DISSERTATION

MERGING YOGA AND OCCUPATIONAL THERAPY FOR PARKINSON'S DISEASE

Submitted by

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ABSTRACT

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Purpose: The purpose of this dissertation was to develop a fall risk self-management program for people with Parkinson's disease (Merging Yoga and Occupational Therapy for Parkinson's Disease [MY-OT for PD]), conduct a feasibility and pilot study, and analyze outcomes following the MY-OT for PD program.

Method: This dissertation includes three studies. Study One was a qualitative study which focused on the adaptation of a program originally designed for individuals with chronic stroke (i.e. Merging Yoga and Occupational Therapy) and development of a new program to specifically meet the needs of people with Parkinson's disease (PwP) (i.e. MY-OT for PD). To complete Study One, we conducted a focus group with PwP and nine expert interviews. Study One results led to the creation of Stage 1 manuals to guide the MY-OT for PD program. In Study Two, we completed the 8-week (14-session) MY-OT for PD program and focused on feasibility and pilot testing. Feasibility was assessed related to the process, resources, management, and scientific basis of the program. The following outcome measures were collected: five fall management scales, concern about falling, balance, balance confidence, and self-reported falls. Study Three was a mixed-methods analysis of health-related quality of life following the MY-OT for PD program. The quantitative outcome was a HRQoL standardized assessment specifically for PwP. The qualitative data were collected via two focus groups with participants after the program in which participants were asked about eight HRQoL domains from the quantitative assessment.

Results: In the qualitative development study, three themes were identified related to revision of the MY-OT program (and development of Stage 1 manuals): revisions to the guiding model, revisions to content, revisions to delivery. We outlined changes to the manuals in relation to each theme and developed a new guiding model (the PD Fall Risk Model), altered manual content, and altered delivery aspects of the manual to create the PD-specific MY-OT for PD Stage 1 program manuals. We then implemented and tested the 8-week, 14-session MY-OT for PD program. Eighteen participants enrolled, one dropped out during the control period, and 17 participants completed an average of 12.82/14 sessions. Improvements were seen on all outcome measures, and significant differences were seen between the control and intervention periods on one of the fall management scales and balance, with significantly greater scores improvements during the intervention period as compared to the control period. HRQoL results were mixed because quantitative results showed no significant differences in HRQoL following the MY-OT for PD program, while qualitative results showed noted improvements in all HRQoL domains. Conclusion: MY-OT for PD is one promising program that decreased the number of self-reported falls during the intervention, improved balance, and participants reported improvements in HRQoL. In order to complete future trials, MY-OT for PD would need to be modified based on participant feedback and analysis of outcomes following the feasibility and pilot testing in Studies Two and Three.

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DEDICATION

To my grandmother, who had a soft voice from Parkinson's disease,

but the loudest love for her family

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CHAPTER ONE: INTRODUCTION

Statement of the Problem

Parkinson's disease (PD) is a neurodegenerative condition marked by cardinal features such as bradykinesia, rigidity, resting tremor, and postural instability (The American Occupational Therapy Association & Parkinson's Disease Foundation, 2015). People with Parkinson's disease (PwP) likely have these cardinal motor features, along with other variable motor and non-motor features (i.e. executive functioning difficulty, attention problems, trouble sleeping, depression and fatigue) (Shulman, Taback, Rabinstein, & Weiner, 2002). Together, these motor and non-motor features make PwP at very high risk to fall. According to a systematic review of 22 studies, 35%-90% of people with PD reported a fall during the study (most frequent time period = one year) (Allen, Schwarzel, & Canning, 2013). Of those people who fell more than once, they reported an average of 21 falls a year. For PwP, falls are not just an isolated experience, rather falls frequently led to injury, or catalyzed activity avoidance (Rudzińska et al., 2013). Injury and fear of experiencing another fall may cause individuals to decrease their activity levels. Additionally, both PwP and key stakeholders in the field of PD identified the management of falls and balance problems as the top research priority for this population (Deane et al., 2014).

One option to manage falls is participation in programs designed to identify and reduce fall risk factors. Many evidenced-based programs have been developed to reduce fall risk in older adult populations. However, many of these established programs exclude PwP (Barnett, Smith, Lord, Williams, & Baumand, 2003; Clemson et al., 2012; Kovacs, Prokai, Meszaros, & Gondos, 2013; Rubenstein et al., 2000). Exclusion could be due to distinctive physical

challenges, or the unique combination of fall risk factors present for PwP. According to a recent comprehensive review of falls in PD, fall prevention interventions "should take inspiration from what is already done in non-PD patients while bearing in mind the differences that PD itself poses" (Fasano, Canning, Hausdorff, Lord, & Rochester, 2017, pp. 1532-1533). In the older adult population, multifactorial fall interventions are recommended (Leland, Elliott, O'Malley, & Murphy, 2012), and similarly, multifactorial interventions may be beneficial to reduce falls or fall risk factors for PwP. Multifactorial simply means an intervention involving multiple factors, or several parts to the program.

Therefore, we decided to adapt a multifactorial intervention designed for individuals with chronic stroke to meet the needs of PwP. The Merging Yoga and Occupational Therapy (MY-OT) program was an 8-week program that combined group occupational therapy (OT) (lecture, guided discussion, and graded activity) with adaptive yoga (Schmid, Van Puymbroeck, Portz, Atler, & Fruhauf, 2016). The group OT portion focused on self-management skills to identify and reduce fall risk factors. Individuals with chronic stroke experienced a significant improvement in fall risk factor management following the MY-OT program. Due to the limited fall risk programming available for PwP, we decided to adapt and pilot the MY-OT program to meet the needs of PwP. This dissertation was completed to adapt the original MY-OT program, develop the Merging Yoga and Occupational Therapy for Parkinson's Disease (MY-OT for PD) program (including program manuals), and assess the preliminary efficacy of the MY-OT for PD program through a pilot and feasibility study, including specific analyses on health-related quality of life (HRQoL).

Guiding Model

The MY-OT for PD program was designed to improve fall risk factor management for PwP. Throughout this dissertation, fall risk factors are understood and categorized through use of the World Health Organization (WHO) Risk factor model for falls in older age (World Health Organization, 2007). The model was developed as part of the WHO Global Report on Falls Preventions in Older Age (2007) from an international collation designed to develop conclusions and recommendations for fall prevention globally through literature reviews and consensus building processes. The model presented fall risk factors that impact older adults in the domains of biological, behavioral, environmental, and socioeconomic. For the purposes of this dissertation, the model was modified to reflect the unique fall risk factors present for PwP. The model was refined during Study One based on my review of the literature pertaining to fall risk factors in PD and through discussion and feedback from PwP and experts.

Fall Risk Factors in PD

As part of the first step in modifying the WHO risk factor model for falls in older age, a comprehensive literature review was completed to determine the predominant fall risk factors for PwP. PD causes features that impact individuals across functional domains and create unique fall risk factors. For individuals with PD, falls have been shown to negatively impact the following domains: mobility, emotional wellbeing, activities of daily living, cognition, and social supports (Michalowska, Fiszer, Krygowska-Wais, & Owczarek, 2005). In response to the concern surrounding falls and effect of falls, the National Parkinson Foundation's (NPF) Falls Task Force published systematic recommendations to address fall risk in PD (van der Marck et al., 2014). The NPF recommendations have since been used to further understand the nature of falls and fall risk in PD (Fasano et al., 2017). Based on a multi-tiered, consensus-based process, 31 fall risk factors were identified for PwP. The final factors were determined after a review of literature and

guidelines, recommendations from 27 clinical professionals at NPF centers, and refinement through a diverse expert group of 12 clinical practitioners. Of these 31 factors, 16 factors were recognized as generic risk factors that overlapped with age-related changes (e.g. anxiety, old age, weakness due to inactivity), and 15 factors were recognized as specific to PD (e.g. disease severity, freezing of gait, dyskinesia). In order to understand these risk factors, there are many ways that risk factors can be categorized. PD risk factors can be explored through the domains represented by the WHO, with the understanding that the domains interact (World Health Organization, 2007).

Biological risk factors. Biological risk factors are classified as factors relating to demographics (age, gender, disease duration, and disease severity/staging), motor risk factors, and non-motor risk factors. Some fall risk factors are not modifiable, such as older age, female gender, or disease severity. Although older age and female gender have been linked to PwP as fall risk factors based on the older adult population (van der Marck et al., 2014), specific application to increased PD fall risk is divisive (Canning et al., 2015; Gray & Hildebrand, 2000) and oftentimes falls relate more to disease severity than age. Disease duration and severity have been found to be significant predictors of self-reported falls in multiple studies for PwP (Almeida, Valença, Negreiros, Pinto, & Oliveira-Filho, 2014; Gazibara et al., 2015; Schrag, Choudhury, Kaski, & Gallagher, 2015). When compared to non-fallers, fallers had significantly greater disease PD severity on the Hoehn & Yahr (HY) scale (a scale used to classify the progression of PD), and significantly longer disease duration in years (Gazibara et al., 2015; Schrag et al., 2015). More specifically, Unified Parkinson's Disease Rating Scale (UPDRS) scores were also associated with increased falls; PwP who had fallen reported significantly higher symptom severity ($p < .01$) (Gray & Hildebrand, 2000; Kerr et al., 2010). Some

researchers reported that overall UPDRS scores were significantly higher among fallers (Allen et al., 2013; Ashburn, Stack, Pickering, & Ward, 2001; Kerr et al., 2010), while others found motor or activities of daily living (ADL) UPDRS subscales to be the most significantly associated with falls (Almeida, Valença, Negreiros, Pinto, & Oliveira-Filho, 2017; Gray & Hildebrand, 2000; Matinolli, Korpelainen, Sotaniemi, Myllylä, & Korpelainen, 2011).

PD associated body functions are frequently associated with falls such as freezing of gait (FOG) (Paul et al., 2014; van der Marck et al., 2014), postural instability (van der Marck et al., 2014), impaired balance (Canning, Paul, & Nieuwboer, 2014; Paul et al., 2014), and decreased lower extremity strength (Paul et al., 2014). In a scoping review of modifiable fall risk factors for PwP, FOG and impaired balance were the two modifiable risk factors most commonly correlated with falls (Canning et al., 2015). According to the NPF recommendations, graded cueing and cognitive strategies can be used to combat FOG, and balance can be addressed with medication, surgery, balance training, strengthening, or task retraining (van der Marck et al., 2014).

Regarding non-motor body functions, cognitive impairment in PwP is frequently associated with falls (Canning et al., 2015). Impaired orientation, frontal lobe functioning (Paul et al., 2014), attention (Allcock et al., 2009), and executive functioning have been associated with increased fall risk in PD (Schrag et al., 2015). These impairments in higher level processing could lead to falls due to difficulty with initiation, decision making, and sequencing for complex activities, therefore, placing individuals at risk to fall. Attentional deficits in PwP create difficulties with dual tasking (Allcock et al., 2009), which is a separate but potentially interrelated behavioral fall risk factor (van der Marck et al., 2014).

Behavioral risk factors. The following behavioral fall risk factors are considered in the context of fall risk management because each is either considered a primary risk factor across

research studies or represent a factor that could be addressed through OT intervention: fall history, dual tasking; transfers, medication usage, fear of falling, and activity concession. Some behavioral risk factors may be influenced by biological risk factors because PD related impairments in body function then interact to affect functioning at activity and participation levels.

The strongest predictor of future falls was commonly found to be the presence of a previous fall (Kerr et al., 2010). Even compared to other high risk populations, "a history of falls increases the risk of future falls threefold in the general elderly population and fivefold in PD" (Fasano et al., 2017, p. 1527). Experts from the NPF Falls Task Force agreed that a previous fall was the number one risk factor, but were not able to identify any suggested treatment strategies to address this risk factor (van der Marck et al., 2014).

Dual tasking and transfers were two areas identified by the NPF Falls Task Force as ideal fall risks to be addressed by occupational therapists (van der Marck et al., 2014). Dual tasking occurs when someone is completing two things at once, creating greater vulnerability to fall while attention is divided. For example, if someone is talking on the phone while preparing a meal they may be more likely to fall due to divided attention between two tasks. For PwP, transfers like getting out of bed or even standing up produce high risk situations. "Cognitive movement strategies" were a proposed intervention for these risk factors, which can involve activity retraining and graded cueing during participation in activities (van der Marck et al., 2014, pp. 364-365).

Medications play a large role in fall risk for individuals with PD, and medication use has been more heavily studied than other behavioral risk factors (van der Marck et al., 2014). The use of PD-specific medications has been cited as a risk factor for falling, and these medications

typically fall into three categories: dopaminergics, MAO inhibitors, and anticholinergics (The American Occupational Therapy Association & Parkinson's Disease Foundation, 2015). Medications that support dopamine action in the basal ganglion, or dopaminergics, are the primary method used to treat the motor symptoms associated with PD (ex. levodopa and dopamine agonists). Another option to treat motor symptoms is medication that slows the breakdown of dopamine (ex. MAO inhibitors). Finally, some medications block neuro-transmission effects that could damage dopamine (ex. anticholinergics).

