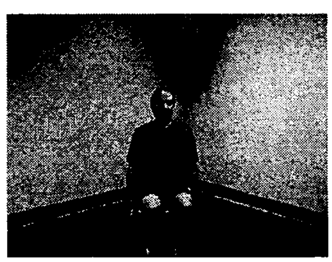
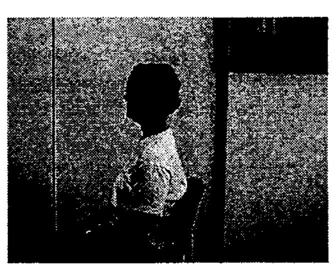
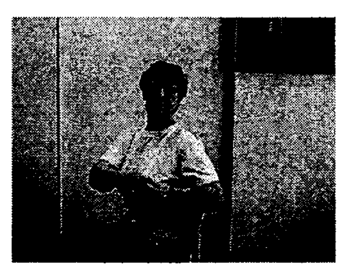
Class Quick Review

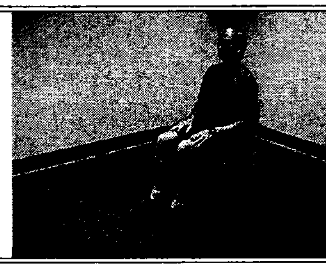
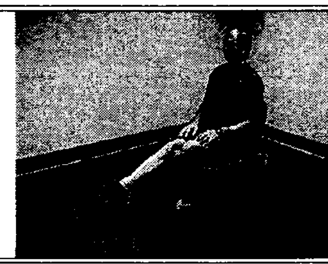
Warm-up		
1. Posture correction *Stand tall with feet shoulder width apart.* *Pull your abdominals in.* *Head and chest up.* *Shoulders rolled back.* *Chin tucked in.* *Thumbs facing forwards with palms facing sides.*		
2. Diaphragmatic Breathing *Standing, gently place palms over lower abdomen.* *Take a full breath in through nose, allowing diaphragm to expand. Abdomen will lift out.* *Slowly breathe out through mouth. Abdomen will pull in.* *Repeat 5 times.*		
3. Deep Breathing Exercise *Stand tall with feet hip width apart.* *Cross arms over one another in front of you.* *Take in a deep breath, begin lifting arms up and open.* *Breathe out, lower arms to starting position.* *Perform for 5 deep breaths.*		
4. Marching on the spot *Stand tall with feet hip width apart.* *March on the spot with small steps for1 minute. Let arms swing naturally.* *High step for 3 minutes.*		

Standing/Stretching Hold 10 seconds, Repeat 3-5 times		
1. Posture at wall *Stand back against wall, feet 2 inches away.* *Pull in abdominal muscles.* *Flatten lower back and shoulder blades against wall.* *Pull chin back towards wall.* *Head does not need to touch wall.* Errors - feet too far from wall, shoulders round, head tips up or down		
2. Wall stretch *Stand back against wall, feet 2 inches away.* *Pull in abdominal muscles.* *Flatten lower back and shoulder blades against wall.* *Pull chin back towards wall.* *Raise elbows to shoulder height and rest forearms on wall* Errors - head pokes forward, low back arches, forearms not touch wall		
3. Stretching tall *Stand back against wall, feet 2 inches away.* *Pull chin back towards wall and reach arms overhead.* *Stretch as though trying to make yourself taller.* Errors - chin pokes, rise onto toes, reach arms back		
4. Stretching arms behind back *Move away from wall.* *Stand with back straight and feet firmly on floor, hip distance apart.* *Clasp hands behind back.* *Gently lift arms up and away from back. Very little movement.* Errors - bend forward from hips, shoulders round, chin pokes		
5. Calf stretch *Stand facing wall, one arms length away. Place hands on wall at shoulder height.* *Step back with left foot.* *Keep left leg straight, gently bend right knee.* *Lean forward into wall.* *Repeat with opposite leg.* Errors- heels up, toes out, bend forward from hips		

Strengthening Hold 5 seconds, repeat 5-10 times each side		
1. Weight shifting *Stand behind chair, legs a little wider apart than shoulder width.* *Rest hands lightly on chair.* *Shift weight slowly onto one leg.* *Hold.* *Shift weight to other leg. Hold.* Errors - body twists/hip drops, foot off floor, feet too far or too close, knees buckle		
2. Backwards leg swing *Stand behind chair, feet couple inches apart.* *Rest hands lightly on chair.* *Keep right leg straight, slowly swing back from hip. Hold.* *Slowly bring leg back to starting position.* Errors - lean forward, bend knee		
3. Heel raises *Stand behind chair, feet couple inches apart.* *Rest hands lightly on chair.* *Push straight up onto toes.* *Hold.* *Slowly lower back down.* Errors - rock back onto heels or forward onto arms, push up using chair		
4. Toe lifts *Stand behind chair, feet couple inches apart.* *Rest hands lightly on chair.* *Lift toes of one foot up off floor.* *Keep knees straight, move from ankle only.* *Hold.* *Slowly lower toes back down.* Errors - lean forward at waist, bend knees		
5. Mini squats behind a chair *Stand behind chair, feet flat on floor hip distance apart.* *Rest hands lightly on chair.* *Slowly do small knee bend. Keep shoulders in line with hips.* *Knees do not bend past feet.* *Hold.* *Slowly straighten up.* Errors - lift heels, stick bottom out, pull up with arms		

