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Identifying the Types of Physical Exercise that Help Individuals with Parkinson's Disease Manage Their Symptoms: A Modified Delphi Study

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**Identifying the Types of Physical Exercise that Help Individuals with Parkinson's
Disease Manage Their Symptoms: A Modified Delphi Study**

by

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A Thesis

Submitted to the Graduate Faculty of

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Master of Science in

Exercise Science

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Abstract

It is largely accepted that exercise results in short-term benefits that have a positive effect on activities of daily living and quality of life. Similarly, there is growing evidence that exercise results in long-term benefits^{36,42-44,48,63,67,69,71}. Despite the growing awareness of benefits of incorporating exercise as a part of therapy, there is little consensus on ideal dosages and types of exercise needed to target the wide range of symptoms that occur with Parkinson's²⁶. The purposes of this study were to identify types of exercise people with Parkinson's have used for symptom management and to determine which types they have found most beneficial in relieving the symptoms of Parkinson's. The results will help future researchers use resources efficiently by identifying interventions with high benefit potential that avoid barriers and directing future research away from areas with low benefit potential. The 10 most common types of exercise identified through this modified Delphi study were walking, cycling, yardwork, Static Exercises, resistance training, stretching, Slow Moving Exercises, dancing, Physical Therapy, and Speech Therapy. This list provides some direction for future research by identifying common types of exercise that people with Parkinson's are willing and physically able to do at some point throughout the course of their disease. Investing future resources to identify better intervention strategies for any of these types of exercise may be warranted since innovations could influence a large percentage of the Parkinson's community. Once the ten most common types of exercise were identified, subjects determined which types they have found most beneficial in relieving the symptoms of Parkinson's. Results identified walking, stretching, resistance training, and cycling as relatively high ranked types of exercise. Therefore, all 10 types of exercise warrant future research but walking, stretching, resistance training, and cycling may provide additional benefits from the investment of future resources.

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Part 1: Review of Literature

Overview of Parkinson's Disease

Prevalence

Idiopathic Parkinson's disease (Parkinson's) is the second most common neurodegenerative disease after Alzheimer's disease. The prevalence of Parkinson's in industrialized countries is estimated to be 0.3% of the entire population and about 1% of people over the age of 60¹. Currently, about one million Americans and between seven to 10 million people worldwide have been diagnosed and are living with the disease. Each year in the United States, there are approximately 60,000 newly diagnosed patients with men having one and a half times greater risk than women. Since age is a major risk factor, as the baby boomer generation ages Parkinson's is expected to impose an increasing social and economic burden on our society in the future².

Pathophysiology

The basal ganglia refer to a large and functionally diverse group of nuclei located deep within the cerebral hemispheres. Select nuclei in the basal ganglia work together with the substantia nigra pars compacta (SNpc) and the subthalamic nucleus in the ventral thalamus to make up the subcortical loop. The subcortical loop has a large influence in human movement as it links most areas of the cortex with upper motor neurons in the primary motor cortex, premotor cortex, and the brainstem. When functioning properly the basal ganglia partially inhibits the thalamus, which results in the thalamus having an appropriate excitatory influence on upper motor neurons. Parkinson's disease is characterized pathologically by a relatively selective loss of midbrain dopaminergic neurons in the SNpc. Normally the SNpc provides

appropriate dopaminergic input to select nuclei in the basal ganglia. The cell death in the SNpc throughout Parkinson's causes an imbalance in neurotransmitter levels throughout important basal nuclei that result in an increased inhibitory outflow to the thalamus. Since the thalamus has excitatory influence on upper motor neurons, the increased inhibitory effects from the basal ganglia cause decreased levels of motor excitation³. Consequently, the loss of these dopaminergic neurons cause many of the motor symptoms in Parkinson's including bradykinesia, resting tremor, rigidity, and postural instability⁴. It is important to clarify that Parkinson's being a result of dopaminergic neuron degeneration in the SNpc is a common and over simplistic view that only addresses a small part of the pathology of Parkinson's. With this neuron death, there must also be an accumulation of intracellular fibrillar aggregates called Lewy bodies. Strictly speaking, Lewy bodies are masses of misfolded and insoluble proteins found in the cell body and terminals of dopaminergic neurons. In addition to the SNpc, dopaminergic neuron death is present throughout the brain including tegmental area and other catecholamine-containing neurons, such as the locus ceruleus⁵. The complex network of interactions involving many normal functioning and dysfunctional nuclei throughout the brain result in the extensive list of motor and non-motor Parkinsonism symptoms.

Although the initial causes and mechanisms of Parkinson's are still unknown, there are accepted factors involved in the disease. These include mitochondria dysfunction, protein degradation dysfunction, Lewy bodies, α -synuclein, oxidative stress, neuroinflammation, and injury susceptibility of catecholamine-containing neurons⁵. General risk factors include things that negatively affect one or more of these factors. There are many known risk factors and the

literature is extensive⁵⁻¹³. However, if all subtypes of Parkinson's are included, risks can be generalized as oxidative stress, genetic, environmental toxins, endogenous toxins and head trauma¹¹⁻¹³.

Clinical Diagnosis

Clinical diagnosis of Parkinson's focuses primarily on the motor symptoms and usually requires the manifestation of at least two of the following symptoms: resting tremor, bradykinesia, rigidity, and/or postural instability. In addition to the presence of motor symptoms, asymmetric symptom onset and response to the primary anti-Parkinson medication that increases concentrations of dopamine in the brain, levodopa, are supportive for a diagnosis of Parkinson's and help rule out other diagnoses¹⁴. A pathological diagnosis requires an autopsy with the finding of Lewy bodies and degeneration of catecholaminergic neurons post-mortem^{15,16}. Although these criteria seem straight forward, Parkinson's is challenging to clinically diagnose especially during early stages for many different reasons. The first signs and symptoms are often subtle and vague which can often be overlooked, possibly by being assumed to be a normal part of aging or a part of a separate disorder or condition.

Even when the disease progresses and symptoms become more prominent, the expression of symptoms happens in a non-patterned manner. Neither the rate of disease progression nor the combination of experienced symptoms can be predicted. One example is resting tremor, which is considered one of the hallmarks of Parkinson's. A study by Hughes and colleagues reported 69% of patients with Parkinson's had resting tremor at initial diagnosis and only 75% of these same patients experienced resting tremor over the course of

their disease. In addition, 9% of those patients who experienced this symptom became tremor free late in the disease¹⁷. Even a study with high tremor presence reported that 11% of their subjects never experienced this¹⁸. Because of this, disorders such as Essential tremor, arteriosclerotic (vascular) pseudoparkinsonism, drug induced parkinsonism, multiple system atrophy, and progressive supranuclear palsy are often misdiagnosed as Parkinson's. Autopsy studies over the past three decades report correct clinical diagnoses ranging from 76-90%¹⁷⁻²⁰.

Current Treatments

The primary treatment option is the clinical administration of the anti-Parkinson medication levodopa, often in combination with other anti-Parkinson medications. Although pharmacologic therapies are appropriate early in the disease, levodopa loses effectiveness over time and leads to distressing side effects, such as dyskinesias. After levodopa loses its ability to effectively suppress symptoms, patients and health care providers often turn to neurosurgical options, such as deep brain stimulation. Although neurosurgical interventions are often initially effective at relieving patients' symptoms, these treatments come with additional risks and limitations²¹. Even with the combined use of pharmacologic and neurosurgical therapies, the progression of the disease consistently results in inadequately managed symptoms that lead to a general decrease in physical activity, an increased risk of falling, immobility, and cognitive impairments^{22,23}.

The current deficits in the treatment of Parkinson's show a potential for significant benefits in identifying supplemental therapies that, in combination with pharmacologic and neurosurgical therapies, can further aide patients in their symptom management. This has led to some authors suggesting alternative treatment options to slow disease progression and help

patients maintain movement control^{21,24}. In recent years, supportive evidence for including physical therapy in the management of Parkinson's has grown and is now included in select national management guidelines²⁵⁻²⁸. This has led to an increased number of referrals, with a survey by Parkinson's UK in 2008 reporting that 54% of the 13,000 participants had seen a physiotherapist, compared with only 27% in a similar survey undertaken in 1998^{29,30}.

Exercise Interventions for Symptom Management

Increasingly over the past few decades, there have been numerous studies that have focused on exercise interventions to alleviate the motor and non-motor symptoms of the disease³¹⁻⁷¹. Due to the diversity of Parkinsonism symptoms, researchers have investigated the benefits of many different types of exercise programs in an attempt to identify ideal interventions for patients with Parkinson's. Although many forms of exercise have shown promising results for treating specific problems experienced in Parkinson's, ideal interventions remain undetermined. The subsequent sections attempt to review motor related issues and the potential benefits of cardiovascular, neuromotor, flexibility, and resistance training.

Cardiovascular Training

Alterations in gait are normal as people age. People, on average, transition to a more stable gait. Compared to young healthy people, elderly gaits have increased coactivation, slower natural walking velocity, reduced stride length, wider step width, increased double-support stance time, decreased push-off power, and a more flat-footed landing⁷²⁻⁷⁴. The cause of altered gait appears to be a result of decreased muscle strength, balance, joint mobility and cardiovascular fitness⁷⁴. Although this is advantageous in some ways, such as preventing falls,

it comes at a metabolic cost. As a result, people have to expend more energy, causing them to have to work at a relatively higher intensity. Elderly people also experience a progressive decrease in their aerobic capacity⁷⁵. This combination can result in elderly people having to work at a much higher percentage of their VO_{2max} during daily activities. As long as this does not become excessive, mobility and quality of life can remain unaffected.