The dopaminergic levodopa is the most commonly used medication to treat PD (Katzenschlager & Lees, 2002), and has been shown to reduce long-term disability (The American Occupational Therapy Association & Parkinson's Disease Foundation, 2015), especially motor symptoms like rigidity and bradykinesia (Parkinson's UK). However, there are many clinical symptoms that do not respond to levodopa. For example, the top two PD concerns that persist despite levodopa treatment are falls (in 81% of patients), and cognitive decline (in 84% of patients) (Hely, Morris, Reid, & Trafficante, 2005). Additionally, although levodopa reduces long-term disability it also can cause random involuntary movements (dyskinesias) during peak dose times. In a regression analysis of fall risk factors for PwP, dyskinesia was found to be a symptom that was significantly associated with falls in PwP ($RR = 1.14$) (Paul et al., 2014). Gray & Hildebrand (2000) found that more PwP reported falls when medication was effective rather than when it was wearing off or ineffective, which could be related to the risk of falls from peak dose dyskinesia. Dyskinesia also has an impact on many other domains affecting daily functioning. According to a patient survey by the NPF (2001), dyskinesia greatly affects activities of daily living, such that, individuals with PD reported interference with walking (61%), sleeping (58%), eating (46%), talking (44%), dressing (38%), and thinking (36%) (The

American Occupational Therapy Association & Parkinson's Disease Foundation, 2015). The NPF Falls Task Force cited PD medications, and dyskinesias as two independent PD-specific fall risk factors (van der Marck et al., 2014). Although occupational therapists do not address medication prescription, there is a role for OT in medication management and improving an individual's ability to take medication as recommended (American Occupational Therapy Association, 2017). Occupational therapists frequently address methods to promote safe medication management, which may include scheduling or understanding timing and promoting an appropriate medication routine, as well as improving self-advocacy in the coordination with prescribing healthcare professionals.

One risk factor that was not selected as a primary risk factor by the NPF Falls Task Force was fear of falling (FoF), although FoF has been frequently cited as a predictor of falls in PwP or a risk factor for recurrent falls (Almeida et al., 2017; Gazibara et al., 2016; Latt, Lord, Morris, & Fung, 2009). FoF is a complex risk factor that has been shown to lead to decreased engagement in daily life (Cumming, Salkeld, Thomas, & Szonyi, 2000). Healthy older adults with high FoF scores had significantly lower ADL performance ability as compared to older adults with low FoF scores ($p < .001$) (Cumming et al., 2000). Education led by occupational therapists can focus on improving falls efficacy, in order to decrease FoF, and consequentially maintain meaningful activity performance (Leland et al., 2012). In a between-groups comparison of fallers and non-fallers with PD, fallers had given up significantly more activities in which they usually participated ($p = .01$) (Gray & Hildebrand, 2000). Part of the OT role could involve maintaining meaningful activities while reducing fall risk factors, since occupational therapists specialize in promoting performance and participation for PwP (The American Occupational Therapy Association & Parkinson's Disease Foundation, 2015).

Environmental factors. Environmental hazards were identified by the NPF Falls Task Force as a primary fall risk factor for PwP that should be addressed by an OT (van der Marck et al., 2014). According to a content analysis focused on fall research, primary environmental hazards in the home included insufficient lighting, obstacles in a person's path, and slippery surfaces (Clemson, 1997). In addition to considering environmental factors, an OT must also consider the person's ability to make safe decisions surrounding potential hazards and activity selection (Peterson & Clemson, 2008). Home visits by an OT are one way to ensure appropriate environmental modifications (van der Marck et al., 2014) and interventions involving an OT home visit have shown a significant reduction in falls (Clemson et al., 2004).

Socioeconomic risk factors. The WHO (2007) identified both "lack of social interactions" and "lack of community resources" as socioeconomic fall risk factors for older adults (p. 5). Although these risk factors are rarely discussed for PwP, each factor may be important to consider for future fall risk self-management interventions. PwP spend more time at home as compared to their peers, which could create a sense of social isolation (Liddle et al., 2014). In a between-groups study of fallers and non-fallers with PD, those who were alone more often were more likely to report falls (Gray & Hildebrand, 2000). Time alone was not related to living alone or not having another person there assisting, rather, time alone was just time spent independently, suggesting that increased social isolation is associated with greater risk to fall.

Stages of Behavioral Interventions

Stage Zero Background

I considered the Stage Model for Behavioral Intervention Development when developing this dissertation, as this model was endorsed by the National Institute on Aging (National Institute on Aging, n.d.). The model includes six cyclic stages to the development of behavioral

interventions, stages zero to five (Onken, Carroll, Shoham, Cuthbert, & Riddle, 2014). Stage zero includes interventions on the mechanisms behind behavioral change and incorporates basic science questions. Although there remains work to be done in this area, the original MY-OT study discussed some of these behavioral mechanisms and the behavioral rationale for merging two related interventions (Schmid et al., 2016). Essentially, yoga and occupational therapy were combined because an 8-week yoga intervention alone improved balance but not fall risk factor management (Schmid, Miller, Van Puymbroeck, & DeBaun-Sprague, 2014), and an 8-week group OT intervention alone improved fall risk factor management but not balance (Schmid et al., 2015). When merged together the intervention improved both balance and fall risk factor management, which together likely improved participants functioning and potentially reduced their overall fall risk. Separately, other research has been done in the field that supports some of the basic science concepts and background for changes in certain outcomes regarding yoga or OT.

Yoga and stage zero. Yoga typically consists of physical postures, breathing techniques, and mindfulness and various mechanisms of change have been reported during yoga practice. Outcomes for PwP and yoga interventions are frequently discussed in conjunction with the following mechanisms: functional, hormonal, neural, and placebo-type.

Functional mechanisms. According to a recent systematic review of yoga applications for PwP, functional mechanisms seen in yoga practice are likely related to changes in muscle strength and endurance, flexibility, and balance (Roland, 2014). Functional strength improvements are seen because some standing poses target key muscles involved in gait—"the hip extensor, the knee extensor, and the ankle plantar flexor" which could account for the improvements seen in "functional mobility and lower-limb strength" (Roland, 2014, pp. 4-5).

Additionally, changing physical postures promotes the utilization of different muscle fibers with recruitment from various motor units that can then increase muscle endurance (Roland, 2014). The physical postures in yoga consist of static holds and prolonged stretch that may increase flexibility especially for PwP who tend to be flexed forward with rounded shoulders. Yoga includes postures that help PwP with upright posturing and facilitate mindfulness to maintain optimal upright positioning when outside of the class in the context of everyday life. The mechanism of change for balance improvement may be due to the focus on challenging balance and vestibular systems to improve the body's awareness of grounded and equalized positioning. Additional balance improvements may actually be due to changes in balance confidence through yoga practice, which leads to decreased fear of falling, and consequently increased activity participation and balance (Roland, 2014; Schmid, Van Puymbroeck, & Koceja, 2010).

Hormonal mechanisms. One systematic review of yoga treatment found strong evidence to support the effect of yoga on the endocrine system (McCall, 2013). In this review, many authors reported decreased cortisol following participation in yoga which was associated with decreased stress, anxiety, and improved wellbeing.

Neural mechanisms. Through deep breathing techniques and postural holds, yoga may decrease reactive sympathetic engagement and promote parasympathetic responses that are calming in nature (McCall, 2013; Roland, 2014). For PwP, parasympathetic engagement reduced stress, initiated positive feelings, and assisted with muscle relaxation (Roland, 2014).

Placebo effects. Part of the mechanism of change in yoga might also be due to the placebo effect experienced by PwP (Ghaffari & Kluger, 2014). For PwP, the placebo effect is highly beneficial because dopamine is released in the brain when someone anticipates a clinical treatment benefit. Although dopamine release has not been proven to be powerful enough to

replace medications, it could be an important added therapy for PwP. Additionally, some PwP feel an increased internal locus of control due to participation in alternative treatment techniques—like yoga. With a greater sense of control over their own health, PwP could experience changes in both subjective and objective measures of function (Roland, 2014).

Impact of yoga on function and fall risk factors for PwP. The benefits of yoga for PD regarding motor and non-motor features is still preliminary (Ghaffari & Kluger, 2014). Authors of a systematic review of yoga for PwP found that yoga is an acceptable "alternative therapy and symptom management modality in PD" and demonstrates improvements in flexibility, strength, balance, and overall QoL (Roland, 2014, p. 6). The effect of yoga in improving flexibility or reducing rigidity may reduce fall risk since axial rigidity is a fall risk factor for PwP (van der Marck et al., 2014). In one randomized controlled trial (RCT) of PwP, the yoga group experienced a significant reduction in rigidity as compared to the group that received health education ($p < .01$) (Ni, Mooney, & Signorile, 2016). Weakness is another fall risk factor that is addressed through yoga practice, because yoga promotes physical engagement and has been shown to increase strength for PwP. For example, PwP who received a yoga intervention showed a significant improvement in UPDRS motor scores ($F(2) = 8.30$, $p < .01$), and lower extremity strength as compared to the control group (Colgrove et al., 2012). Participants in the yoga group also experienced significant balance improvements measured by the Berg Balance Scale (BBS) ($p = .05$). Compared to other mind-body interventions (i.e. Tai Chi or dance), yoga had the strongest effect on motor improvements as measured by the UPDRS motor subscale (Kwok, Choi, & Chan, 2016). Regarding posture, there were no significant quantitative changes before and after the 12-week yoga intervention for PwP ($p = .14$), but qualitatively, four individuals experienced visible improvements in posture ranging from improvements in equal weight

distribution to a wider base of support (Colgrove et al., 2012). These improvements indicate that a 12-week yoga program could target the following essential PD behavioral and biological fall risk factors: weakness due to inactivity, postural instability, and overarching balance (van der Marck et al., 2014). Interestingly, the most change was seen during the first six weeks of the yoga program and then maintained through the remaining six weeks (Colgrove et al., 2012), so a shorter yoga program for PwP may reach the same significant benefits.

Preliminary evidence is mixed regarding yoga's effect on non-motor features of PD. One pilot study examined eight weeks of adaptive yoga and found no significant improvements on the Hospital Anxiety and Depression Scale (HADS), a self-report measure of anxiety and depression (Boulgarides, Barakatt, & Coleman-Salgado, 2014). Conversely, in an eight-week trial of yoga for PD, participants experienced an increased HADS score during the control period, and a decreased HADS score during the yoga intervention period, which indicated a significant decrease in anxiety and depression during the intervention vs control period ($p = .01$) (Boulgarides et al., 2014). Additionally relating to non-motor features, there are promising results regarding the effects of yoga on fatigue for PwP (Mendoza et al., 2016). In a RCT pilot intervention, PwP who received yoga experienced a significant positive change on the Parkinson's Fatigue Scale (PFS) following the intervention ($t = 2.4$, $p = .03$) (Mendoza et al., 2016).

Impact of yoga on HRQoL for PwP. HRQoL is affected by changes in motor and non-motor features of PD, and additionally many researchers have shown improvements in overall HRQoL for PwP post yoga. In a 12-week RCT that included measurement of HRQoL using the Parkinson's Disease Questionnaire—39 (PDQ-39), the individuals randomized to the yoga group reported improved HRQoL scores while the control group participants had a decline in self-

reported HRQoL during the study period (Ni et al., 2016). However, in a comparison of yoga and resistance training for PwP, there were no significant between-group differences on the PDQ-39, yet these results could be attributed to the large dropout rate in this study (Bega, Stein, Zadikoff, Simuni, & Corcos, 2016).

Impact of yoga on fall risk factors for general older adults. More comprehensive outcomes are seen in the general older adult population vs. specifically for PwP regarding motor and non-motor factors. In the general older adult population, yoga has been shown to improve strength, mobility, flexibility, gait, and reduce stress levels (Ghaffari & Kluger, 2014), all of which are related to PD fall risk factors. Yoga outcomes are similar to promoted exercise outcomes for fall prevention. In a review of falls in the elderly, researchers concluded that "the most effective approach to reduce both the risk and rate of falls in elderly community-dwelling individuals is multi-component exercise programs targeting strength, balance, flexibility, or endurance" (Karlsson, Magnusson, von Schewelov, & Rosengren, 2013, p. 757). Authors of a RCT of middle aged and older adults (45-70 years old) reported that participants in a yoga group showed significant improvements in the chair stand test, an indicator of lower extremity strength, as compared to the routine care groups ($p < .01$). Since transfers, like standing from a chair, and weakness are both fall risk factors for PwP (van der Marck et al., 2014), yoga may be an intervention to explore for fall risk reduction.

With the improvements seen in mobility and balance for older adults who have participated in yoga programming, authors of one systematic review called for further research investigating the effect of yoga on falls for older adults (Youkhana, Dean, Wolff, Sherrington, & Tiedemann, 2015). A pilot program trialed 16-weeks of yoga home exercise vs. home relaxation for adults 60 years or older (Hamrick, Mross, Christopher, & Smith, 2017). Both groups

experienced a significant reduction in self-reported falls from the beginning of the study to six months after the intervention ($p < .05$) (Hamrick et al., 2017). The only significant between-group difference was seen in balance confidence ($p < .05$), indicating that yoga targets balance confidence more than relaxation programs alone. The yoga home exercise group reported fewer falls ($n = 6$) following the intervention than the home relaxation group ($n = 8$), but the difference was not statistically significant as both groups had a reduction in reported falls.