6. Seated Posture correction *Sit bottom at back of chair, tuck feet slightly under knees.* *Use book or riser under feet if not touch floor.* *Sit up tall. Pull in abdominal muscles, pull chin in slightly, draw shoulders back.* *Maintain posture throughout seated exercises.* Errors - slouch, shoulders round, chin pokes		
7. Knee extensions *Sit with bottom at back of chair, feet firmly on floor.* *Slowly straighten left knee while tightening thigh muscles. Keep toes pulled up.* *Hold.* *Slowly lower leg.* Errors - quick movement, turn leg out, toes not pulled up, slouching		
8. Chair sit to stand *Scoot bottom forward to edge of chair, feet flat on floor shoulder width apart. Tuck feet slightly under knees.* *Place hands on thighs, push up into standing.* *Slowly lower back down onto chair.* Errors - rock forward, "plunk" onto chair, feet slide		
9. Triceps strengthening *Sit bottom at back of chair, feet firmly on floor. Slide bottom to right side of chair.* *Place left hand on left thigh for support. Lean forward at waist, keep back straight.* *Raise right elbow behind you to 90 degrees.* *Straighten elbow – "kickback" Keep shoulder and upper arm still.* *Hold. Bend elbow back down.* Errors - slouch, elbow drifts down, quick movement		
10. Arm raises to the side *Sit bottom at back of chair, feet firmly on floor.* *Place arms at side.* *Slowly raise left arm up to just below shoulder height.* *Keep elbow straight and palm facing floor.* *Hold.* *Slowly lower arm back down.* Errors - slouch, arm drifts forwards, shrug shoulder		

Seated/Stretching Hold 10 seconds, repeat 3-5 times each side		
1. Turtle tuck *Sit with bottom at back of chair, feet firmly on floor.* *Pull abdominal muscles in and sit up tall.* *Pull chin straight back.* *Hold.* Errors - slouch, tuck chin to chest, arch back over chair		
2. Forward stretch in chair *Sit with bottom at back of chair, feet firmly on floor.* *Slowly relax forward- roll head, shoulders and back down towards floor.* *Let arms and head hang down.* *Hold.* *Slowly roll back up to starting position. Begin with low back, upper back, shoulders and let head come up last.* Errors - poke head up on way down, lead with head on way up, slouching		
3. Backwards stretch in chair *Sit with bottom at back of chair, abdominals pulled in.* *Lightly rest fingers at base of skull.* *Slowly lean backwards over chair- keep ears in line with shoulders. Hold.* Errors - poke chin/pull head forwards, elbows drift out, slouch		
4. Side stretch in chair *Sit with bottom at back of chair, feet flat on the floor. May sit to one side of chair.* *Lift right arm up to the side and slowly reach over head to opposite wall. Anchor left arm on chair. Hold.* Errors - lean forwards, drop shoulder and tip to side, poke chin out		
5. Upper back rotation in chair *Sit with bottom at back of chair, feet flat on floor.* *Place left arm on back of chair.* *Reach around in front of you with right arm to grab back of chair on left side.* *At the same time turn head and look back over left shoulder.* *Hold.* Errors - slouch, tip head back, struggle to reach back of chair		

6. Arm raises in chair *Sit with bottom at back of chair, feet flat on floor.* *Clasp hands together in front, slowly lift arms overhead taking a deep breath in.* *Hold.* *Slowly lower arms back down as you breathe out.* *Repeat.* *Use wand or cane if available.* Errors - arch low back, round shoulders, poke chin out		
7. Hamstring stretch in sitting *Sit at edge of chair with right leg bent (foot flat on floor) and left leg straight resting on heel.* *Sit up tall, lean forward from hips.* *Hold.* Errors – slouch, knee bends, poke chin out		
8. Ankle circles *Sit with bottom at back of chair.* *Left foot on floor, lift right foot up off floor.* *Move right foot in slow complete circles.* Errors - move entire leg, small or incomplete circles		
9. Shoulder blade squeezes *Sit with bottom in middle of chair seat, feet firmly on floor.* *Tuck elbows in at sides at 90 degrees.* *Pull shoulder blades back and down in a V movement.* *Hold.* Errors - slouch, throw shoulders back, poke chin out		

Cool-down		
1. Marching *Stand tall with feet hip width apart.* *Maintain moderate stepping for 3 minutes to cool down the body.* *Keep arms swinging at sides.*		
2. Diaphragmatic Breathing *With good standing posture do 5 slow deep breaths in and out to cool the body down.*