In addition to this “normal” decline in walking capacity as one ages, the symptoms that patients with Parkinson’s experience also contribute to a functional decline. This puts them at an increased risk to lose their mobility and experience a decline in quality of life. Part of this is because most patients have difficulty walking. Gait disturbances are often considered one of the hallmarks of Parkinson’s and have been studied extensively⁷⁶⁻⁷⁹. At initial diagnosis, gait alterations are often undetected and may have little to no impact on the patients’ mobility. During the early stages of the disease, alterations in gait often include increased stride length variability and reduced gait speed⁷⁶. As the disease progresses and symptoms become more severe, gait alterations become increasingly debilitating^{77,78}. In the later stages of the disease, the symptoms usually lead to the inability to walk and becoming wheelchair bound. Characteristics of Parkinson’s gait typically includes reduced walking velocity, shorter stride length, increased stepping frequency, stooped posture, rigidity, freezing, reduced arm swing, instability, asymmetry, diminished left-right bilateral coordination, and stride-to-stride variability compared to age-matched controls⁷⁹.

Although Parkinson’s gait has been studied extensively, there have been very few studies that have looked at economy of movement in people with Parkinson’s^{31,76,80,81}. In the earliest study on economy in patients with Parkinson’s, Protas and colleagues⁸⁰ compared

exercise performance between eight men with Parkinson's and seven healthy age-matched subjects during two exercise testing protocols; one using a bicycle ergometer and the other using an arm-cranking ergometer. They reported that subjects with Parkinson's had a reduced lower body and upper body peak power compared to the age-matched subjects. In addition, their results (based on graphs since no statistical comparisons were given) showed that subjects with Parkinson's had the same VO_{2max} as controls but had a VO_2 about 20% higher at the same power outputs throughout both tests. Thus, providing the first evidence that people with Parkinson's may have a poor economy of movement by finding increased energy consumption at given power outputs⁸⁰.

Stanley and colleagues⁸¹ later performed a similar study comparing exercise performance using 13 men and seven women with Parkinson's to healthy gender and age-matched subjects during an exercise testing protocol using a bicycle ergometer. The study had similar results showing that, when compared to age-matched controls, men with Parkinson's had the same VO_{2max} , reduced lower body peak power, and elevated VO_2 at the same power outputs. While there was a trend for women with Parkinson's to consume more oxygen, it was not significantly different from controls⁸¹. Interpretations of their results are difficult since the data in both studies by Protas and colleagues had low statistical power because of small sample sizes. While their results provided the first hint that patients with Parkinson's may have poor economy during cycling activities, studies addressing movement economy during activities of daily living in patients with Parkinson's appears to be lacking in the literature during this time period.

Several years later, Christiansen et al.⁷⁶ performed a study to determine if walking economy is atypical in subjects with Parkinson's. They compared VO_2 during treadmill walking between 90 Parkinson's patients and 44 control subjects at walking speeds from 1.0-3.5 mph at 0.5 mph increments. Across all speeds, VO_2 was 6-10% higher in Parkinson's patients with larger differences at faster walking speeds. Based on their data, they concluded that walking economy was significantly worse in Parkinson's patients than in controls at all speeds above 1.0 mph⁷⁶. Their findings agreed with previous studies^{80,81}, in that patients with early to mid-stage Parkinson's have a relatively poor economy of movement, specifically the movement of walking. In the most recent investigation, Katzel et al.³¹ measured economy of gait during submaximal treadmill walking in 79 subjects with Parkinson's. They reported that patients with Parkinson's averaged 64% of VO_2 peak at their self-selected treadmill walking speed with 3 subjects approaching 90% of their VO_2 peak. This study suggests the physiological stress during activities of daily living is increased in Parkinson's patients, and is believed to contribute to the elevated level of fatigue that is characteristic of Parkinson's³¹.

Several researchers have examined the potential use of cardiovascular training to help offset the mobility issues that result from these gait abnormalities and poor economy of movement³¹⁻⁴⁴. Numerous studies have shown short-term cardiovascular training using treadmills and bicycle ergometers result in improvements in VO_{2max} , Movement Disorder Society Unified Parkinson's Disease Rating Scale scores (MDS-UPDRS scores), balance, coordination, dexterity, gait, and quality of life in persons with Parkinson's³¹⁻³⁹, with most benefits persisting at least four weeks³⁶⁻³⁹. Although there are too few studies to be conclusive, there is evidence for additional benefits when patients exercise at forced

intensities^{33,37,40,41}. For instance, Ridgel et al.³³ compared the effects of voluntary exercise to forced exercise (approximately 30% more than subjects' preferred rates) in 10 men using a stationary tandem bicycle. After an 8-week intervention, Parkinson's patients in both groups had a significant increase in their VO_{2max} . However, only the forced exercise group showed significant improvements in rigidity, bradykinesia, and bimanual dexterity, with results lasting at least four weeks³³. Interestingly, researchers found that Parkinson's patients exercising at forced intensities obtain benefits almost immediately. Patients with Parkinson's were compared to conventional training and a control group, after only a single session of either speed-dependent treadmill training or limited-progressive treadmill training, Parkinson's patients showed improvements in gait⁴⁰. Similarly, after a single session of high intensity assisted cycling, Parkinson's patients showed reductions in tremor and bradykinesia without experiencing excessive fatigue⁴¹.

While there are few studies confirming the long-term benefits of cardiovascular training in Parkinson's patients, there is a growing body of data suggesting that this is the case^{36,42-44}. Two short-term exercise interventions have provided some evidence of long-term benefits in patients with Parkinson's^{36,42}. Miyai et al.³⁶ had 11 patients participate in body weight-supported treadmill training (BWSTT) three days per week for four weeks. At the end of the intervention, subjects showed improvements in gait as measured by an increase in stride length. Despite training being only four weeks, subjects maintained their increase in stride length when tested 16 weeks after the intervention³⁶. Similarly, van Eijkeren and colleagues⁴² found improvements in gait, functional mobility, walking capacity, and quality of life in a group of 19 subjects with Parkinson's after six weeks of Nordic walking. They reported

statistically significant improvements persisting in all parameters when the group was tested 20 weeks after intervention⁴².

Further evidence was presented from two long-term interventions executed by Schenkman and colleagues^{43,44}. In 2007, the researchers published a case study on three patients who underwent 4 months of supervised cardiovascular training regimens supplemented with an additional 12 months of home exercise. Results showed sustained improvements in MDS-URS scores, functional performance, and walking economy during the entire course of training⁴³. In 2012, Schenkman and colleagues⁴⁴ published another study comparing short- and long-term responses in 121 patients with Parkinson's to cardiovascular training, flexibility/balance/functional training, and a home-based exercise program (controls). Subjects in both experimental groups were supervised three days per week for the initial four months and then once monthly for the remainder of the 16 months. While not all benefits shown in the case studies were repeated, the 31 subjects in the aerobic exercise group did show improved walking economy at four, 10, and 16 months⁴⁴.

Current literature suggests that cardiovascular interventions can provide short-term benefits that result in improvements in quality of life and functional ability to complete activities of daily living. Despite many promising publications, there is a lack of evidence to say one form of cardiovascular training might be superior to another. Furthermore, long-term adherence to cardiovascular training is believed to be beneficial but its influences in long-term symptom management have not been identified due to the shortage of long-term data.

Regardless of type of cardiovascular intervention, almost all studies reviewed reported some beneficial outcomes related to symptom management. Therefore, as long as the activity is

appropriate for the patients' ability level, performing any cardiovascular exercise appears advisable but more research is needed to determine ideal exercise programs to be incorporated in clinical treatments.

Neuromotor Training

Gait impairments, postural instability, and falls can lead to an increased risk of mortality and morbidity in patients with Parkinson's^{82,83}. In the general population, it is estimated that 50-70% of individuals with Parkinson's fall within a one-year period⁸⁴, many of which are predicted to be reoccurring fallers. A study by Wood et al. reported 74% of subjects who had fallen over a one-year period were classified as reoccurring fallers⁸⁵. Moreover, in a survey of 100 people with Parkinson's, 13% reported falling more than once per week, with most of them falling multiple times a day⁸⁶. Studies have shown that falling often causes injury, reduced activity levels, decreased quality of life, and increased fear of falling⁸⁷⁻⁸⁹. Consequently, falling is believed to increase a patient's risk for future falls. The fear of falling, often a result from previous falls, has been shown to lead to reduced activity levels⁹⁰. The reduction in activity can lead to a reduction in muscular strength and endurance, which increases the risk for future falls^{91,92}. Other risk factors include high MDS-UPDRS scores, loss of arm swing, freezing, flexed posture, cognitive impairment, postural instability, and leg weakness^{85,91}.