Occupational Therapy for Falls and Stage Zero

Again, the original MY-OT program merged yoga and group OT and led to improvements in balance and fall risk factor management (Schmid et al., 2016). Compared to the evidence for basic mechanisms behind yoga practice, less research exists on the mechanisms behind OT practice for fall risk factor management. However, the role of OT and benefits of OT interventions have been reported through improvements in related outcomes for PwP. Occupational therapists are trained in preventative techniques, rehabilitation of physical, cognitive, social, and emotional domains, and modification of the environment or lifestyle (American Occupational Therapy Association, 2015). With this skill set, occupational therapists explicitly collaborate with the individual throughout the evaluation and treatment process (American Occupational Therapy Association, 2015). Additionally, in the context of PD, occupational therapists have training in the process of aging, and adaptation of participation based on motor and non-motor features, which creates a unique role in the treatment of PwP who experience multi-faceted functional impairments (Foster, Bedekar, & Tickle-Degnen, 2014).

Based on a systematic review of OT interventions for PwP, three primary categories of treatment emerged: “(1) exercise or physical activity; (2) environmental cues, stimuli, and objects; and (3) self-management and cognitive behavioral strategies” (Foster et al., 2014, p. 40).

Regarding exercise/physical activity interventions, research showed that occupational therapists primarily used single task treatment strategies to promote physical activity which increased motor skills, postural stability, and/or balance. Additionally, task-specific interventions led to the greatest improvements (i.e. balance improved most with balance specific exercises). The researchers explored some exercises that were not single task activities—carrying objects while walking—which improved overall dual task performance.

Occupational therapists also frequently employ environmental cueing as another strategy in the treatment of PwP. A systematic review found that auditory cueing generated the greatest improvement in various performance measures, while multisensory cueing or divided attention training decreased performance capabilities (Foster et al., 2014). The OT review included seven studies that focused on general self-management interventions. The interventions used individualized goal setting, task training and practice, and reinforcement techniques to address habit retraining. Effective outcomes were seen specifically with 20 or more self-management sessions over six to eight weeks. In the OT review, researchers concluded that:

> practitioners should incorporate client-centered self-management strategies into intervention with clients with PD to enhance self-efficacy and maintain participation in valued activities and roles, thus mitigating the negative effects of PD on health and quality of life. (Foster et al., 2014, p. 45)

Additionally, the researchers determined that individualized OT interventions were important, but practitioners must also consider the importance of the social participation for PwP that can be gained from group environments (Foster et al., 2014). Group OT adds an interpersonal component that could increase QoL by exposing individuals to other PwP and care partners in similar situations and with similar considerations surrounding daily life and the management of

disease processes.

Based on the primary needs identified by individuals with PD (Deane et al., 2014), programs are needed that more specifically address the needs of a complex neurodegenerative condition within the context of a primary concern—falls. Self-management interventions can be designed differently, depending on the individuals the program serves (Newman, Steed, & Mulligan, 2004). Creating or adapting a fall risk self-management program requires understanding falls in this population, inclusion of strategies for fall risk management, and measuring modifiable outcomes related to falls like fall efficacy, fall management, and behaviors/strategies related to PD specific fall risk.

Occupational therapy and fall risk self-management. When reviewing the literature, there were no self-management programs designed specifically for PwP. Because there were no specific programs for PD, programs for other neurodegenerative conditions must be considered. Finlayson, Peterson, and Cho (2009) developed an occupational therapist led fall management program for individuals with MS. The program focused on addressing behaviors, attitudes, activities, symptoms, and the environment (BAASE) and how these constructs come together to influence falls and fall risk. The Safe at home BAASE program was a six-week self-management intervention led by an OT, where each class was specific to MS fall risk factor management. The researchers found significant improvements in the Falls Management Scale and Falls Prevention and Management Questionnaire following the intervention.

Schmid et al. (2016) used elements of the BAASE model to create the MY-OT program (for individuals with chronic stroke). Due to this population's specific needs, the program was expanded to 16 sessions, included yoga, and addressed stroke specific fall risk factors. The program used a small-group format with lectures, goal setting, activities, and peer feedback. The

MY-OT program was chosen for adaptation into MY-OT for PD because it is one of the few fall risk management programs designed for a neurological population, and the foundation of the program came from a neurodegenerative specific program (MS). Although not specifically for populations with neurological conditions, occupational therapists have recently been filling a growing role in general fall prevention. In 2017, the American Occupational Therapy Association (AOTA) and American Physical Therapy Association (APTA) released a program called "Step up to Stop Falls" which included a PowerPoint defining falls, explaining the preventative nature of falls, examining risk factors, and promoting a holistic approach to management (i.e. understanding exercise, medication management, vision, and environmental modifications) (American Occupational Therapy Association & American Physical Therapy Association, 2017).

Based on a systematic review of OT interventions for fall prevention, interventions ranged from environmental modification, to exercise programs, to multifactorial interventions (Leland et al., 2012). Some environmental interventions in the systematic review of OT for falls consisted of just one home visit with an OT who evaluated environmental hazards and made recommendations for fall prevention (Cumming et al., 1999; Greene, Sample, & Fruhauf, 2009; Pardessus et al., 2002; Peel, Steinberg, & Williams, 2000). In two RCTs, there were no significant reduction in falls between those who received the home safety assessment and control groups (Pardessus et al., 2002; Peel et al., 2000). Cumming et al. (1999) reported reduced likelihood of falling in the group who received a home visit. While, Green, Sample, and Fruhauf (2009) measured adherence to environmental modification suggestions as an outcome, and 81% of participants made at least one of the recommended modifications in their home. However, the researchers suggested that future research should address behavioral changes and problem-

solving techniques specific to the individual for fall reduction. Although individuals had made a home adaptation, other areas relating to fall management needed to be explored to more holistically prevent falls and change future behavior patterns.

Authors of the systematic review of OT interventions in fall prevention examined three studies which focused on functional exercise to reduce falls (Leland et al., 2012). One study concentrated on exercise training throughout everyday activity (i.e. balancing while completing meal preparation in the kitchen) and found significantly reduced fall frequencies in the 'lifestyle integrated functional exercise' (LiFE) group (Clemson et al., 2012). Individuals in the LiFE group received seven sessions total during the program, which focused on incorporating exercise into everyday activities and in turn reduced falls. In a different 16-month intervention where participants engaged in walking, group exercise, self-care as recommended by an OT, or home exercises as recommended by a physical therapist (PT), no significant reduction in fall risk was seen (Luukinen et al., 2007). The researchers suggested that participants may not have been compliant with the recommended home exercise or self-care programs. Perhaps the recommendations were not explicitly attached to functional activities the participants completed daily, or their own personal goals, creating difficulty with carry-over.

Five multifactorial interventions were reviewed in the systematic review regarding OT's role in fall prevention, essentially meaning that each program consisted of multiple intervention components (Leland et al., 2012). All three multifactorial RCTs included in the review reported either decreased fall risk or decreased recurrent falls. One program was entitled "Stepping On" and aimed to improve fall self-efficacy, promote behavioral changes, and reduce fall incidence (Clemson et al., 2004). The "Stepping On" program consisted of seven two-hour educational sessions, an OT home safety visit, and a three-month booster session. Guided by theoretical

foundations from social cognitive theory, and adult learning principles (older adults have continued learning capacities), the program showed decreased fall risk and improved self-management strategies.

The other two multifactorial programs utilized OT as the home safety and functional portion of a comprehensive medical and allied health intervention program. Both programs recruited individuals from an emergency room (ER) visit where they either had come due to a fall or had a history of falls. The primary outcome was reduced fall risk for participants with a fall history and reduced recurrent falls for those who were seen in the ER due to a fall. Conversely, a predominantly PT driven RCT found no significant differences in self-reported falls between groups. The intervention included "progressive resistance strength training, movement strategy training, and education about methods in which to prevent falls" (Morris et al., 2017, p. 95). The control group completed "non-specific life skills training" led by an OT, PT, or speech-language pathologist (Morris et al., 2017, p. 94), and both interventions were provided in the participant's home. Interestingly, authors stated that if the therapist could not complete all of the intervention activities, strength-training was prioritized. From this statement, the reader can assume that sometimes fall prevention education was not included due to time restraints, and since the program was only six weeks long the education portion may have occurred rarely. Additionally, the fall prevention education used was a generalized fall prevention program designed for any older adults—not those specifically diagnosed with PD. While the multifactorial program showed no significant differences in fall rates between groups, this could be attributed to a variety of factors: skilled therapists individualizing the control group intervention, de-prioritization of fall education, and the global population format of the fall prevention education program. These limitations represent some of the areas that should be

considered in the development of future fall risk self-management programming.

Current Stage of the Dissertation: Stage One

The MY-OT for PD intervention was adapted from the original version to meet the needs of PwP. Therefore, further research within stage zero may need to be completed eventually because, "adapting the intervention in response to practical constraints is an inherently risky endeavor: The intervention may or may not retain the elements that make it work" (Onken et al., 2014, p. 6). Although I may return to stage zero for future research, in this dissertation I intend to complete work in stage one of the Stage Model for Behavioral Intervention Development. The format of this dissertation contains three manuscripts that are ready for publication in a peer-reviewed journal. This mixed-methods dissertation, and corresponding three studies, fall within stage one in the Stage Model. Stage one includes adapting existing interventions "and it culminates in feasibility and pilot testing" (National Institute on Aging, n.d., p. 1). Stage one can involve developing materials (i.e. manuals) and adapting the program to make it easier to implement. Study One (Chapter 2) addresses how the program was adapted through qualitative analysis of transcripts from focus group and interviews with the goal of adapting the facilitator and participant manuals. Studies Two and Three (Chapters 3 and 4) address feasibility and pilot testing of the MY-OT for PD program with an additional mixed-methods focus on HRQoL.

Conceptual Framework of the Dissertation

The three-manuscript dissertation was designed to fit together, with Study One forming a foundation through the development of the MY-OT for PD program, and Study Two and Study Three assessing differing outcomes of the MY-OT for PD program. Figure 1.1 offers a conceptual framework on the relation of each paper and the foundation to my dissertation design.

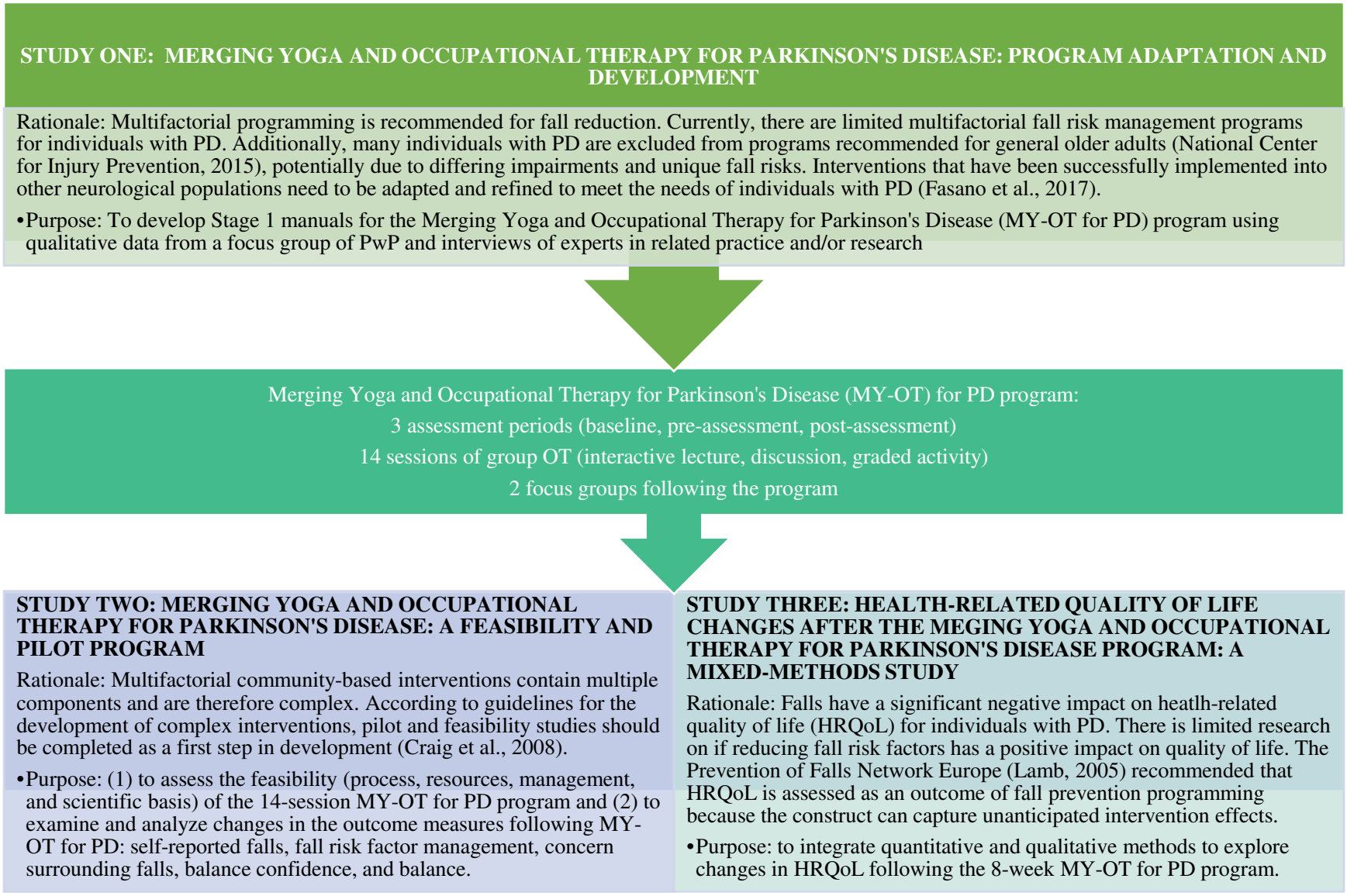

Figure 1.1. Conceptual framework of the three-manuscript dissertation

CHAPTER TWO: MERGING YOGA AND OCCUPATIONAL THERAPY FOR PARKINSON'S DISEASE: PROGRAM ADAPTATION AND DEVELOPMENT

Introduction

Parkinson's disease (PD) is a neurodegenerative condition consisting of symptoms such as: rigidity, bradykinesia, postural instability, executive functioning difficulties, sleep disturbances, and other motor and non-motor symptoms. Collectively these symptoms make people with Parkinson's disease (PwP) at very high risk to fall (The American Occupational Therapy Association & Parkinson's Disease Foundation, 2015). At least 35%, and up to 90%, of PwP fell during participation in research studies that lasted one year or less (Allen et al., 2013). A fall is not only a traumatic event in the moment, but can also greatly reduce quality of life and participation in meaningful activities for PwP (Sturkenboom et al., 2011; Thurman, Stevens, & Rao, 2008). Therefore, programs designed to reduce falls in this population must be developed and implemented.