Neuromotor exercises, often called functional fitness exercises, incorporate motor skills such as balance, coordination, gait, agility, and proprioceptive training. Researchers have investigated a variety of neuromotor exercises in an attempt to relieve impairments that contribute to falls⁴⁵⁻⁶³. Tai chi, Qigong, Pilates, and yoga are multifaceted physical activities

consisting of varying combinations of neuromotor, resistance, and flexibility exercises. Studies have reported these modes of exercise are as effective as cardiovascular and resistance training programs for improvements in balance and gait⁴⁵⁻⁴⁷. A noteworthy study by Li and colleagues⁴⁸ investigated the impact of a 24-week Tai Chi class compared to resistance training or low-intensity stretching in 195 patients. They reported that Tai Chi significantly improved maximum excursion, directional control, gait, and muscular strength with benefits maintained 12 weeks post intervention. Their results are further noteworthy in that Li and colleagues are currently the only group to demonstrate a significant reduction in fall rates in a large-scale trial as a result of exercise⁴⁸.

In a meta-analysis, Keus et al. suggested patients with Parkinson's who participated in physical therapy that emphasized functional training using cueing techniques were significantly better able to perform activities of daily living⁹³. Cueing is defined as using external temporal or spatial stimuli to facilitate movement (gait) initiation and continuation. Nieuwboer and colleagues⁴⁹ performed a 3-week home cueing program with 153 subjects with Parkinson's using auditory, visual, or tactile cues while training in a variety of situations and daily activities. The study showed that cueing training resulted in beneficial effects on gait, freezing, and balance⁴⁹. In addition, the use of external cues has been reported in gait training, balance exercises, and strength training programs⁴⁹⁻⁵¹. For instance, studies have shown gait training with auditory, visual and tactile cues show improvement in electromyographic parameters, stride length, and stride rate in Parkinson's patients⁵²⁻⁵⁶. In view of that, it is not surprising that dance therapy has become an appealing option in recent years. Dancing can be a type of functional fitness training and uses auditory cues in the form

of music. Furthermore, elderly people consider dance more enjoyable than traditional exercise, which promotes better adherence and enhances motivation⁵⁷. Over the past decade, Hackney and colleagues have published multiple studies looking at the effects of Argentine tango, foxtrot, and waltz⁵⁸⁻⁶². All forms of dance showed improvements in balance when compared to traditional exercise therapies, with benefits persisting at least three months⁵⁸. Though all forms of dance resulted in improved balance, gait speed, mobility, and quality of life, the authors reported tango as superior⁶⁰. Even with equal benefits when comparing partnered to non-partnered dance interventions, the authors recommended partnered dances for additional social benefits⁶². Duncan and Earhart⁶³ reported on the effects of a 12-month community-based tango program for individuals with Parkinson's. Compared to the control group, subjects who participated in Argentine Tango dance classes demonstrated a significant reduction in MDS-UPDRS scores, as well as significant improvements in gait, balance, and upper extremity function⁶³.

Overall, studies have shown significant results for Tai Chi and Argentine Tango^{45,48,58-63}. Although these forms of exercise show unique potential, there is currently not enough evidence to determine their roles in future clinical treatments. Neuromotor exercise programs have produced improvements in MDS-UPDRS scores, freezing, gait speed, mobility, and quality of life in patients with Parkinson's. Although the literature suggests neuromotor training can be used to decrease some of the risk factors related to falls, only one study has demonstrated a significant reduction in fall rates⁴⁸. Therefore, future research is needed to determine if exercise therapy can reduce fall rates in the Parkinson's population and to

determine if proactive exercise interventions could slow the transition of non-fallers becoming reoccurring fallers.

Resistance Training

People with Parkinson's have been shown to reduce levels of physical activity more quickly than their healthy peers and have lower levels of strength and functional ability^{22,94}. Although aging and physical inactivity contribute to muscle weakness, the primary cause of weakness is believed to be insufficient activation of motor neurons as a result of the disease^{94,95}. Studies have shown that patients with Parkinson's have decreased isokinetic muscle strength affecting multiple muscle groups, particularly the flexors and extensors of the hip, knee, and wrist⁹⁵⁻⁹⁸. This is problematic in that muscle weakness in the lower limbs of individuals with Parkinson's is correlated to their ability to perform various functional activities such as sitting to standing and walking^{98,99}. Furthermore, muscle weakness has been shown to contribute to postural instability and may promote the progression of the flexion posture experienced in patients¹⁰⁰. Despite recommendations for the inclusion of resistance training into Parkinson's treatment about 20 years ago, strength training has not been traditionally included as treatment and there is a shortage of research looking at the beneficial effects⁹⁴. Although the current body of literature is limited, evidence supports that resistance training is effective in improving muscular fitness and physical function in persons with Parkinson's^{50,51,64-67}.

Only a few smaller studies have addressed the effects of short-term resistance training programs on people with Parkinson's. In a group of 14 subjects with Parkinson's, Scandalis et al.⁶⁴ reported gains in strength similar to six healthy age-matched controls following an 8-

week concentric resistance training program that focused on lower limb contractions. Subjects with Parkinson's also displayed additional improvements in stride length, walking velocity, and postural angles compared with their pre-intervention values⁶⁴. In another study, Hirsch and colleagues⁵⁰ compared the effects of supplementing resistance training with balance training. For 10 weeks, six subjects received balance training and resistance training (ankle plantarflexion, knee extensors and flexors), while nine subjects only received balance training. Subjects who participated in balance and resistance training programs showed additional increases in strength, balance, mobility, and gait speed immediately after training, with effects persisting for at least four weeks⁵⁰. Several years later, Hass and colleagues reported gains in strength and endurance in upper body muscles following a 12-week resistance training program, with greater gains when subjects received creatine monohydrate supplementation⁶⁵.

Some researchers have suggested muscular strength and functional gains are greater when high-intensity protocols are used involving primarily eccentric contractions^{51,66}. Dibble and colleagues⁵¹ compared the effects of a 12-week high intensity eccentric resistance training program to a standard exercise management program in 19 subjects with Parkinson's. The eccentric group demonstrated greater improvements in quadriceps muscle volume, muscle force production, and mobility compared to the standard exercise management group⁵¹. Dibble and colleagues later performed another study to examine changes in muscle force production, clinical measures of bradykinesia, and quality of life following the same protocol. Similarly, the high intensity eccentric resistance training group showed greater improvements in all outcomes compared to those that received standard exercise management⁶⁶.

Although these studies have shown that progressive resistance exercise can result in short-term benefits for patients with Parkinson's, only one published study has measured the beneficial effects of a long-term intervention. Corcos and colleagues⁶⁷ looked at the effects of a 24-month progressive resistance training program compared to a stretching, balance, and strengthening exercise program in 38 subjects with Parkinson's. They reported clinically significant reduction in MDS-UPDRS_{III} scores, increased upper limb muscle strength, and increased movement speed in the progressive resistance training group compared to the stretching, balance, and strengthening exercise group⁶⁷. While the study by Corcos and colleagues provides evidence that long-term progressive resistance exercise programs can have lasting effects of patients with Parkinson's, more studies are needed to confirm these results as it appears to be the only study of its kind in the literature.

Current studies show some degree of evidence that progressive resistance training is effective in improving short-term muscular fitness and physical function in persons with Parkinson's. Researchers recommend the inclusion of resistance training and suggest that the most advantageous volume of exercise should maximize intensity while minimizing fatigue. Due to a shortage of long-term data, the ideal types and long-term effects of progressive resistance training programs in the treatment of Parkinson's are unknown. Compared to cardiovascular and neuromotor training, resistance training has received significantly less attention. Therefore, future research is needed for both short-term and long-term interventions with Parkinson's patients before ideal resistance programs can be determined.

Flexibility Training

Rigidity, one of the cardinal symptoms of Parkinson's, causes stiffness and inflexibility of the limbs, neck, and trunk in patients. Compared to age matched controls, Parkinson's patients have decreased flexibility causing alterations in gait and posture. This abnormal posture impairs Parkinson's patients' ability to control their center of gravity and results in difficulties with balance, agility, and increases their risk of falling^{68,69}. In addition, Vaugoyeau et al. demonstrated decreased flexibility in the body axis of patients with Parkinson's may impair their ability to perform activities that require trunk mobility, such as movement in bed and turning while walking⁷⁰. Although benefits from flexibility exercise have been shown in subjects with mild Parkinson's, current literature shows little benefit for individuals with more advanced Parkinson's^{68,69}.

Studies have shown that people with mild Parkinson's who engage in flexibility exercise training improve their joint range of movement to a similar degree as healthy age matched controls. In addition, exercises designed to improve axial range of motion have been shown to improve functional reach distance, timed gait tasks, and balance in subjects with mild Parkinson's^{68,69}. For instance, Schenkman and colleagues⁶⁸ performed a 10-week flexibility program with 46 subjects that emphasized exercises for axial mobility to increase range of motion of the neck and trunk in subjects. The 23 subjects with Parkinson's in the flexibility program showed significant improvements in spinal flexibility and physical performance compared to subjects in the control group⁶⁸. Several years later, Reuter et al.⁷¹ compared the effects of a 6-month flexibility and relaxation program to a walking or Nordic walking program. The researchers measured walking speed, stride length, stride length

variability, MDS-UPDRS scores, and quality of life. Results from this study showed less overall benefits in the 30 subjects who were in the flexibility and relaxation group compared to either the 30 subjects in the walking group or the 30 subjects in the Nordic walking group. However, subjects in the flexibility and relaxation group still showed a significant reduction in pain, increased balance, and improved quality of life⁷¹.

As previously cited, Schenkman and colleagues⁴⁴ compared short- and long-term responses between a flexibility/balance/function exercise program, a supervised aerobic exercise program, and a home-based exercise program (control) over a 16-month period. The 33 subjects in the flexibility/balance/function exercise group performed individualized spinal and extremity flexibility exercises followed by group balance/functional training. Subjects in the flexibility/balance/function exercise group showed significant improvements in activities of daily living at four and 16 months. Interestingly, at four months, subjects in the flexibility/balance/function exercise group were the only group to show a significant improvement in functional performance but decreased back to baseline values at 10 and 16 months. The reason for the loss of benefit experienced in the flexibility/balance/function exercise group is unknown but the authors speculated that decreased supervision after the fourth month in the study may have influenced the level of subject participation in the group⁴⁴. If that is the case, there may still be long-term benefits from flexibility/balance/function exercises with strict adherence.

Based on the current literature, there is reason to believe that patients with Parkinson's can at least experience short-term benefits from flexibility training. However, there are not enough studies to determine if flexibility training can provide long-term symptom relief. Even

if the short-term benefits can be maintained with strict adherence to a program, the benefits appear limited and patients will probably find greater benefits by including flexibility training as a part of a more broad exercise routine.

Summary and Suggestions for Future Research

It is largely accepted that exercise results in short-term benefits that have a positive effect on activities of daily living and quality of life. Similarly, there is growing evidence that exercise results in long-term benefits^{36,42-44,48,63,67,69,71}. Despite the growing awareness of benefits of incorporating exercise as a part of therapy, there is little consensus on ideal dosages and types of exercise needed to target the wide range of symptoms that occur with Parkinson's²⁶. In an attempt to develop standardization, the Royal Dutch Society for Physical Therapy developed clinical practice guidelines for physical therapists to use as a reference when treating their patients²⁸. The report recommends interventions aimed at improving activities of daily living should be a minimum four weeks and at least eight weeks to improve physical capacity. In addition, they reported strategies to treat specific physical needs in patients. For instance, they included a variety of recommendations for interventions to help normalize gait. Some of these include incorporating both strength training and exercises that improve trunk mobility, using cueing strategies to treat freezing, and using visual or verbal feedback to help correct excessive flexion in posture. Although these guidelines have started to develop uniformed treatment interventions in clinical settings, many of the recommendations are subjective. Since the guidelines do not regulate factors like volumes, modes of exercises, and durations of interventions, the development of many aspects when designing exercise programs rest in the discretion of physical therapists. Therefore, it is

logical that there are considerable variations in dosages and types of exercises used in clinical settings. Given the inconsistencies in treatments, it is clear that ideal interventions have yet to be identified leaving many patients receiving inadequate therapy.

Despite the increase in research over the past few decades, the available data are limited. The majority of studies to date are of short duration, highly supervised, facility based, and included a limited amount of participants, all of which point toward a need for further research. Since Parkinson's is a long-term degenerative disorder, studies with longer durations are vital to determine how exercise can contribute to their long-term symptom management. The benefits demonstrated by numerous short-term studies have warranted future long-term studies on a variety of exercise interventions in an attempt to find ideal long-term interventions. However, with limited resources it is not feasible to perform large-scale long-term studies on all types of exercise interventions. Therefore, it is important for researchers to determine types of interventions that are likely to yield the greatest benefits for the Parkinson's population as a whole.

Ultimately, the goal is for patients to develop long-term self-management strategies through lifestyle changes to perform therapy without an excessive reliance on physical therapists. In 2010, only about 11 percent of people age 65 and over met the current national recommendations for leisure-time aerobic and muscle strengthening activities¹⁰¹. Based on studies reporting that people with Parkinson's tend to be less active in activities of daily living compared to their peers, the percentage of patients with Parkinson's meeting recommended activity levels is most likely even lower¹⁰²⁻¹⁰⁴. With such a low percentage of people engaging in regular physical activities, ideal interventions should incorporate strategies to avoid barriers

that may prevent people with Parkinson's from engaging in regular exercise. Likewise, ideal interventions should also be enjoyable and engaging to promote regular participation.

Studies examining factors associated with exercise rates in people with Parkinson's have reported self-efficacy, low outcome expectation, lack of time to exercise, and fear of falling to be important perceived barriers^{105,106}. Because of these barriers, the dosages and types of exercise that yield the largest benefits in research settings may differ from ideal interventions in clinical and social settings. For instance, treadmill training has shown significant benefits in research settings³⁶, but using a treadmill may not be appropriate as the disease progresses due to postural instability and fear of falling. Using a safety harness to compensate for postural instability and fear of falling, BWSTT has also shown significant benefits in research settings and is a safe alternative for many Parkinson's patients. However, this type of equipment is usually restricted to clinical and research settings. Due to limited availability and time requirements to use these facilities, BWSTT may not be the best choice for many Parkinson's patients. The lack of long-term data, barriers that prevent patients from exercising, and limited resources for large-scale long-term studies hinder researchers' ability to find ideal long-term interventions to help manage symptoms.

The Delphi Method

The Delphi Method is a forecasting approach in which experts in a specific area have an unbiased debate to form a group consensus¹⁰⁷. The method is founded on the rationale that experts will make assumptions using rational judgements rather than merely guessing and that a group's consensus is more predictive than an individual's opinion¹⁰⁷⁻¹⁰⁹. In addition, the method requires anonymity as direct confrontation may result in a biased conclusion. For

instance, during a group debate there may be group pressure for conformity or disproportionate contributions due to individuals being socially dominant or timid. Therefore, to form a true consensus the method requires anonymity to ensure that all ideas receive fair consideration and that each member has equal role in deliberation.

Method

The Delphi Method seeks consensus through a series of anonymous surveys where subjects receive feedback between each round, and then provide further input based on the results from the previous survey. In the literature, reaching consensus usually takes four rounds¹¹⁰. However, depending on the level of consensus desired and the nature of group's responses, two rounds is the minimum when using the Delphi Method¹¹¹. The first round consists of open-ended question(s) that help generate ideas and allows participants complete freedom in their responses. During this stage, subjects are encouraged to donate as many opinions as possible to maximize the chance of presenting the most important opinions and issues. After receiving group's responses from the initial stage, the researchers evaluate responses that appear to be the same and group the data together in an attempt to provide one universal description. The collected information is then converted into a questionnaire for the second round of data collection. During this round, subjects are usually required to rate or rank-order items to establish priorities among items. As a result, consensus begins forming and the actual outcomes can be presented among the participants' responses. During the third, and any additional rounds, subjects are provided with feedback related to their own rating on each item and the group's rating on the same items with a summary of comments made by the group. This feedback process makes each subject aware of the range of opinions and the reasons underlying those opinions. After receiving this feedback, subjects are given the

opportunity to re-rate each item. In general, the rounds of surveys continue until a predetermined level of consensus is reached or no new information is gained^{107,109,112,113}. However, only a slight increase in the degree of consensus can be expected, as most convergence of panel responses occurs between round one and two¹¹⁴.

Subject Selection

Many authors consider the choosing of appropriate subjects as the most important step of the Delphi Method as it directly relates to the quality of the results generated^{109,113,114}. To determine expert consensus, it is important to select criteria to identify appropriate subjects that are experts relating to the question(s) of interest. Unfortunately, there is debate in the literature over the term 'expert' and the methods used to identify subjects as experts. In general, having expertise implies that the subject is knowledgeable concerning the selected issue(s). However, choosing individuals who are simply knowledgeable is often not sufficient and is not recommended¹¹⁵⁻¹¹⁷. Some authors recommend selecting subjects that also possess certain work experience or have a firsthand relationship with the issue of interest^{118,119}. Although not appropriate for all situations, an expert can be considered as an individual who possesses more knowledge than the public and has firsthand experiences with the issue(s) of interest.

After identifying appropriate subjects, the desired sample size for the study needs to be determined. Delbecq and colleagues suggested using the minimally sufficient number of respondents¹²⁰. However, an optimal number of subjects for a Delphi study never reaches consensus in the literature. Parentè and colleagues suggest the panel should include at least 10 members, while Delbecq and colleagues suggest 10-15 subjects could be sufficient if the subjects' backgrounds are homogeneous^{120,121}. Additionally, there is no defined upper limit,

although the approximate number of subjects is generally under 50¹²². Ludwig documents that, “the majority of Delphi studies have used between 15 and 20 respondents”¹²³. Dalkey et al. demonstrated increase in the reliability of group responses with increasing group size. Reliability was found with a group size of 13 with a correlation coefficient approaching 0.9¹²⁴. In summary, the number of Delphi subjects is variable depending on the population and the issue(s) of interest. Based on these reports, the appropriate number of subjects for most studies should be at least 10, but having 15 or more subjects is better.

Data Analysis

Brooks identified consensus as the “gathering of individual evaluations around a median response, with minimal divergence”¹²⁵. Unfortunately, there is currently no agreement regarding the minimum percentage of response needed to demonstrate consensus. Authors have suggested that consensus on a topic can be decided if a certain percentage of the votes falls within a prearranged range¹²⁶. The values usually range from 70-80% of subjects rating within two to three points on a seven-point Likert scale^{127,128}. However, the kind and type of criteria to use in order to both define and determine consensus in a Delphi study is subject to interpretation.