In order to reduce falls, fall risk factors can be managed through fall prevention interventions (Guirguis-Blake, Michael, Perdue, Coppola, & Beil, 2018). However, PwP are often excluded from evidence-informed fall prevention programming (Barnett et al., 2003; Clemson et al., 2012; Kovacs et al., 2013; Rubenstein et al., 2000; Stevens & Burns, 2015). The exclusion of PwP could be due to the unique fall risk factors that are associated with a diagnosis of PD (i.e. freezing of gait, festination, rigidity, increased difficulty dual-tasking), and researchers frequently recognize that neurodegenerative conditions require a different approach to fall prevention (Guirguis-Blake et al., 2018). If programs are specifically developed for PwP,

those programs could potentially reduce falls, corresponding injuries, hospital admissions, and in-turn improve overall quality of life (Radder et al., 2017; Schrag et al., 2015).

The Informing Program

According to a recent evidence-based review of falls in PwP, the development of new programming for PwP should utilize aspects from established programs for non-PD participants while considering the differences and unique challenges of PD (Fasano et al., 2017, pp. 1532-1533). Therefore, given the critical need to create fall prevention programs for PwP, the development of a new program was based upon the Merging Yoga and Occupational Therapy (MY-OT) program (Schmid et al., 2016). MY-OT was selected as the informing program because it was designed for a neurological population (individuals with chronic stroke), improved the management of fall risk factors, and the investigators had access to program manuals. Developers of the MY-OT program initially tested a yoga intervention for individuals with chronic stroke and found that 8-weeks of adaptive yoga alone improved balance and balance confidence (Schmid et al., 2012), but the program did not necessarily decrease fall risk. Those researchers then tested an 8-week group occupational therapy program and found that group occupational therapy alone improved fall risk factor management (Schmid et al., 2015). MY-OT was formed by integrating yoga and group occupational therapy which resulted in the successful improvement of all of the following outcomes: fall risk factor management, fear of falling, balance, and balance confidence (Schmid et al., 2016).

Prior to the adaptation of the MY-OT program, it was important to create defined structure and content for the new program, which can be accomplished through manualization (Carroll & Nuro, 2002). Therefore, to meet the needs of PwP, the current study examined how the MY-OT program could be adapted to create the Merging Yoga and Occupational Therapy for

Parkinson's Disease (MY-OT for PD) program. The development of manuals for both the program facilitator and program participants offered one evidence-informed method to outline program structure and content (Carroll & Nuro, 2002).

The Adaptation of MY-OT

According to best practices, program manuals should be developed in stages that correspond with the stages of behavioral research programs (Carroll & Nuro, 2002; Onken et al., 2014). Stage 1 of manual development occurs during program development, prior to pilot and feasibility testing. At this stage, manuals should specify "treatment techniques, goals, and format" (Carroll & Nuro, 2002, p. 398). The development of Stage 1 manuals involves: the conceptualization of a strong rationale, development of a purpose, distinction between other similar approaches, definition of the intervention components and content, and development of an overall format (Carroll & Nuro, 2002). Regarding content and format for the MY-OT for PD program, a pre-established adaptive yoga for PD program was integrated with the group occupational therapy portion. Therefore, this study focused primarily on adapting the occupational therapy manuals and how to best merge the occupational therapy portion with an ongoing community-based adaptive yoga for PD program.

When adapting program manuals, qualitative designs foster client-centered program development by gathering insight from potential participants which could ultimately improve program attendance and adherence by incorporating those expressed needs in the development stage (Dickinson et al., 2011; Howard et al., 2018). However, qualitative designs are rarely used to support program development and refinement for intervention research (Fonteyn & Bauer-Wu, 2005). Because qualitative designs can address questions that are difficult to answer solely with quantitative methods, qualitative data collection and analysis are important to utilize when

developing a complex intervention (Gitlin, 2013; Glesne, 2015). For example, early consideration of program context and potential barriers can assist in program refinement, lead to more positive outcomes during the pilot testing stage (Gitlin, 2013), and improve applicability in clinical practice (Fonteyn & Bauer-Wu, 2005). Therefore, the purpose of this study was to develop Stage 1 manuals for the MY-OT for PD program using qualitative data from a focus group of PwP and interviews of experts in PD practice and/or research. This study was guided by the following research question: What changes must be made to the MY-OT program manuals in order to create MY-OT for PD program manuals?

Methods

Design

The researchers selected a pragmatic qualitative design for this study (Savin-Baden & Major, 2013). Pragmatic qualitative designs focus on the utilization of practical methods to answer a research question, and are beneficial to apply when developing programs (Mackenzie & Knipe, 2006). Using a pragmatic qualitative design allowed the research question to remain central during data collection and analysis (Mackenzie & Knipe, 2006; Savin-Baden & Major, 2013). With the aim to adapt the MY-OT program and create MY-OT for PD manuals, it was important to maintain that focus throughout data analysis. See Figure 2.1 for outlined steps in the MY-OT for PD development of Stage 1 Manuals.

[Insert Figure 2.1 Here]

Reflexivity

When engaging in qualitative research, it is important to identify "motives, presuppositions, and personal history" in relation to the line of inquiry (Caelli, Ray, & Mill, 2003, p. 5). Prior to data collection, the first author (LS) volunteered at an adaptive yoga class in the community consistently for over one year prior to data collection. Her *motive* through

observation was to gain an understanding of the context of the class, group dynamics, and build rapport with the teachers, volunteers, and participants. Additionally, LS practiced as an occupational therapist in acute/subacute settings for over five years. She worked with many patients with PD across the healthcare continuum, and many patients who had experienced severe fall consequences (i.e. injury, change in living arrangements, and a decline in quality of life). Therefore, her goal was to design a program that she felt would reduce fall risk when individuals were functioning in a community-based setting and given her background her *presupposition* was that occupational therapy was the best intervention option to prevent some of the situations she frequently saw. The team entered this inquiry with the *assumption* that not all falls are preventable, but that fall risk factors can be managed and therefore the number of falls a participant experiences can be reduced.

Procedures

All procedures and semi-structured interview questions were approved by the University's Institutional Review Board. The development of MY-OT for PD Stage 1 manuals required three steps: (1) a comprehensive literature review of falls and fall risk factors for PwP and development of first draft manuals, (2) a focus group of PwP, and, (3) individual interviews of researchers or clinicians with expertise in preselected areas (see Figure 2.1 for MY-OT for PD development of Stage 1 Manuals).

Comprehensive literature review (step 1). The comprehensive literature review formed the foundation of the MY-OT for PD manuals that were then presented (in part) during semi-structured interviews. PD-specific fall risk factors were considered using recent reviews for falls and PwP (Fasano et al., 2017; Michalowska et al., 2005; van der Marck et al., 2014). A few frequently cited PD-specific fall risk examples included freezing of gait (Paul et al., 2014; van

der Marck et al., 2014), postural instability (van der Marck et al., 2014), impaired balance (Canning et al., 2014; Paul et al., 2014), and decreased lower extremity strength (Paul et al., 2014). Generic fall risk factors for older adults were also considered (e.g. environmental hazards, limitations in access to resources) (National Center for Injury Prevention, 2015; World Health Organization, 2007). The literature was reviewed primarily as a method to alter initial stroke-specific content to PD-specific content (e.g. changing language related to an affected side), while retaining elements that apply to both populations (e.g. environmental hazards).

Following step 1 in Stage 1 manualization, the following changes were made and first draft MY-OT for PD manuals were formed: the World Health Organization Risk Factor Model for Falls in Older Age (referred to as the WHO Model) was selected as a guiding model (2007), PD-specific fall risk factors were added to the model and manuals, and a partnership with an ongoing community-based adaptive yoga for PD class was formed.

Focus group (step 2). In order to capture other necessary components of Stage 1 manual development (distinction between the informing programs, development of components and content, and structure), a focus group involving PwP was completed. A convenience sample was used to select participants for the focus group. PwP were recruited using an oral presentation following a community-based adaptive yoga for PD class. All participants met the following inclusion criteria: had a self-reported diagnosis of PD, were at least 18 years old, and agreed to arrange their own transportation to a local athletic club for the focus group.

The focus group took place at a community athletic club. Participants first completed a general health questionnaire, and demographic questionnaire (included age, years since PD diagnosis, marital status, and highest education level). LS facilitated the focus group using the semi-structured focus group guide (see Table 2.1). According to focus group recommendations,

the group was limited to 6-10 people to promote optimal engagement (Merriam, 2009). Additionally, questions were designed to facilitate clarity by providing visuals to reference (e.g. modified WHO Model, program outline, potential topics list), using familiar language throughout, and asking neutrally worded questions to reduce guided responses (Merriam, 2009). Each participant was offered a $10 gift card for their time at the completion of the focus group. The focus group was audio-recorded and transcribed verbatim.

[Insert Table 2.1 Here]

Expert interviews (step 3). To recruit experts, a purposive sampling method was used (Merriam, 2009). Researchers and clinicians with expertise in at least two of the following domains were targeted: Parkinson's disease, occupational therapy, fall risk, feasibility/pilot/community programs, and yoga. The expert interviews took place either in person on the affiliated university campus, on the phone, or through an audio/visual online application. LS facilitated all interviews using semi-structured guiding questions (see Table 2.1 for a sample of guiding questions). Interview questions were created using guidelines for semi-structured interviews (Merriam, 2009). Similar to PwP, experts were presented with program handouts to reference throughout, and asked neutrally worded questions to reduce guided responses, alongside hypothetical questions elicit more detailed responses. Experts were offered $10 gift cards at the completion of the interview for their time. Each interview was audio-recorded and transcribed verbatim.

Data Analysis

Based on pragmatic qualitative research design recommendations, the following steps were followed for qualitative data analysis: visual familiarization with the data, generation of conclusions, and result verification (Cooper & Endacott, 2007; Savin-Baden & Major, 2013). As

a first piece of visual familiarization with the data, LS transcribed the focus group and three of the interviews. A paid occupational therapy student with prior job experience in paid transcription transcribed the remainder of the interviews. LS and TK (author three) read the transcripts multiple times prior to the initiation of any coding to familiarize themselves with the data.

Generation of conclusions. All transcripts were uploaded into NVivo software for coding (QSR International Pty Ltd., 2018). Based on the semi-structured interview questions and purpose of the study, three primary a priori codes were created with corresponding secondary codes (see Figure 2.2 for deductive coding schema). The two analysts coded the focus group and all interviews independently. The analysts additionally allowed for inductive codes to emerge that related to the development of the MY-OT for PD program manuals and became apparent during the analysis process. Inductive codes which emerged included: content and using manuals (under 'Practicality'), and future considerations (under 'Program Need'). Throughout coding, LS and TK met frequently to discuss codes until consensus was reached and kept a corresponding audit trail to document these meetings. When disagreement occurred, the analysts returned to the raw data to discuss accurate representation before continuing. Together, the analysts considered all coded data and discussed reoccurring patterns in relation to the purpose of the study in order to develop final themes and related subthemes. LS re-analyzed all coded data and reorganized raw data into the final themes.

[Insert Figure 2.2 Here]

Results verification. TK reviewed all raw data captured within the themes for congruency between codes and themes. The two analysts then discussed any potential misrepresentation and reached consensus regarding the capture of participant perspectives within

each theme. Ultimately, themes were related to program revisions, which has been successfully used in other occupational therapy interventions to guide the process of manualizing an intervention (Pyatak, Carandang, & Davis, 2015).

Procedures to address credibility, consistency, and transferability. To ensure credibility, triangulation and reflexivity were used (Merriam, 2009). Researchers employed *triangulation* of data sources (one focus group, multiple interviews) and analysts (two independent coders). Additionally, first author biases for developing the MY-OT for PD program were stated in this manuscript as a method to promote open *reflexivity*. LS and TK used a *memo audit trail* in NVivo software to enhance consistency. To promote transferability, experts were selected based on targeted areas of expertise to ensure that *variation* was provided in suggestions for program adaptation. Additionally, each theme was supported by multiple participants in the focus group and interviews to ensure *maximal variation* in perspectives.

Results

Demographics

The focus group consisted of seven PwP and lasted 44 minutes. Participants in the focus group were aged 66-78 (average age = 71.86 years old). On average they had been diagnosed with PD for 7.36 years (range = 1-15 years). Focus group participants were predominantly female (57%), married (71%), and indicated some level of fear of falling (100%). See Table 2.2 for full focus group participant characteristics.

[Insert Table 2.2 Here]

Nine experts participated in interviews which ranged from 32-76 minutes (average length = 54 minutes). Interviewed experts had experience in three or more of the targeted areas, but predominantly had a background in occupational therapy (71%), were female (78%), and

represented four states in the United States and three different countries (see Table 2.3). Three themes were developed using the perspectives from PwP and experts: revisions to the guiding model, revisions to content, and revisions to practicality of delivery. See Figure 2.3 for a summary of final themes and subthemes related to necessary program revisions.

[Insert Table 2.3 Here]

[Insert Figure 2.3 Here]

Revisions to the Guiding Model

The program model was initially informed by the WHO Model, which later developed into the PD Fall Risk Model. The PD Fall Risk Model then formed the backbone for the MY-OT for PD program. After essential revisions were made, the model was referenced throughout the manuals to organize fall risk factors. Participant responses are presented with the following fall risk factor categories as subthemes for model revisions: behavioral, biological, environmental, and socioeconomic. The PD Fall Risk Model is presented in Figure 2.4 as a representation of how it evolved from the original WHO Model, informing program, literature review, focus group, and expert interviews in order to become a manual-ready version for the MY-OT for PD program.

[Insert Figure 2.4 Here]

Behavioral fall risk factors. Under behavioral risk factors, one expert expressed how wording limited how a risk factor was conceptualized. For example, 'physical activity' was initially listed as 'lack of physical activity', and Expert 9 commented that "you know so the way you have lack of physical activity, it could just be physical activity is the fall risk factor, right? Not necessarily lack of it, but sometimes during it. So, it goes both ways." Understanding risk factor wording helped to also guide the program manual adaptation with a consideration that

doing more does not necessarily mean fewer falls. Another example of a model modification was the transition from 'alcohol use' to 'drug and alcohol use' which was again prompted by a thought from Expert 9: "drug and alcohol use. There's a lot of people with Parkinson's using marijuana." Additionally, this study was completed in a state where marijuana is legal to use recreationally, inciting increased use and the need for further discussion on drug use and fall risk.

Concepts such as freezing of gait, dual tasking, and shuffled steps were added to the model following the comprehensive literature review from a consensus based study of general and PD-specific fall risk factors (van der Marck et al., 2009). Many experts and focus group participants resonated with the importance of these risk factors for the PD population. Expert 4 underscored the significance of developing a PD-specific program because "of course with Parkinson's you have other factors like the freezing of gait, and you know there are specific things with Parkinson's that warrant a different approach." Additionally, Expert 1 discussed the different approach required for PwP and stated "there is research on dual-tasking and multi-tasking that you know, might be true for everybody but it's a particularly salient issue in PD."

Biological fall risk factors. Initially when presented to participants, examples of risk factors in biological fall risk did not detail cognitive fall risk factors. Expert 1 suggested how to handle naming risk factors such as impulsivity, executive functioning difficulties, stress, anxiety, hallucinations, and psychosis: "you could sort of lump them into a similar care category like mental issues or something." Eventually with further review, 'mental functions' was selected as a term to capture these important risk factors. Additionally, Expert 7 brought up cognitive impairment, impulsivity, and impaired judgement as key fall risk factors in the PD population. In the focus group, mental functions also came up when Participant 1 introduced himself and stated, "I'm fighting, I'm struggling with psychosis, and what are the names of things, I can't

remember, psychosis, hallucinations" and later asked "can you get over psychosis?" which all reinforced a need to include these potential risk factors in the model. 'On-off cycling' of PD medications was another central biological risk factor that was added by Expert 8, who discussed the importance of "identifying higher risk activities like taking a shower, carrying laundry, and doing them when you're on. And coming up with the plan to be doing your more sedentary times when you're off."

Environmental fall risk factors. Focus group Participant 7, Expert 8, and Expert 9 all discussed weather as a fall risk factor, so it was explicitly added to the model. Given that the focus group took place in a small town in the western area of the United States, changes in weather can be critical to examine for fall risk. Expert 9 also cited the importance of adding 'small animals' to the model, stating that "such an enormous risk factor for people is their small animals. Tripping over their cats and dogs." Although already on the model he was shown, focus group Participant 1 reiterated the importance of discussing cords as a fall risk: "one thing I really related to be the cords in the walkways, as you are going down stairs you are dragging them with you. Extension cords, you can really hurt yourself. You know? Because you try to catch yourself and you just can't because the cord is holding your leg back."

Socioeconomic fall risk factors. Focus group participants did not initially perceive socioeconomic risk as a large concern in the PD population. However, with further prompting, some of the focus group participants recognized that there are many people who might not have the same access and resources. As a whole, focus group participants agreed that socioeconomic fall risk factors should be retained as a category that contributes to fall risk, even though they all cited the three other categories as their primary concern. With reflection, Participant 4 later discussed the importance of socialization because "with Parkinson's you need socialization, it's

really important to have us as a group. And to be at home alone all the time, I don't care if you are being taken care of, that's very lonely." Beyond income, Expert 7 stated that "under socioeconomic I think the ability to afford medications…could be kind of a big important one to add." He also explained that access to a movement disorder specialist is important to consider for PwP, and in the context of falls.

Revisions to Content

Revisions to content emerged as a second theme in the creation of the MY-OT for PD program manuals. The PD Fall Risk Model categories were incorporated into each session and therefore used as a reference point throughout the program for facilitators and participants. See Table 2.4 for the program outline and corresponding content revisions, made following focus groups and interviews. Revisions to content were addressed through changes to the participant manuals and handouts, addition of facilitator discussion points in the facilitator manual, slight changes to activities, or changes to participant incentives. The program outline was adapted and included in both participant and facilitator manuals.

[Insert Table 2.4 Here]

Revisions to Delivery

The final theme identified was revisions to delivery, with five subthemes: amount of content, care partner consideration, dosage, merging with yoga, and size of group. Delivery components were important to consider for Stage 1 manual content and formatting, but not all suggested revisions were incorporated in Stage 1 program manuals. See Table 2.5 for revisions to delivery of the MY-OT for PD program.

[Insert Table 2.5 Here]

Discussion

The purpose of this study was to complete the process of adapting the MY-OT program and the corresponding development of the MY-OT for PD program manuals. In order to adapt the program for a different population, it was necessary to follow the process of developing Stage 1 manuals. Other occupational therapy programs have used a similar process [e.g. literature review, focus groups, interviews] to develop an intervention and Stage 1 manuals, and have successfully implemented a pilot/feasibility trial following this stage (Pyatak et al., 2015). Receiving feedback about the program model, content, and delivery provided the opportunity to make critical changes prior to program implementation.

The PD Fall Risk Model was created as a way to tie the program together and organize content in the manuals. Because the informing WHO Model was designed for all older adults (World Health Organization, 2007), integrating perspectives from PwP and experts was important during Stage 1 manual development. Insight from participants in this study helped refine the model and increase applicability to PwP. PD-specific additions such as "access to PD specialists," "dual-tasking and multi-tasking," and "dyskinesia" were all included in the Stage 1 manuals. Additionally, culturally or geographically specific suggestions of "weather," "drugs [recreational use]," and "small animals" were all added to the model. Overall, MY-OT for PD became a comprehensive and evidence-informed program because of the iterative process of creating 'first draft' manuals and completing a qualitative analysis of focus group and expert feedback prior to the creation of preliminary manuals.

Participants in this study also suggested essential revisions to content of the MY-OT manuals (Revisions to Content were delineated in Table 2.5). Other fall prevention needs assessments have shown that remaining client-centered during program development is necessary (Howard et al., 2018). Older adults are often aware of the changes that need to be

made to their behaviors or environment to reduce falls, and they (1) make those changes, and (2) want to share their experience with others (Howard et al., 2018). In this study, participant expertise was used to add manual content and build in group discussion.

Revisions to delivery emerged as a main theme, and most participant suggestions were incorporated in manual changes (see Table 2.5 for Revisions to Delivery). One of the main changes from the original MY-OT program delivery was the decision to partner with a community-based yoga program. Fall prevention program adherence is expected to be better when individuals are familiar with the environment and the program is in a community setting (Hedley, Suckley, Robinson, & Dawson, 2010). The original MY-OT program took place in a University lab setting (Schmid et al., 2016). The decision to partner with a community adaptive yoga program for the MY-OT for PD program resulted in cascading changes to the delivery of the program. For example, the space was then limited to a community athletic center conference room, and participants were then required to pay $5 for the yoga portion of the MY-OT for PD program. Due to space limitations some participant suggestions could not be incorporated in Stage 1 manuals, such as, manuals were not adapted to include care partners because of the limited space. A recent literature review on fall prevention programming supports the experts' suggestion, stating that the inclusion of care partners could enhance social support and the understanding of which fall risks are important to each person (McMahon, Talley, & Wyman, 2011). Regarding yoga class cost, experts suggested scholarships to minimize participant burden. Four scholarships were added as part of the MY-OT for PD program plan. Ultimately, fall prevention programs that collaborate in a community-based manner are more sustainable (Lovarini, Clemson, & Dean, 2013), and therefore it was important to maintain the typical yoga-class cost when forming a partnership with a community-based program.

In relation to delivery, initially MY-OT was designed for a 20-person cohort and the manuals were outlined to reflect this group size. Experts in this study were adamant that a smaller group was necessary to optimize rich discussion of fall risk factors. In other evidence-based self-management programs, such as the Stanford Chronic Disease Self-Management Program, there are typically 10-16 participants in a group (Lorig, Ritter, Laurent, & Plant, 2006; Lorig, Sobel, Ritter, Laurent, & Hobbs, 2001). The MY-OT for PD cohort was split to create smaller groups, and though the manuals were not changed, the fidelity checks became important to ensure each group was receiving similar content. Additionally, fostering rich discussion is important because the socialization involved in fall prevention programs is likely one reason that individuals are motivated to attend (Bunn, Dickinson, Barnett-Page, Mcinnes, & Horton, 2008; Dickinson et al., 2011).

Limitations

Focus group participants were all recruited from a convenience sample of individuals who attended an adaptive yoga for Parkinson's disease class. These individuals were all from one western town in the United States and were not representative of all PwP. However, the group was able to provide feedback on the merging of yoga and occupational therapy within the context of the community in which it was being offered. Experts however were from differing states and countries and therefore may not be aware of the local context and potential limitations within a small-town environment. Finally, manuals were adapted following both focus group and expert feedback. Perhaps adapting the manuals with feedback from PwP first, and then turning to experts would have created more opportunity for refined manuals.

Implications for Future Research

This study helped to outline the steps involved in adapting an efficacious program for a

different population than originally designed. Additionally, a program was created for a population with a critical need for fall prevention programming. Developing Stage 1 manuals required iterative feedback prior to the development of preliminary manuals. In Pyatak and colleagues' development of a manualized occupational therapy intervention for people with diabetes, the next steps involved feasibility and pilot testing, followed by the development of Stage 2 manuals (Pyatak et al., 2015). Stage 2 manual development occurs after pilot and feasibility testing and before efficacy trials (Carroll & Nuro, 2002). During this stage, developers focus on the training of facilitators, development of comparison approaches, and program evaluation. Therefore, the next step for the current study involves feasibility and pilot testing of the MY-OT for PD program. Following feasibility and pilot testing, Stage 2 manuals will be developed that include training protocols for the occupational therapist and yoga teacher, and changes based on program evaluation from participants and feasibility components.

Conclusion

This study outlined the process taken to create the MY-OT for PD program and corresponding Stage 1 manuals. There are currently no occupational therapy fall-risk self-management programs for PwP. Prior to piloting a novel program for PwP, it was important to gain insight from PwP and experts regarding potential needs for such a program. The suggested revisions were incorporated into Stage 1 manuals to create the MY-OT program. The ultimate goal was to use this development stage to increase rigor of program implementation and participant adherence during pilot testing.