After the level of consensus has been determined and data has been collected, the major statistics used are measures of central tendency (mean, median, and mode) and level of dispersion (standard deviation and inter-quartile range) to illustrate the subjects’ responses. In the literature, the use of median score, based on Likert-type scale, is favored^{114,129,130}. However, authors have reported that there is no consistent method for reporting findings. A number of approaches have been used including a variety of graphical representations, and

statistical results outlining central tendencies, variance, and ranks¹³¹. In conclusion, the type of rating scales used, level of consensus, and the interpretation of results is variable depending on the characteristics and goals of each study.

Proposal

Since age is a major risk factor, as the baby boomer generation ages, Parkinson's is expected to impose an increasing social and economic burden on our society in the future². Even with the combined use of pharmacologic and neurosurgical therapies, the progression of the disease consistently results in inadequately managed symptoms that lead to a general decrease in physical activity, an increased risk of falling, immobility, and cognitive impairments^{22,23}. Increasingly over the past few decades, numerous studies have focused on exercise interventions to help alleviate the motor and non-motor symptoms that pharmacologic and neurosurgical therapies fail to suppress³¹⁻⁶⁸.

Research has shown that exercise results in short-term benefits that have a positive effect on activities of daily living and quality of life^{31-39,45-47,49-62,64-66,68,69}. There is also growing evidence that exercise results in long-term benefits^{36,42-44,48,63,67,69,71}. Although many forms of exercise have shown promising results for treating specific problems experienced in Parkinson's, there is little consensus on the ideal dosages and types of exercise needed to target the wide range of symptoms that occur with Parkinson's²⁶. The benefits demonstrated by numerous short-term studies have warranted future long-term studies on a variety of exercise interventions in an attempt to find ideal long-term interventions. Despite many potential benefits, to perform large-scale long-term studies on all types of exercise interventions is not practical or possible due to limited resources. As a result, researchers face

the challenge of attempting to ascertain ideal intervention strategies as quickly as possible while avoiding wasting resources on unsatisfactory interventions.

Since the goal is for patients to develop long-term self-management strategies through lifestyle changes to perform therapy without an excessive reliance on physical therapists, finding exercise interventions that will result in the greatest symptom reduction is only part of the solution. Ideal interventions should also incorporate strategies to avoid barriers that may prevent people with Parkinson's from engaging in regular exercise. In 2010, only about 11% of people age 65 and over met the current national recommendations for leisure-time aerobic and muscle strengthening activities¹⁰¹. Based on studies reporting that people with Parkinson's tend to be less active in activities of daily living compared to their peers, the percentage of patients with Parkinson's meeting recommended activity levels is most likely even lower¹⁰²⁻¹⁰⁴. Accordingly, future research should find intervention strategies that are highly beneficial for symptom management while avoiding barriers that may prevent people with Parkinson's from engaging in regular exercise.

Though numerous studies have indicated potential benefits for many types of exercise interventions, they fail to provide a concrete direction for what types of interventions will result in greatest large-scale long-term benefits. While recent systematic reviews have provided recommendations for future areas of research, their predictive value may be restricted by the quality of data available in that majority of studies to date have been short duration, highly supervised, facility based, and included a limited amount of participants. This lack of large-scale long-term data indicates potential benefits for the use of the modified Delphi Method as a way to distinguish types of interventions that are likely to yield the

greatest benefits for the Parkinson's population as a whole. Since the Delphi Method is a forecasting approach based on experts' consensus in a specific area, past experiences of people with Parkinson's can be used to contribute predictive value while avoiding the potential bias introduced by other methods from the limitations in current literature. People with Parkinson's can use qualitative data based on past experiences to make predictions without being influenced by the limits of available quantitative data. The Delphi Method may provide insight on beneficial interventions that avoid barriers by having subjects identifying and prioritizing types of exercises they have done. If a barrier prevented participation in an exercise intervention, the person would be less likely to have experienced high beneficial outcomes. In theory, they would then have a tendency to give poorer ratings to interventions that are strongly influenced by barriers. For instance, having a low outcome expectation has been identified as an important perceived barrier for people with Parkinson's^{105,106}. Since the rankings are based on experiences, people should be more likely to continue interventions that they rank as highly beneficial since they have already experienced high outcomes. Because of these unique strengths, the use of the Delphi Method is merited as it could help provide future researchers direction in identifying intervention strategies that are highly beneficial for symptom management while minimizing barriers.

Purpose

The purposes of this study are to identify types of exercise people with Parkinson's have used for symptom management and to determine which types they have found most beneficial in relieving the symptoms of Parkinson's. The results will help future researchers

use resources efficiently by identifying interventions with high benefit potential that avoid barriers and directing future research away from areas with low benefit potential.

Hypotheses

It is hypothesized that people with Parkinson's more commonly use certain types of exercise interventions for symptom management and these types of exercise interventions can be identified using a modified Delphi Method. It is also hypothesized that although the expression of symptoms in Parkinson's happens in a non-patterned manner, certain types of exercise interventions provide greater benefits for symptom management and these types of exercise interventions can be identified using a modified Delphi Method through qualitative data based on subjects' knowledge and experiences.

Methods

Subjects

The subject pool will be composed of members of Parkinson's Disease support groups who have been clinically diagnosed with Parkinson's. Though groups vary in character and focus, meetings are a way for patients to share experiences, educate each other about the disease, and share resources for symptom management. Furthermore, participation in exercise is encouraged in most groups with many support groups hosting Parkinson's specific exercise classes. Subject selection was based on the rationale that members of support groups are more likely to be experienced and knowledgeable about the disease and the impacts of exercise interventions on symptom management compared to the general population. Aside from subjects' expertise, working through group leaders allows for direct contact with subjects while collecting minimal personal information. Thus, subjects' privacy can remain safe while maintaining the ability to contact members to encourage participation throughout the study.

Procedure

Upon IRB approval and consent of group leaders, members from the following support groups will be invited to participate in the study: Capistrant/Bethesda Parkinson support group; Duluth Parkinson's Disease Support Group; Mercy Hospital Parkinson's Disease Support Group; Primrose Retirement Community Parkinson's Disease Support Group; Realife Cooperative Parkinson's Disease Support Group; St. Cloud Parkinson's Disease Support Group; and Struthers Parkinson's Center's Parkinson's Disease Support Groups. Data collection will take place between May 10-June 18. This timeline was selected to minimize time between trials by having subjects complete the surveys during consecutive meetings. Volunteers that have been clinically diagnosed with Parkinson's will complete an electronic or paper copy of the first survey and consent form between May 10-May 22. The initial survey will gather the subjects' information, followed by two questions. Subjects' data will include their name, years since diagnosis, and type of mobility aide if applicable. To ensure confidentiality, each subject's name will be replaced by an ID number chosen at random and will be kept in a log that will be stored in a password-protected computer file available only to the researcher. After subjects provide their information, they will be asked to list all types of exercise they currently do or have done in the past to help manage their Parkinson's symptoms. After all the responses are received from the initial round, the researcher will group responses that appear to be the same and attempt to provide one universal description. The researcher will then take the 10 most frequently listed items and use them to make up the basis of the second survey.

The second round of data collection will take place between May 26-June 18. The 10 most frequent responses will be listed with a brief universal description if needed. Subjects will then be asked to rank each item from most to least beneficial for treating symptoms of Parkinson's based on their experiences and/or knowledge. All items will be ranked on a scale of 1-10, with one being the most beneficial and 10 being the least, and with each number only used once. Responses from survey two will be pooled and central tendencies will be determined and ranked using Excel. Comparative data from excel will be shown through graphical representations to indicate the types of physical exercises are determined most beneficial for symptom management in individuals with Parkinson's.

Part 2: Manuscript

Introduction

Parkinson's is the second most common neurodegenerative disease after Alzheimer's disease. Currently, about one million Americans and between seven to 10 million people worldwide have been diagnosed and are living with the disease. Each year in the United States alone, there are approximately 60,000 newly diagnosed patients. Since age is a major risk factor, as the baby boomer generation ages, Parkinson's is expected to impose an increasing social and economic burden on our society in the future². Clinical diagnosis of Parkinson's focuses primarily on the motor symptoms and usually requires the manifestation of at least two of the following symptoms: resting tremor, bradykinesia, rigidity, and/or postural instability. In addition to the presence of motor symptoms, asymmetric symptom onset and response to the primary anti-Parkinson medication that increases concentrations of dopamine in the brain, levodopa, are supportive for a diagnosis of Parkinson's and help rule out other diagnoses¹⁴.

Even with the combined use of pharmacologic and neurosurgical therapies, the progression of the disease consistently results in inadequately managed symptoms that lead to a general decrease in physical activity, an increased risk of falling, immobility, and cognitive impairments^{22,23}. Increasingly over the past few decades, numerous studies have focused on exercise interventions to help alleviate the motor and non-motor symptoms that pharmacologic and neurosurgical therapies fail to suppress^{31-44,45-48,49-63,64-68}. Research has shown that exercise results in short-term benefits that have a positive effect on activities of daily living and quality of life^{31-39,45-47,49-62,64-66,68,70}. There is also growing evidence that

exercise results in long-term benefits^{36,42-44,48,63,67,69,71}. Although such studies have indicated potential benefits for many types of exercise interventions for Parkinson's patients, they fail to provide a concrete direction for what types of interventions will result in greatest large-scale long-term benefits. While recent systematic reviews have provided recommendations for future areas of research, their predictive value are restricted by the quality of data since most studies to date have been short duration, highly supervised, facility based, and included a limited amount of participants.