Figures and Tables

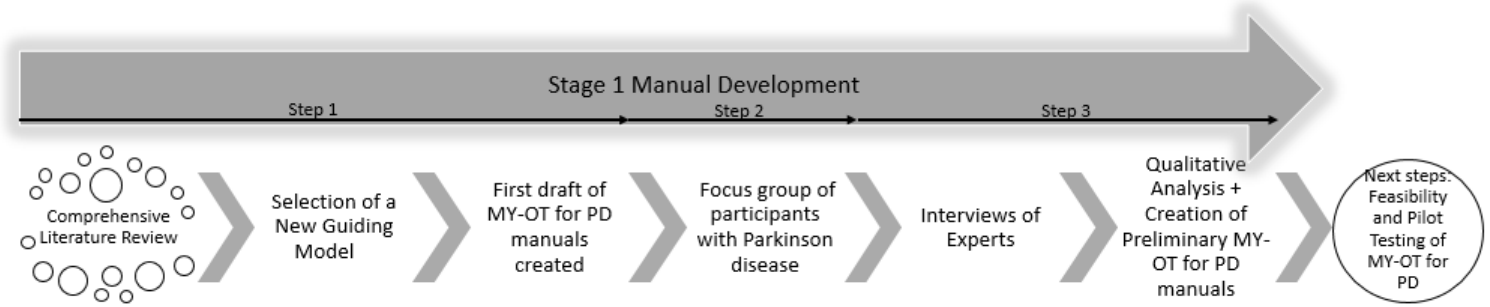

Figure 2.1. MY-OT for PD development of Stage 1 Manuals

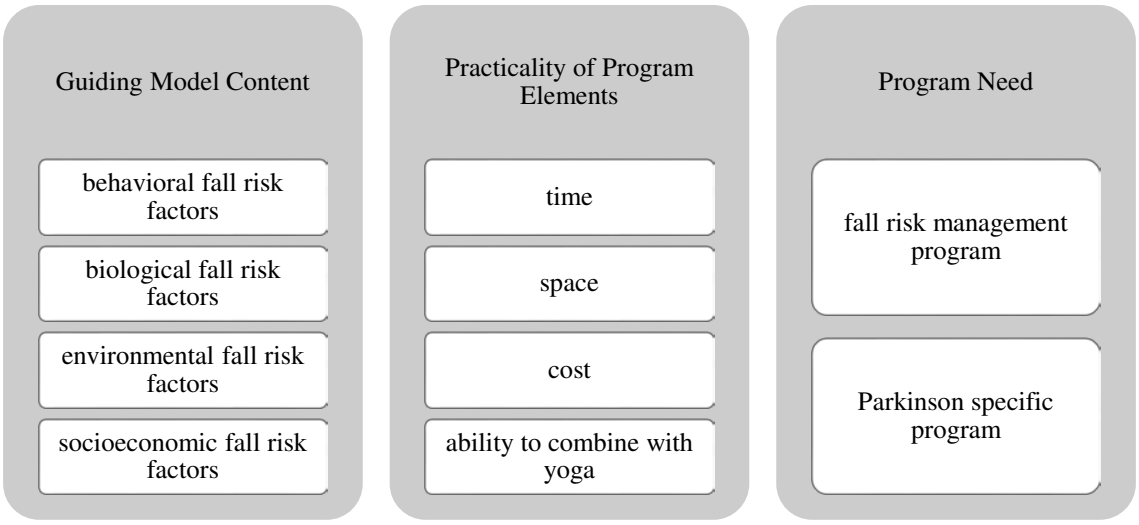

Figure 2.2. Deductive Coding Schema

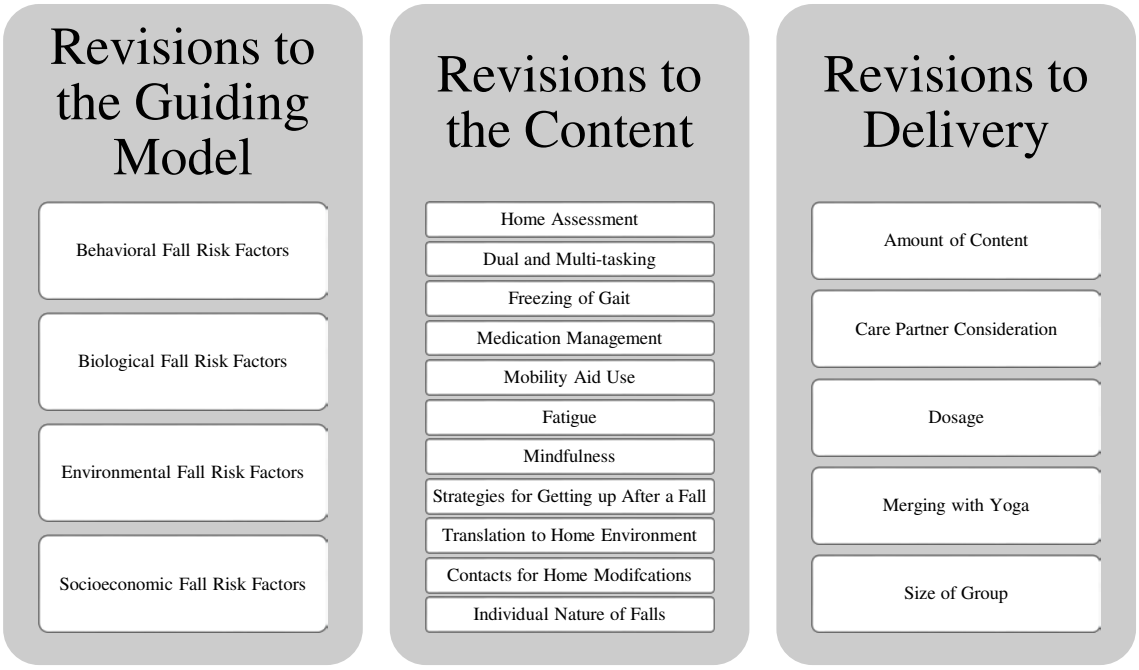

Figure 2.3. Final Themes and Subthemes

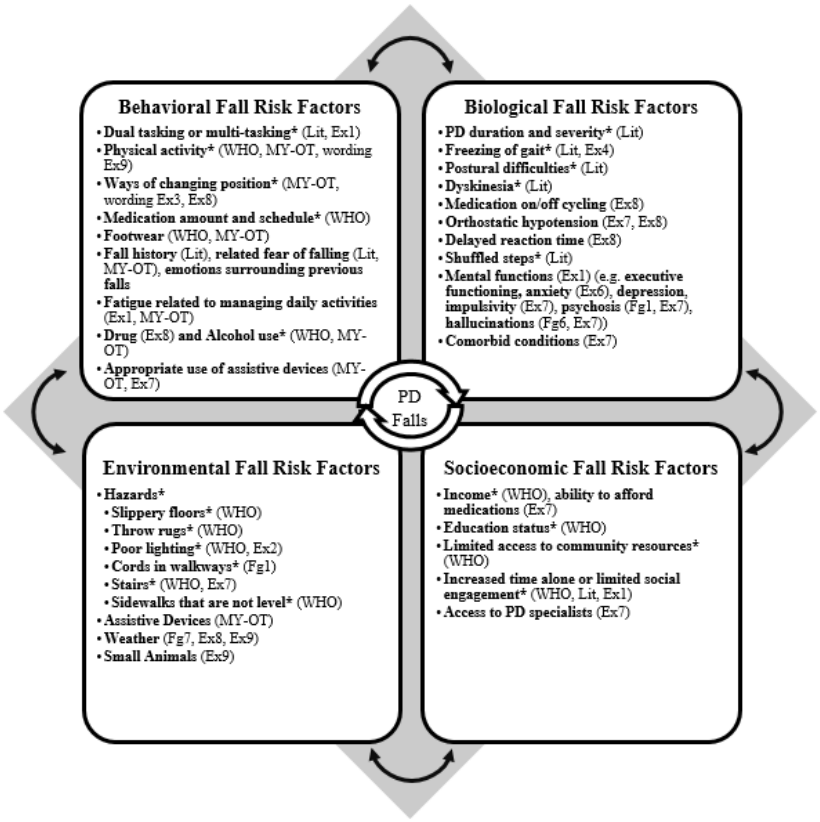

Figure 2.4. PD Fall Risk Model

Note. PD = Parkinson's disease; * = risk factor was presented on the model initially shown to participants; Fg = focus group participant number; Ex = expert interview participant number; Lit = added after comprehensive literature review on fall risk factors in people with Parkinson's disease; MY-OT = risk factor concept from original Merging Yoga and Occupational Therapy program; WHO = risk factor concept from the World Health Organization Risk Factor Model for Falls in Older Age (2007). Permission to reproduce from the World Health Organization non-exclusive license agreement # 278256.

Table 2.1

Sample Focus Group Questions and Expert Interview Questions

Method	Semi-structured Guiding Questions
Focus Group	1. Looking at the modified World Health Organization fall risk model—which category do you believe impacts you the most? a. Prompt: How do you see this as something that puts you at risk to fall? 2. Looking at the program outline—what do you think of the time commitment? Dates/times? Cost? 3. What do you think of the action planning sheet? 4. Potential topic areas—please fill out yes/maybe/no whether or not you think that topic should be included in this program.
Expert Interviews	1. How are falls a topic of concern for you, the person you provide care to, or individuals you know with PD? 2. Looking at the potential topics I sent along—which potential topic areas did you think would be most beneficial to a fall risk program for people with PD? Which do you think are the least important to include in this type of programming? 3. What do you think of the guiding model (PD Fall Risk Model) and program outline? 4. If you could design a program to reduce fall risk for individuals with PD, what would that look like?

Table 2.2

Focus Group Participant Characteristics

Participant Number	Age	Gender	Marital Status	Years since diagnosis of Parkinson's disease	Recent Fall?	Fear of Falling?
Fg1	66	Male	Married	10	Yes (just once)	Yes, somewhat worried
Fg2	74	Female	Married	8.5	Yes (monthly)	Yes, somewhat worried
Fg3	68	Male	Married	15	Yes (monthly)	Yes, very worried
Fg4	71	Female	Married	3	No	Yes, a little worried
Fg5	69	Female	No answer	9	No	Yes, a little worried
Fg6	78	Male	Married	5	No	Yes, a little worried
Fg7	70	Female	Divorced	1	No	Yes, a little worried

Note. Fg = focus group participant number

Table 2.3

Expert Interviews Participant Characteristics

Participant Number	Discipline	Geographical Area	Areas of Expertise related to MY-OT for PD				
			Parkinson's disease	Occupational therapy	Fall risk	Feasibility, pilot, or community programs	Yoga
Ex1	OT	Missouri, USA	X	X		X	
Ex2	OT	Australia		X	X	X	
Ex3	OT	Massachusetts, USA	X	X		X	X
Ex4	OT	The Netherlands	X	X		X	
Ex5	PT	Colorado, USA	X		X	X	
Ex6	Dance	Colorado, USA	X		X	X	
Ex7	MD	Colorado, USA	X			X	
Ex8	OT	Colorado, USA	X	X	X		
Ex9	RT	South Carolina, USA	X		X	X	X

Note. Ex = expert interview participant number, OT = Occupational Therapist, PT = Physical Therapist, MD = Medical Doctor, RT = Recreational Therapist

Table 2.4

Revisions to Content

(Session) Key Topics	**Revisions to Content Subthemes** with Supporting Quote Example(s)	**Resulting change to participant and/or facilitator manuals**
(1) Introduction to falls		The statistics represented in the facilitator manual surrounding falls were modified to be PD-specific rather than stroke specific.
(2) PD Fall Risk Model: behavioral, biological, environmental and socioeconomic fall risk factors	Revisions to the guiding model (see above) were implemented in facilitator and participant manuals	
(3) Fall story analysis and action planning	**Home Assessment:** "Do a home assessment before… you might need to look at rails, you might need to look at access, but you have to look at lighting, you have to look at all of these things…it might be just minimal things, putting in non-stick strips on stairs, and talking about you know, not running to catch the phone, or removing clutter." **–Ex2**	Increased time allotted to a photograph assignment where participants took photos of a risky area at home and shared strategies to reduce this risk with each other.
(4) Managing **biological** risk: effects of PD and their role in falls	**More information on Dual-tasking and Multi-tasking:** "That dual-tasking, multi-tasking. I can't cook anymore. I can paint the house, I can mow the grass. I can think, I can do complicated things but I cannot put a meal together. It overwhelms me." **–Fg4** "I think I've developed a habit of not multi-tasking, just trying to do one thing at a time now." **–Fg5** "Dual-tasking in a safe environment it's almost kind of a form of exercise, right? They are trying to improve their ability to dual task." **–Ex1**	Development of a 'Tips to Avoid Multi-tasking' sheet for participant manuals, and inclusion of a point about dual tasking practice in safe environments and/or with a therapist in the facilitator manual.
	Freezing of Gait strategies: "Although with the freezing, she gave me a laser that really is helpful." **–Fg7** "Share experiences of how they can overcome freezing of gait because I think that's quite individual what would work for each person." **–Ex4**	Development of a 'Strategies to Reduce Freezing of Gait Tip Sheet' that was added to participant manuals. The facilitator manual included script to encourage participants to try different strategies and employ the certain strategies that worked for them. Additionally, participants were given laser pointers to trial.

(5) Managing **behavioral** risk: medications, mobility aids and checking them for safety	**Medication Management specifics**: "You can always tell people 'Become your own monitor. Keep a journal about your medications, ask your care partner to tell you when they notice changes, and don't be afraid to advocate for yourself with the doctor to check if there are ways that you can experiment.' Especially if someone starts exercising a lot, I think, would be really good to check if they can reduce their medication."**—Ex5** "It's also something to be aware of and it's something they might bring up with their primary care doctor. There are definitely a number of medications that have been associated with falls in the elderly. If you can eliminate polypharmacy and things like that, you can reduce fall risk."**—Ex7**	Optional medication scheduling sheet provided in participant manuals. Participant manuals included key questions to ask their doctor. Separate resources were added to manuals regarding the potential interactions of PD-specific medications and food.
(6) Managing **environmental** risk: mobility Aids Managing **behavioral** risk: physical activity and falls	**Emotional feelings with Mobility Aid Use:** "people really don't like being seen with their walker and they'll hide it if the grandchildren are coming over or things like that, certain people." **–Ex7**	Discussion points added to facilitator manual about emotions associated with walker use to help lead group conversation. PD-specific (e.g. U-Step) mobility aid options were added to participant binders so that they were made aware of the variety of choices.
(7) Managing **behavioral** risk: role of endurance, using a pedometer		No Change
(8) Managing **biological/behavioral** risk: role of fatigue as a fall risk, modifying activities	**Addressing fatigue:** "I think the idea behind energy conservation is one that people don't think about. Even one that's sitting down to chop vegetables. That takes so much away to stand up and you can easily accomplish the same task sitting down, so why not do that. If that can help people with their fatigue, that would be fantastic." **–Ex9** "Fatigue…if you have to skip something I would [skip fatigue]. Because that's a whole other topic you know you can talk about that forever as well…So you can address it…as an issue that it is maybe a risk. And I would not probably spend a whole session on fatigue." **–Ex4**	Energy conservation techniques woven throughout discussion of fatigue, building endurance, and modifying activities. Fatigue primarily addressed through modifying activities and building endurance while providing rest opportunities.
(9) Managing **biological/behavioral** risk: fatigue continued, modifying activities continued	**Mindfulness:** "Well, paying attention. I've had some serious falls. There is an area of my kitchen where I have fallen…rehab and a straight leg cast for a month, 6 weeks. Broke my eye socket." **–Fg3**	Explicit discussion added to facilitator manual surrounding mindfulness and body awareness from yoga and bringing that into everyday life to modify activities, especially in risky scenarios.

(10) Managing **biological/behavioral** risk: physical activity, strengthening, practice getting up from the floor	**Strategies for Getting up After a Fall:** "The self-check piece. Check in with yourself before you begin to stand. And some of what I've been teaching on not only the falling, but in getting up, is the mechanics of getting up." **–Ex6**	Modification from stroke which focused on the hemiplegic side. Further promotion of emergency self-check strategies before moving added to facilitator manual.
(11) Managing **environmental/ socioeconomic** risk: action planning for home and the community	**Reinforcement of translation to home environment:** "It sounds like you have great measures. It sounds like the photography piece is fantastic." **–Ex3**	A section was added to the facilitator manual checking in on risky situation fall photographs with a focus on environmental risk.
(12) Managing **environmental** risk: addressing home hazards	**Contacts for Home Modification:** "Volunteers of America will come to your house and install whatever it you needed installed, at no cost."**—Fg4**	Volunteers of America and other local contacts added to a reference sheet in participant manuals.
	Week 7 Holiday Week	
(13) Managing **environmental/socioeconomic** risk: fall management, advocacy with providers, creating emergency contact forms		Emergency contact form options provided: general form, form for refrigerator, and form for wallet. Additionally, free advocacy options like the "Patient Safety Kit" offered by the Parkinson's Foundation were introduced in the facilitator script.
(14) Program Summary: reinforcement of interacting factors	**Reinforcement of Individual nature of Falls:** "I don't know that there would necessarily be a one size fits all because people with Parkinson's fall for very different reasons." –Ex7	The summary session was adjusted to reflect the PD Fall Risk Model domains and corresponding interactions. In the discussion section of the facilitator manual, participants were encouraged to analyze what led to their own falls and make changes in the areas most applicable to them.

Note. PD = Parkinson's disease; Fg = focus group participant number; Ex = expert interview participant number

Table 2.5

Revisions to Delivery

Revisions to Delivery Subthemes	**Supporting Quote Example(s) of Suggestions**	**Resulting manual change or rationale for no change**
Amount of Content	The action plan sheet was "hard to read" **–Fg3** "If it [the amount of writing] is too much, just fill out what you can" **–Fg4** "So my reaction to this is that it [the amount of key topics in the program] seems like too many things"	Reading/writing was minimized and checklists were provided when appropriate in lieu of writing. The program was designed to introduce a variety of fall risk factors, and prevention programs that introduce many risk factors allow for participants to aggregate comprehensive prevention strategies (Hart-Hughes, Quigley, Bulat, Palacios, & Scott, 2004; Ness, Gurney, & Ice, 2003), therefore, no change was enacted.
Care Partner Consideration	"I generally feel it's very important the care partner is aware also of the risk factors and the strategies." **–Ex4** "It's not good if the care partner comes [to the physical therapy session] and then just looks bored the whole time or like sits on the side. So I try to get them to participate too." **–Ex5**	Due to space limitations for the study, manuals were not changed to incorporate care partners.
Dosage	"getting a group interaction, and people talking and problem solving through some of these things together. But that just makes me think again that like, an hour is probably going to be pretty short."**—Ex1** "as long as you make sure that there is sufficient time in-between—so allow for really a proper break between the two program parts then that should be fine I think." **–Ex4**	The facilitator manual was reviewed and practiced to ensure each session's content could be covered in one hour, and allow for a 15-30 minute break.
	"I think it [the timeframe] is accommodating. It's very accommodating"**—Fg4** "some of the issues are when you finish a program like that, how do you maintain things like…keeping up with checking your medications or your exercise, or, you know, when people are more aware of their environment, what changes do they make?"**—Ex2** "I mean I think an ongoing fall prevention program would be great. You know, one where people could come for six months or a year or however long they felt like they needed to or wanted to. Or they could come back whenever they wanted to."**—Ex9**	The program length was maintained from the original MY-OT program (Schmid et al., 2016), and kept consistent for Stage 1 manuals of the MY-OT for PD program.

Merging with Yoga	Paying for the community yoga class at $5/class: "I would assign it [a scholarship] based on need first of all"**—Ex4**	Because yoga was running as an ongoing community-based program, four scholarships were made available to participants. Participants who received the scholarship was noted in the facilitator manual.
	Merging the curriculums: "is the curriculum of the yoga tied to the content of those meetings [occupational therapy sessions]?" **–Ex7**	The yoga instructor was provided with the program outline from the facilitator manual to ensure cohesion of key topics in each session.
Size of Group	"really giving people a chance to, and encouraging them to, go out and try some of these things they are learning in class in their everyday lives and then coming back and processing through them. In which case maybe the smaller the group the better—so maybe like a 7 to 10-person group might be more manageable for something like that."**—Ex1** "People can get ideas from each other and maybe share…so I think that would be nice to have, to really have an interaction all the time. And that's why I would not make the group larger than 10."**—Ex4**	An additional time option was added to the program outline in the manuals. Participants were able to choose between earlier or later sessions.

CHAPTER THREE: MERGING YOGA AND OCCUPATIONAL THERAPY FOR PARKINSON'S DISEASE: A FEASIBILTY AND PILOT PROGRAM

Introduction

Parkinson's disease (PD) is the second most common neurodegenerative condition in the United States (US) (Lee & Gilbert, 2016). According to the most recent projections based on US Census Bureau data, over one million people will have a diagnosis of PD in the US by 2030 (Marras et al., 2018). Neurodegenerative changes from PD can affect physical, cognitive, social, and emotional areas of everyday life for diagnosed individuals (The American Occupational Therapy Association & Parkinson's Disease Foundation, 2015). Since PD is progressive, people with Parkinson's disease (PwP) are likely to experience continually more complex and severe motor and non-motor symptoms, leading to greater impact on daily life through disease progression (Sturkenboom et al., 2011). The interaction of multiple motor (i.e. freezing of gait, postural instability) and non-motor (i.e. sleep disturbances, executive functioning difficulties) symptoms leads to a high risk of falls for people with Parkinson's disease (PwP) (van der Marck et al., 2014). When James Parkinson first described PD over 200 years ago, he cautioned that as the disease progresses, "the utmost care is necessary to *prevent* frequent falls" (Parkinson, 2002, p. 224). Now, 200 years later, fall rates, fall risk factors, and resulting complications remain a primary concern for individuals with PD (Deane et al., 2014) and their care partners (Schrag, Hovris, Morley, Quinn, & Jahanshahi, 2006).

According to a 2014 study in which researchers examined research priorities for PD, the top ranked priority was the management of balance and falls (Deane et al., 2014). Across populations, a *fall* is commonly defined as "an unexpected event in which the participants come

to rest on the ground, floor, or lower level" (Lamb, Jørstad-Stein, Hauer, & Becker, 2005, p. 1619). Reports of fall frequency for PwP range from 35% to 90% (Allen et al., 2013). Part of the large variability in fall frequencies is due to varying time periods used to measure falls, and participant difficulty in accurate recall of past falls. The recall of falls beyond one month for PwP may not be reliable (Schrag et al., 2015), and better data is gathered by following individuals during the fall report time frame, for example with a weekly follow up. In a meta-analysis that aggregated prospective cohort studies, 46% of PwP had fallen in only a three-month timeframe (Pickering et al., 2007). Despite the discrepancies in reporting falls, fall rates for PwP are very high, even when compared with other high-risk populations. According to a recent report, 22% of older adults fall each year (Stevens, Mahoney, & Ehrenreich, 2014), which means that twice as many PwP reported a fall in three months as the general older adult population reported in one year.

Due to the high fall rate in PwP, the effects of falls must be considered. Effects of falls for PwP range from potential injury, admission to a hospital, future fear avoidance, and consequentially generally decreased quality of life (QoL) (M. King & Tinetti, 1995; Radder et al., 2017; Schrag et al., 2015). Since falls are a vast concern for PwP, and have a profound impact on QoL, it is important to explore treatment approaches that address fall prevention in this population. Current recommendations for fall prevention programming include managing or improving: strength, gait, balance/posture, medications, footwear, risky behaviors, and fear of falling (Leland et al., 2012, p. 149). Introducing and addressing many potential fall risk factors is important so that each individual can modify risk factors that have the greatest influence in his/her own life. Therefore, the current recommendation for fall prevention programs for PwP is multifactorial programming (Canning et al., 2014). However, the majority of interventions used

to address fall risk in PwP are either solely-exercise based, or solely medication-based (van der Marck et al., 2009, p. 1529). It is likely that exercise or medication trials do not address many of the fall risk factors identified for PwP.

Because of the wide spectrum of fall risk factors for PwP, and the recommendation of multifactorial programs, interventions that combine multiple fall risk factor reduction strategies in this high-risk population need to be implemented (Leland et al., 2012; Peterson & Clemson, 2008; Schrag et al., 2015). Many current evidence-based programs for fall prevention exclude PwP (Stevens & Burns, 2015); but in a review of fall prevention programming for PwP researchers recommended turning to established programming in other populations to develop programs for PwP (Fasano et al., 2017).

Chronic stroke is another neurological population at risk for falls; the Merging Yoga and Group Occupational Therapy (MY-OT) program improved balance and fall risk factor management among participants that had experienced a stroke (Schmid et al., 2016). In a recent review of falls in PD, researchers suggested that future trials should adjust existing programs to meet the specific needs of PwP (Fasano et al., 2017). As a result, we adapted the MY-OT program and created the Merging Yoga and Occupational Therapy for Parkinson's Disease (MY-OT for PD) program (Swink et al., 2019). MY-OT for PD was designed to integrate adaptive community yoga with occupational therapy focused fall-risk self-management programming for PwP. This study had two primary purposes: (1) to assess the feasibility of the 14-session MY-OT for PD program and (2) to examine and analyze changes in the following outcomes: self-reported falls, fall risk factor management, concern surrounding falls, balance confidence, and balance.

Methods

Design

We completed a pilot and feasibility study, and employed a within-subjects quasi-experimental design (Bhattacherjee, 2012). Feasibility was measured based on process, resources, management, and scientific basis outcomes throughout the program (Tickle-Degnen, 2013). Participants served as their own controls and outcomes were measured at three time points: baseline assessments (eight weeks prior to the intervention), pre-assessments (just before the intervention), and post-assessments (immediately following the 8-week intervention).

Participants

Participants were recruited into the MY-OT for PD program through a convenience sampling method. We recruited through in-person presentations at a community yoga program for PwP, a county PD support group, and distributed flyers in the community. Participants met the following inclusion criteria: had a self-reported diagnosis of PD, were greater than 18 years old, scored greater than or equal to 4 on the short Mini Mental Status Exam (Callahan, Unverzagt, Hui, Perkins, & Hendrie, 2002), were able to stand with or without an assistive device, had transportation to the community athletic center (for the 14-session program) and university campus (for the three assessment times), and committed to pay $5 per class for the required community adaptive yoga portion of the program (or agreed to receive a scholarship).

Intervention

The intervention consisted of 14 biweekly sessions, occurring across 8-weeks. Participants were required to participate in 75 minutes of adaptive yoga for PD, and 60 minutes of group occupational therapy (fall-risk self-management programming), with a 15-30-minute break in-between. Adaptive yoga was led by an experienced 500-hour certified yoga teacher with 20 years of yoga practice experience, and four years of adaptive yoga for PD practice experience. Yoga classes consisted of a variety of graded seated, standing, and supine postures (Table 3.1).