A different approach to address the effectiveness of exercise interventions for Parkinson's patients involves the Delphi Method, a forecasting technique based on experts' consensus in a specific area. Through the use of the Delphi Method, past experiences of people with Parkinson's can be used to contribute predictive value while avoiding the potential bias introduced by other methods from the limitations of available quantitative data in current literature. The Delphi method may provide insight on beneficial interventions that avoid barriers by having subjects identifying and prioritizing types of exercises they have done. If a barrier prevented participation in an exercise intervention, the person would be less likely to have experienced high beneficial outcomes. In theory, they would then have a tendency to give poorer ratings to interventions that are strongly influenced by barriers. For instance, having a low outcome expectation has been identified as an important perceived barrier for people with PD^{105,106}. Since the rankings are based on experiences, people should be more likely to continue interventions that they rank as highly beneficial since they have already experienced high outcomes. Because of these unique strengths, the use of a modified Delphi method is merited as it could help provide future researchers direction in identifying

intervention strategies that are highly beneficial for symptom management while minimizing barriers.

Purpose

The purposes of this study are to identify types of exercise people with Parkinson's have used for symptom management and to determine which types they have found most beneficial in relieving the symptoms of Parkinson's. The results will help future researchers use resources efficiently by identifying interventions with high benefit potential that avoid barriers and directing future research away from areas with low benefit potential.

Methods

Subjects

The subject pool was composed of members of Parkinson's disease support groups who had been clinically diagnosed with Parkinson's. There is debate in the literature over the term 'expert' and the methods used to identify subjects as experts. For this study, a person was considered an expert if s/he possessed more knowledge than the public and had firsthand experiences with the issue(s) of interest. Though groups vary in character and focus, meetings are a way for Parkinson's patients to share experiences, educate each other about the disease, and share resources for symptom management. Furthermore, participation in exercise is encouraged in most groups with many support groups hosting Parkinson's specific exercise classes. Subject selection was based on the rationale that members of support groups were more likely to be experienced and knowledgeable about the disease and the impacts of exercise interventions on symptom management compared to the general population. Aside

from subjects' expertise, working through group leaders allowed for direct contact with subjects while collecting minimal personal information.

Members from the following support groups were invited to participate in the study: Capistrant/Bethesda Parkinson support group; Duluth Parkinson's Disease Support Group; Mercy Hospital Parkinson's Disease Support Group; Primrose Retirement Community Parkinson's Disease Support Group; Realife Cooperative Parkinson's Disease Support Group; St. Cloud Parkinson's Disease Support Group; and Struthers Parkinson's Center's Parkinson's Disease Support Groups.

Invitations for the first round of data collection resulted in 36 subjects clinically diagnosed with Parkinson's. One subject was excluded for insufficient time since diagnosis of approximately four months. Since a recently diagnosed member may lack sufficient knowledge about the disease and would lack long-term experiences of impacts of exercise interventions on symptom management, they would not qualify as an expert. Therefore, inclusion of recently diagnosed subjects would violate a fundamental requirement of the Delphi Method. The range in time since diagnosis for the remaining 35 subjects was between 18 months and approximately 20 years ($M=7.6\pm 5.4$ years) and six subjects required a walking aide for transportation. Invitations for the second round resulted in 24 subjects. Due to unusable responses, six subjects were removed from the second round. The remaining 18 subjects consisted of nine new subjects and nine returning subjects who participated in the first round of data collection. Years since diagnosis and type of mobility aide were not recorded during the second round of data collection and were unknown for the nine new subjects that only participated in the second survey. For the nine subjects who participated in

both rounds, the range in time since diagnosis was between 5 and 14 years ($M=8.3\pm 3.4$ years) and no subjects required a mobility aide for transportation.

Procedure

The first round of data collection was used to collect subjects' data and to identify the 10 most common types of exercise used by those subjects for symptom management. All responses were copied into Microsoft Excel and each subject was given a randomized identification number. Survey 1 resulted in 297 unedited responses for types of exercise used. All repeated responses from individuals were removed so each subject could only contribute one vote for each type of exercise. The 200 unrepeated responses were pooled and duplicate responses from different subjects were combined and tallied. The remaining 117 unique responses were grouped if responses appeared to be different ways of describing the same type of exercise. For example, the following responses were grouped and counted as cycling: bike riding; ride bike; bicycling; trike riding; spinning; biking; bike; short bikes; stationary bike; riding bike (stationary); and recumbent bike (for all grouped responses reference Appendix). Although there are significant differences between types of cycling exercises, grouping those responses minimized potential errors introduced by the researcher from subjective interpretation of responses. Vague responses like "bike" could then be included without precise interpretation. After grouping corresponding responses, individual's responses were recounted to ensure that each subject provided a maximum of one vote for each of the top 10 grouped item. Then responses were tallied again and the top 10 types of exercise were used as the base for Survey 2.

Table 1: Subject Characteristics (average \pm standard deviations)

Measure	Survey 1	Survey 2
Total Volunteers	36	24
Subjects	35	18
Males : Females	21:14	10:8
Time since diagnosis (years)	7.6 \pm 5.4	8.3 \pm 3.4*

*Results based on nine subjects that participated in both surveys.

Survey 2 was sent to all groups with instructions to be completed only by subjects who participated in the first survey. Due to low response rates, the group leaders were contacted and members were requested again to fill out the survey. Since the minimum number of subjects was not met after the second request, the survey was resent to all groups and allowed any group member to participate provided they were clinically diagnosed with Parkinson's. The second survey listed the 10 most frequent responses from the first survey with brief descriptions when needed. Subjects were instructed to rank each item from most to least beneficial for treating symptoms of Parkinson's based on their experiences and/or knowledge. The first part of the Survey 2 (Survey 2a), subjects were asked to only rank the exercises they have personally done in the past. The second part of the Survey 2 (Survey 2b) had subjects rank all 10 items based on what they think from their experiences and knowledge. Items were ranked on a scale of 1-10, with one being the most beneficial and 10 being the least, and each number was only allowed to be used once. All responses from the

second survey were copied into Microsoft Excel and all new subjects were given a randomized identification number.

Results

The top 10 exercises identified in Survey 1 (Table 2) included walking, cycling, yardwork, static exercises that use bodyweight as resistance and involve controlled breathing while holding specific bodily postures (Static Exercises), ending with physical therapy using movements with large amplitudes (Physical Therapy), and speech therapy used to treat dysarthria and/or dysphagia (Speech Therapy).

Table 2: Top 10 Exercises Most Commonly Reported by PD Patients

Type of Exercise	Response Total
Walking	33
Cycling	16
Yardwork	14
Static Exercises	12
Resistance Training	11
Stretching	11
Slow Moving Exercises	10
Dancing	9
Physical Therapy	8
Speech Therapy	8

*For list of all responses, reference Appendix.

For Survey 2_a, subjects ranked all exercises they have personally used in the past to manage their symptoms. Before comparing the group's data for each type of exercise, subjects' data were conditionally edited. A third of the ranked types of exercise with the lowest values from each subject were replaced with a value of one. A third of the ranked types

of exercise with the highest values from each subject were replaced with a value of negative one. All other rankings were replaced with zero (see Table 3).

Table 3: Values Replacing Subjects' Rankings Based on Total Types of Exercise Used by Each Subject

Subject(s)	Type(s) of exercise ranked	Ranking(s) given a value of +1	Ranking(s) given a value of 0	Ranking(s) given a value of -1
1	10	1-3	4-7	8-10
3	9	1-3	4-6	7-9
0	8	N/A	N/A	N/A
1	7	1-3	4-5	5-7
5	6	1-2	3-4	5-6
2	5	1-2	3	4-5
3	4	1	2-3	4
1	4	1	2	3
2	2	1	N/A	2
0	1	N/A	N/A	N/A

After subjects' values were replaced, the sum was calculated for each type of exercise and reported as a quotient of the total responses for each type of exercise. In descending order, types of exercise ranked in Survey 2_a were walking, stretching, cycling, resistance training, Static Exercises, Slow Moving Exercises, Physical Therapy, Speech Therapy, yardwork, and dancing. Since data were edited and statistical interpretations were limited, types of exercise were also grouped and less emphasis was put on the order of the ranked quotient values. Walking, stretching, cycling, and resistance training were grouped as types of exercise with relatively high quotient values. Static Exercises, Slow Moving Exercises, and Physical Therapy were grouped as types of exercise with relatively moderate quotient values. Speech Therapy, yardwork, and dancing were grouped as types of exercise with relatively low quotient values (see Table 4).

Table 4: Quotients (sum divided by number of responses) and Relative Groupings for Each Type of Exercise in Survey 2_a

Type of Exercise	Quotient	Relative Groups of Ranked Quotients
Walking	+27.78	High
Stretching	+27.27	High
Cycling	+18.18	High
Resistance Training	+16.67	High
Static Exercises	+9.09	Moderate
Slow Moving Exercises	0.00	Moderate
Physical Therapy	-11.11	Moderate
Speech Therapy	-33.33	Low
Yardwork	-50.00	Low
Dancing	-66.67	Low

For Survey 2_b, subjects ranked all 10 exercises based on their experiences and/or knowledge. Before comparing the group's data, data were edited for three subjects. Two subjects failed to rank one exercise. Missing data for each subject was replaced with a value of 10. Similarly, one subject failed to rank two exercises and 9.5 replaced both missing data points. Justification for artificially adding data was based on trends from the group's 176 reported rankings. Based on results from Survey 2_a, Subjects had personally done 103 of the ranked exercises out of the total 176. The remaining 73 ratings were based on subjects' knowledge without direct experience. The average rankings, in Survey 2_b, for exercises subjects had done in the past was 4.27 and for exercises subjects had not done in the past was 7.4 (see Table 5).

Table 5: Averages for Each Type of Exercise in Survey 2_b after Data Were Separated Based on Indicated Experience in Survey 2_a

Type of Exercise	Average ₁ Without Experience	Average ₂ With Experience	Difference Average ₁ -Average ₂
Walking	N/A	3.22	N/A
Stretching	7.29	2.45	4.83
Slow Moving Exercises	7.45	3.86	3.60
Static Exercises	8.00	5.36	2.64
Resistance Training	6.00	3.58	2.42
Yardwork	8.33	6.08	2.25
Speech Therapy	7.33	5.33	2.00
Cycling	5.86	4.09	1.77
Physical Therapy	5.63	4.11	1.51
Dancing	7.18	6.50	0.68
All Responses	7.04	4.27	2.77

This difference indicated a tendency for subjects to give poor rankings (higher values) to types of exercise if they had not personally used them for symptom management. Since all four of the missing data points were exercises that the three subjects had not done in the past, replacing the missing rankings with high values appeared more appropriate than leaving the responses blank or giving lower values. After giving values to the missing data, types of exercise were compared using averages. In descending order based on averages, types of exercise ranked Survey 2_d were walking, stretching, resistance training, cycling, Physical Therapy, Slow Moving Exercises, Static Exercises, Speech Therapy, yardwork, and dancing. Types of exercise were also grouped, as in Survey 2_a, for comparative purposes. Walking, stretching, resistance training, and cycling were grouped as types of exercise with relatively high average rankings. Physical Therapy, Slow Moving Exercises, and Static Exercises were grouped as types of exercise with relatively moderate average rankings. Speech Therapy,

yardwork, and dancing were grouped as types of exercise with relatively low average rankings (see Table 6).

Table 6: Average Ranked Values and Relative Grouping of Each Type of Exercise in Survey 2_b

Type of Exercise	Average	Relative Groups of Ranked Averages
Walking	3.22	High
Stretching	4.33	High
Resistance Training	4.58	High
Cycling	4.78	High
Physical Therapy	5.11	Moderate
Slow Moving Exercises	6.06	Moderate
Static Exercises	6.50	Moderate
Speech Therapy	6.67	Low
Yardwork	6.83	Low
Dancing	7.08	Low

Discussion

Results from this study represent the opinion(s) of the subjects and are not intended to express the views of the Parkinson's community or a different group of experts. However, the results may be applicable to people throughout the Parkinson's population. Experts in this study and people throughout the Parkinson's community constantly experience the same inadequately managed symptoms as the disease progresses and have to avoid common barriers that affect exercise rates in people with Parkinson's. Therefore, in addition to expressing the views of subjects in this study, this study intends to give direction to future research by identifying types of exercise that are likely to avoid common barriers related to exercise rates in people with Parkinson's.

Unlike a classical Delphi Method, each round of data collection did not use the same experts. The 10 most common types of exercises identified in Survey 1 may not represent the most common types of exercise for the subjects who participated in Survey 2. Since different subjects were used, results from each survey should be interpreted separately. The data from Survey 1 indicates the types of exercise used among those 35 subjects. Data from Survey 2 indicates the relative rankings of the 10 types of exercise provided. Instead of representing the group's consensus, results from Survey 2 represent the views of only those 18 subjects who participated. In addition, the quality of the data from Survey 2 may be restricted due to assumptions of expertise (see Limitations).

Survey 1

Lack of consensus in current literature warrants future research for a wide range of potential exercise interventions. Results from Survey 1 identified the following types of exercise as the most widely used among 35 members of Parkinson's support groups. In descending order, the top 10 most common types of exercise identified were walking, cycling, yardwork, Static Exercises, resistance training, stretching, Slow Moving Exercises, dancing, Physical Therapy, and Speech Therapy. This list provides some direction for future research by identifying common types of exercise that people with Parkinson's are willing and physically able to do at some point throughout the course of their disease. Investing future resources to identify better intervention strategies for any of these types of exercise may be warranted since innovations could influence a large percentage of the Parkinson's community. Although these types of exercise are common, ideal interventions may include exercises not identified in this study. Studies looking at forced exercise intensities have demonstrated

promising results and may be vital to identifying ideal interventions^{33,37,40,41}. If less common exercises like Nordic walking continue to demonstrate benefits, the key may be the investment of resources to increase participation in such activities.

Survey 2

For Survey 2_a, subjects only ranked the types of exercise they had personally used for symptom management. The intention was for subjects to base their rankings on both experience and knowledge. Since reported rankings were not influenced by subjects' lack of experience, the data could show true expert opinion. Although this method may have improved the quality of data, the different quantities in types of exercise ranked by each subject limited interpretation. Since the initial rankings for each type of exercise were not directly comparable, the data was conditionally edited to allow for direct comparison and visual representation of the data.

For Survey 2_b, subjects ranked all 10 types of exercise based on their experiences and/or knowledge. By ranking all types of exercise, data was easier to interpret and direct comparisons could be made with minimal editing. The design for Survey 2_a was based on the assumption that a lack of experience might prevent subjects from making predictions using rational judgements. However, lack of experience may only have a negligible influence if subjects made predictions using rational judgements based on their knowledge. If lack of experience did not influence subjects' ability to make rational judgements, results from Survey 2_b could be a better representation of the group's opinion since the data could be accurately interpreted.

Since each method of data collection had potential limitations, both methods were used for comparative purposes. When comparing both parts of Survey 2 the ranking orders were different. The difference in rankings may have been due to the interpretation of data in Survey 2_a or due subjects' lack of experience when ranking types of exercise in Survey 2_b. Regardless of the cause, the ranking orders were similar and each type of exercise fell into the same category when grouped. Since common trends could be extrapolated from the data, the level of consistency was appropriate for the intentions of this study.

Relative Rankings

In addition to symptom management, ideal interventions should enable self-management, help reduce symptoms, and maximize participation rates throughout the Parkinson's community. In Survey 2, walking and stretching had high relative rankings compared to the other types of exercise for symptom management. Both of these types of exercise can be performed safely, independently, in a variety of settings, and both require little to no equipment. However, walking appears to have an advantage in that it was the most common type of exercise in both surveys. Walking may also enable social benefits from participation in community activities like walking groups. These data may suggest a potential benefit in exploring intervention strategies that incorporate walking such as hiking, powerwalking, community walking groups, and/or treadmill walking.

Other promising types of exercise were stretching, resistance training, and cycling. All three had high relative rankings in Survey 2 and were moderately common in both surveys. There may be additional benefits from further exploring stretching, resistance training, and cycling. Each of these types of exercise may be more appropriate under certain circumstances.

If decreased muscular strength was a person's most severe symptom, resistance training may have better outcomes than walking if the primary goal of their intervention is to maintain or increase muscle mass. Since many different symptoms can become problematic as the disease progresses, ideal interventions will probably not be a one size fits all and regimens that incorporate a combination of types of exercise may prove valuable. As a result, all four types of exercise warrant further research.

The relative rankings from Survey 2 are intending to prioritize the types of exercise that should receive future research based on subjects' experiences and opinions. Since rankings were relative, poor rankings do not imply that those types of exercise are not beneficial for symptom management. Although high rankings may suggest potential benefits from future research, each of these types of exercise have shown benefits for symptom management in patients with Parkinson's. Investing future resources to identify better intervention strategies for any of the 10 types of exercise identified in Survey 1 may be worthwhile since they show potential to influence a large percentage of the Parkinson's community. With limited data, it is difficult to say more than exercise in general has beneficial effects for symptom management in patients with Parkinson's. Ideal intervention strategies may be for patients to find types of exercise they enjoy and are likely to have long-term adherence.

Limitations

One limitation to this study is potential bias introduced by the researcher when counting responses from Survey 1. BIG and LOUD is a program for patients with Parkinson's that includes a type of physical therapy (BIG) and a type of speech therapy (LOUD). Physical

therapy and/or speech therapy may have been overly represented due to subjective interpretation by the researcher of the response “BIG and LOUD”. All responses that included both BIG and LOUD were considered as separate therapies. This resulted in six responses being counted twice, six votes for physical therapy and six votes for speech therapy (see Appendix).

Another limitation to this study was the assumption that nine subjects were experts based solely on membership in a support group. For members who were recently diagnosed with Parkinson’s, this assumption would not be appropriate. The major concern was if a large percentage of members were utilizing support groups to seek information about disease after a recent diagnosis. Since a recently diagnosed member may lack sufficient knowledge about the disease and would lack long-term experiences of impacts of exercise interventions on symptom management, their participation would violate a fundamental requirement of the Delphi Method. Based on subjects’ recollections, the average time since diagnosis was 7.4 ± 5.5 years for the 36 subjects who participated in the first survey and 8.3 ± 3.4 years for the nine subjects who participated in both surveys. One subject was removed from the study for being diagnosed approximately four months before participation in Survey 1. The limitation of this study was that the time since diagnosis was not determined for the nine subjects who only participated in Survey 2. Although the majority of subjects from the Survey 1 were appropriate, assuming expertise for those nine subjects may have violated a fundamental feature of the Delphi Method.

Conclusion

The 10 most common types of exercise identified in Survey 1 were walking, cycling, yardwork, Static Exercise, resistance training; stretching, Slow Moving Exercises, dancing, Physical Therapy, and Speech Therapy. This list provides some direction for future research by identifying common types of exercise that people with Parkinson's are willing and physically able to do at some point throughout the course of their disease. Investing future resources to identify better intervention strategies for any of these types of exercise may be warranted since innovations could influence a large percentage of the Parkinson's community. Data from Survey 2 showed walking, stretching, resistance training, and cycling as relatively high ranked types of exercise. Therefore, all 10 types of exercise warrant future research but walking, stretching, resistance training, and cycling may provide additional benefits from the investment of future resources.

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Appendix

Identification # _____

Date: _____

Saint Cloud State University

Survey 1

Identifying Modes of Physical Exercises that Benefit Individuals with Parkinson's Disease: A Modified Delphi Study.

Name: _____

How many years have you been diagnosed with Parkinson's disease? _

Do you require a walking aide or wheelchair for transportation? Yes No

If you selected yes, please indicate what type of walking aide you

use: _____

As you list **all** the physical exercises that you currently do or have done in the past to manage your symptoms, please include all types of activities that you feel have helped. Examples of physical exercise include, but are not limited to, gardening, shoveling snow, weight lifting, power walking, dancing, martial arts, playing darts, or yoga.

What types of exercise do you currently do to help manage your symptoms?

What types of exercise have you done in the past to help manage your symptoms?

Identification # _____

Date: _____

Saint Cloud State University

Survey 2

Identifying Modes of Physical Exercises that Benefit Individuals with Parkinson's Disease: A Modified Delphi Study.

Name: _____

Part 1: Please rank the exercises that you currently use, or have used in the past, in order from most to least beneficial. Only rank the types of exercises you have personally used and leave all other exercises unranked. **Each Number can only be used once.** The following provides examples:

Example 1) If you have personally used all 10 forms of exercise, you will rank all exercises in Table 1 as follows. 1=most beneficial type, 2=second most beneficial type... 10=least beneficial type

Example 2) If you have personally used 6 forms of exercise, you will only rank those 6 options and leave the remaining 4 types of exercise blank. 1= most beneficial type, 2=second most beneficial type... 6=least beneficial type

Description	Examples	Rank
Static exercises that use bodyweight as resistance and involve controlled breathing while holding specific bodily postures	Yoga; Pilates	
Slow moving exercises that use bodyweight as resistance and involve controlled breathing while alternating between specific bodily postures	Tai Chi; Tae Guk Kwan Do	
Walking	Walking on a treadmill; Daily locomotion; Walking in neighborhood or on a trail; Walking pet	
Speech exercises	LSVT LOUD; Personalized speech therapy	
Yard work	Mowing; Gardening; Chopping wood; Rock picking; Shoveling snow	
Strength training	Using resistance machines, free weights, or elastic bands; Planks and sit-ups	
Dancing	Square dancing; Tango; Instructional dance videos; NIA	
Cycling	Using a bicycle, tricycle, tandem bike, and/or stationary bike; Spin classes	
Stretching	Static stretches; Dynamic stretches; Range of motion exercises	
Physical therapy using movements with large amplitudes	LSVT BIG	

Part 2: Please rank **all** of the following exercises from most beneficial to least beneficial based on what you **think**. If you have not personally performed a type of exercise, you should still rank that type of exercise by how beneficial you think it would be for treating symptoms of Parkinson's disease. **Each Number can only be used once and all types of exercise need to be ranked.**

Please complete all of Table 2 as follows. 1= most beneficial type, 2=second most beneficial type... 10=least beneficial type

Description	Examples	Rank
Static exercises that use bodyweight as resistance and involve controlled breathing while holding specific bodily postures	Yoga; Pilates	
Slow moving exercises that use bodyweight as resistance and involve controlled breathing while alternating between specific bodily postures	Tai Chi; Tae Guk Kwan Do	
Walking	Walking on a treadmill; Daily locomotion; Walking in neighborhood or on a trail; Walking pet	
Speech exercises	LSVT LOUD; Personalized speech therapy	
Yard work	Mowing; Gardening; Chopping wood; Rock picking; Shoveling snow	
Strength training	Using resistance machines, free weights, or elastic bands; Planks and sit-ups	
Dancing	Square dancing; Tango; Instructional dance videos; NIA	
Cycling	Using a bicycle, tricycle, tandem bike, and/or stationary bike; Spin classes	
Stretching	Static stretches; Dynamic stretches; Range of motion exercises	
Physical therapy using movements with large amplitudes	LSVT BIG	

Grouped responses from Survey 1.

Grouped Responses	Item Total	Combined Total	Rank
Walking			
walking	20	33	1
walks	1		
walk	2		
Walking (power walk)	1		
5,000 steps/day	1		
Walking assistance dog (some steps)	1		
Leisure walking	1		
Treadmill	3		
Walking outside or at the mall	1		
Hiking	2		
Cycling			
bike riding	2	16	2
ride bike	2		
Bicycling	1		
Trike riding	1		
Spinning	1		
Biking	3		
bike	1		
Short bikes	1		
stationary bike	2		
Riding bike (stationary)	1		
Recumbent bike	1		
Yard work			
flower gardening in summer	1	14	3
farm activities like rock picking and wood cutting.	1		
gardening on hands & knees	1		
mowing lawn	1		
mowing a large lawn by hand (7 months/year)	1		
Yard work	3		
shoveling snow	1		
gardening	2		
snow shoveling	1		
lawn mowing	1		
Working around house and yard	1		

Grouped Responses	Item Total	Combined Total	Rank
Static Exercises			
Yoga	8	12	4
Pilates	3		
Yoga classes	1		
Strength/Resistance Exercises			
weight training	1	11	5
sittups	1		
plank	1		
weight machines	1		
Some resistance (strength)/(weight)	1		
Lifting weight	1		
weights	1		
knee bends on upside-down Bosu	1		
Elastic bands	1		
light weghts/dumbells	1		
Snap Fitness (gym/weights)	1		
Stretching			
morning stretchers	1	11	6
stretches	1		
stretching	8		
Big & Loud (35 Min of various stretching each morning)	1		
Slow Moving Exercises			
Tae Guk Kwan Do	1	10	7
Tai Chi	8		
Tai Chi classes	1		
Dancing			
square dancing	1	9	8
Dancing	4		
Dance	2		
nia (dance)	1		
watch dance & exercise videos	1		
Physical Therapy			
"Big" program exercises	1	8	9
Big & Loud	4		
Big hand	1		
LSVT BIG & LOUD	1		
Big & Loud (35 Min of various stretching each morning)	1		

Grouped Responses	Item Total	Combined Total	Rank
Speech Exercises			
Big & Loud	4	8	10
LSVT BIG & LOUD	1		
speech therapy	1		
Voice	1		
Big & Loud (35 Min of various stretching each morning)	1		
Cardiovascular General			
elliptical	2	7	
jogging	1		
Running	1		
stair stepper	1		
treadmill at steepest incline	1		
elliptical machine	1		
ADL and Housework			
Home maintenance	1	6	
Make the bed	1		
Light housekeeping	1		
house cleaning	2		
housework	1		
Swimming			
Swimming	4	4	
Hand Dexterity			
drawing	1	4	
Writing	1		
Clay class	1		
crocheting	1		
General Group Exercise Classes			
Silver Sneakers	2	4	
Group exercise (The Capistrant Center)	1		
exercise group (general)	1		
Group Power Classes/Exercises			
PWR exercise class	1	4	
Power Class at Struthers	1		
power moves	1		
weighted ball tossing/catching	1		

Grouped Responses	Item Total	Combined Total	Rank
Family/Activities of Daily Living			
Caregiving husband	1	3	
Playing ball with grandchildren	1		
Pet dog	1		
Traditional Balance			
Balance (Matter of Balance)	1	2	
Balance exercises	1		
Independent Responses			
Nordic Walking	5		
Golf	2		
Cross country skiing	1		
Massage (deep tissue and reflex)	1		
Bowling	1		
Sledding in winter	1		
Tennis	1		
Skiing	1		
Bag exercises	1		
"CLEVER-Parkinson's Disease" (Health Partners)	1		
Car repairs	1		
Tai kwon doe	1		
Grapevine while passing object in front and behind	1		
Uncategorized Responses			
General life activities	1		
At home exercise	1		
YMCA	1		
General exercise for seniors	1		
Exercise machines	2		
Weight bearing exercise	1		
Weight bearing movement	1		
Arm and trunk exercises	1		