The first author (LS) led the group occupational therapy sessions; she is a licensed and registered occupational therapist with five years of clinical practice experience. For the group occupational therapy sessions, LS followed a detailed, standardized facilitator manual with fidelity checks for session content (Table 3.2). Participants received participant manuals which included handouts, and worksheets for each session to complete at home (e.g. action planning forms). In order to keep class sizes smaller, participants selected a morning or afternoon occupational therapy class, and were split for one of the weekly yoga classes. Participants chose class time at the beginning of the program, and then remained in their designated group for the duration of the program.

[Insert Table 3.1 Near Here]

[Insert Table 3.2 Near Here]

Outcomes

Throughout the program, feasibility measures were tracked in four constructs: process, resources, management, and scientific burden (Tickle-Degnen, 2013) (Table 3.3). Feasibility related to the *process* construct was considered using the following tracking forms: eligibility, attrition, attendance, attrition, and participant time commitments. Eligibility was calculated based on participants who expressed interest following presentations, and percent who then participated in the study. We expected 20% attrition (3/18 people), based on estimates from other short-term trials for PwP (L. King et al., 2015). Additionally, we expected participants to attend 75% of sessions (10-11/14) of the sessions, because in a physical therapy for PD trial, 90% of participants attended at least 75% of the classes in an 8-week program (McGinley et al., 2012). Feasibility related to *resources* were descriptively reported including space, equipment, software, and administrative needs. Facilitator time, observer time, fidelity completion, and data safety and

monitoring were all used to assess the *management* construct of feasibility. Feasibility related to *scientific burden* was primarily assessed through the analysis of outcome measures and tracking of adverse events.

[Insert Table 3.3 Near Here]

Outcomes measures were collected at the three assessment points: baseline, pre-assessment, and post-assessment. Additionally, we completed weekly in-person, email, or phone check-ins to assess potential falls (and completed a fall analysis form when a fall occurred), and weekly yoga practice. These weekly check-ins took place throughout the control and intervention periods. At each assessment time, participants completed written assessment packets containing the outcome measures, and participant health and demographic information. Trained research assistants were available to answer questions, clarify content, and assist with writing as needed. An outpatient physical therapist who was not part of the program sessions completed the clinical balance assessment.

Weekly Check-ins. We assessed self-reported falls and yoga practice status using weekly check-ins. Recall of falls beyond one month may not be reliable (Schrag et al., 2015). Therefore, we provided falls calendars, a fall analysis form, completed weekly phone calls or email checks to assess falls during the control period, and in-person checks during the intervention period. Measuring falls through self-report is a "recommended starting point" that is one of the "least cumbersome and expensive approaches" and therefore is appropriate for a pilot and feasibility study (Fasano et al., 2017, p. 1527).

Participants reported the number of yoga classes they attended during control and intervention period through weekly check-ins. Individuals who had been practicing yoga prior to

the program and through the intervention were classified as 'yoga experienced'. Individuals who began yoga on the intervention start date were classified as 'yoga novices'.

Fall risk factor management. Fall risk factor management is difficult to assess given the complex nature of falls, and was therefore measured with the five fall risk management scales used previously in the MY-OT study (Schmid et al., 2016). The five scales included: the Falls Control Scale (FCS), the Falls Management Scale (FMS), the Fall Prevention and Management Questionnaire (FPMQ), the Fall Management Behavior Questionnaire (FMBQ), and the Fall Prevention Strategies Survey (FPSS). The scales were slightly modified from their previous versions to reflect the changes needed for PwP, for example words like "stroke effects" were changed to "Parkinson's symptoms." Four of the scales (FCS, FMS, FPMQ, and FPSS) used varying Likert scales, with higher scores indicating better scores on each construct (Table 3.4). The FMBQ required a 'yes' or 'no' response for each statement and on the post-assessment includes follow-up questions on why a participant did or did not employ a certain fall management behavior after the program.

[Insert Table 3.4 Near Here]

Concern about falls. There is not a validated assessment of concern about falling specifically for PwP, therefore, concern surrounding falls was measured using the Falls Efficacy Scale—International (FES-I) (Yardley et al., 2005). The FES-I is a 16-item self-report measure with scores ranging from 16-64, where higher scores indicate a higher concern about falls. Additionally, cut off scores have been established for older adults, with scores of 28-64 indicating high concern surrounding falls (Delbaere et al., 2010). An example of an item on the assessment is: "how concerned are you that you might fall while taking a bath or shower?" For older adults in the community, the FES-I has excellent test-retest reliability (intraclass

correlation coefficient = .96) and excellent internal consistency (Cronbach's alpha = .96) (Dewan & MacDermid, 2014). The FES-I has limited testing specifically for PwP, but fear (or strong concern) surrounding falls has been frequently cited as a predictor of falls in PwP or a risk factor for recurrent falls (Almeida et al., 2017; Gazibara et al., 2016; Latt et al., 2009).

Balance confidence. Balance confidence was measured using the Activities-Specific Balance Confidence Scale (ABC). The ABC is a 16-item self-report measure, with higher scores indicating increased balance confidence. Participants were provided the 16 questions relating to completing a certain activity and asked to rate their confidence that they will not lose their balance while completing each activity. Participants rated each question on a scale from 0% (no confidence) to 100% (completely confident). Total scores were summed, divided by the number completed, and multiplied by 100 to express the overall score as a percentage. For older adults, the ABC demonstrated excellent internal consistency, and test-retest reliability (Huang & Wang, 2009; Powell & Myers, 1995). Additionally, in a sample of PwP, ABC scores greater than 80% were significantly associated with decreased fall risk (Mak, Pang, & Mok, 2012).

Balance. Balance was assessed by an overall score on the Mini Balance Evaluation Systems Test (Mini-BESTest). The Mini-BESTest is highly recommended for PwP who are stage 1-4 on the Hoehn and Yahr scale (HY scale) (Kegelmeyer et al., 2014). Based on the inclusion criteria that participants had to be able to stand with or without an assistive device, individuals in HY scale stage 5 were not included, making the Mini BESTest an appropriate measure. The Mini-BESTest was used to assess the overarching construct of dynamic balance, through an examination of four different dynamic balance components: anticipatory postural adjustments, reactive postural control, sensory orientation, and dynamic gait (Franchignoni, Horak, Godi, Nardone, & Giordano, 2010). The assessment consists of 14-items, each item is

scored 0-2 and higher scores indicate better dynamic balance. Overall, the Mini-BESTest has demonstrated excellent test-retest and inter-rater reliability for PwP (Godi et al., 2013; Leddy, Crowner, & Earhart, 2011), as well as excellent concurrent validity with the Berg Balance Assessment (L. King, Priest, Salarian, Pierce, & Horak, 2012; McNeely, Duncan, & Earhart, 2012).

Data Analysis

Feasibility and demographic data were predominantly considered using descriptive statistics. All feasibility measures were managed using means, standard deviations, frequencies, percentages, or general description. We used linear mixed modelling in R software to examine the differences in outcomes measures (e.g., five fall management scales, FES-I, ABC, Mini-BESTest) between the control and intervention periods (Pinheiro, Bates, DebRoy, Sarkar, & R Core Team, 2018; RStudio Team, 2015). Because the FMBQ was a dichotomous outcome, this outcome was considered with a generalized linear mixed model (Bates, Maechler, Bolker, & Walker, 2015). Assessment time, yoga practice status (experienced or novice), and the interaction between time and yoga practice status were included in each model as fixed effects. Participant number was included as a random effect to account for repeated measures across the three time points (baseline, pre-assessment, post-assessment). We compared change in the control and intervention periods for each outcome of interest by defining a contrast in R (change between pre-assessment and baseline assessment compared to change between post-assessment and pre-assessment). To determine least squares means, standard error, and effect sizes, we used the emmeans package in R (Lenth, Singmann, Love, Buerkner, & Herve, 2019). We calculated the effect size estimation with the following formula: $d_r = \frac{M_1 - M_2}{Standard\ devation\ of\ the\ residuals}$ (Rouder, Morey, Speckman, & Province, 2012).

We inspected residual quantile-quantile plots to assess the normality of the residuals for each outcome. Two different assessments (ABC, and FPSS) had one value that did not appear to satisfy the normality assumption. We excluded the participant with the extreme value and reconsidered the model. For the ABC, there were no changes in the interpretation of the main effects and we therefore retained the extreme value in the final model. For the FPSS, the interpretation of interaction effects changed, and the model without the extreme value satisfied the normality assumption. FPSS results are therefore reported without the participant with the extreme value.

Results

Demographics

Participants were aged 64-82 years old (average age = 71.72 years old) and had been diagnosed with PD ranging from 9 months-18 years (average = 6.93 years since diagnosis). Demographic data are reported for all 18 participants enrolled at baseline (Table 3.5). Most participants were male (55%), married (72%), white (100%), college graduates (44%), and retired (89%). Considering yoga practice status of those who completed the study, 10 participants were yoga experienced, and 7 participants were yoga novices.

[Insert Table 3.5 Near Here]

Feasibility

Related to the feasibility *process* construct, 26 individuals were screened for the MY-OT for PD program. Of those screened, 23 were eligible, and 18 enrolled in the study (Figure 3.1). One participant dropped out during the control period, citing being busy and overwhelmed by the potential time commitment (attrition = 5.6%). The 17 participants who completed the study attended an average of more than 12 (out of 14) sessions. The reasons sessions were missed included: vacation, surgery, and other pre-scheduled commitments. We calculated a high time

commitment for both participants and program staff. The maximum participant time required for all assessments and program sessions was 44.75 hours. *Resources* required for feasibility included space and equipment was donated by the local athletic center, items for participants were covered by the granting mechanism, and software/administrative services were covered by the university. For the *management* construct of feasibility, program staff completed a total of 207.75 hours with program set-up and implementation, but not including outside follow-up with participants, transportation, or program development. Each session, more than 75% of fidelity checks were addressed, and fidelity points that were not completed were added to the next session. We planned and completed double data entry for 20% of the data. Related to the *scientific basis* construct of feasibility, no adverse events were reported during the control or intervention period. Refer to table 3.3 for full feasibility reports.

[Insert Figure 3.1 Near Here]

Outcomes Measures

Self-reported falls. There was a 40% overall decrease in total self-reported falls from the control to the intervention periods (control=10 self-reported falls, intervention=6 self-reported falls). During the control period, six falls occurred at participants' homes and four falls occurred out in the community. During the intervention period, all six falls occurred in the person's home. Only one fall required medical attention during the control period, when one participant sought medical attention for a shoulder strain; otherwise, no serious were injuries reported.

Fall risk factor management. Improvements were seen across all outcomes following the program, although not all improvements were significant. In the linear mixed-effects model, two outcomes (FPMQ, FPSS) had a significant interaction effect between assessment time and yoga practice status (Table 3.6). On the FPMQ, assessing how participants perceive they can

prevent falls and manage falls that do occur, yoga novices had higher scores at baseline (least squares mean (*LSM*) = 36.5, standard error (*SE*) = 2.67) than those who were yoga experienced (*LSM* = 34.7, *SE* = 2.27), $t(15) = -.51$, $p = 1.00$ (Figure 3.2). At pre-assessment, the yoga experienced group had higher scores (*LSM* = 37.9, *SE* = 2.22) than yoga novices (*LSM* = 33.4, *SE* = 2.67), $t(15) = 1.31$, $p = .78$. At post-assessment, scores were similar with yoga novices having slightly higher scores (*LSM* = 41.7, *SE* = 2.60) than those who were yoga experienced (*LSM* = 40.5, *SE* = 2.17), $t(15) = -.36$, $p = 1.00$. Despite the interaction effect, scores were not significantly different at any time point based on yoga practice status, so we considered the two groups together and analyzed differences between the control and intervention period. Regardless of yoga status, there was a significant difference on FPMQ scores during the intervention period (*LSM difference*= 5.45, *SE difference* = 1.25, *d* = 3.47) compared to the control period (*LSM difference* = .03, *SE difference*= 1.34, *d* = .26), $t(25) = 2.41$, $p = .02$ (Table 3.7). FPMQ scores significantly improved following the intervention as compared to the control period.

[Insert Figure 3.2 Near Here]

The FPSS measured participants perceived strategies employed to prevent falls. Yoga novices had higher FPSS scores at baseline (*LSM* = 11.2, *SE* = 1.35) than people who were yoga experienced (*LSM* = 10.2, *SE* = 1.09), $t(14) = -.55$, $p = .99$ (Figure 3.3). At pre-assessment, those who were yoga experienced had higher scores (*LSM*= 13.9, *SE* = 1.07) than yoga novices (*LSM* = 11.5, *SE* = 1.35), $t(14) = 1.39$, $p = .73$. Following the intervention, at post-assessment, the yoga experienced group still had higher scores (*LSM* = 14.6, *SE* = 1.07) than the yoga novice group (*LSM* = 13.3, *SE* = 1.35), $t(14) = .72$, $p = .98$. There was a significant interaction effect between assessment time and yoga practice status such that yoga novice scores remained relatively stable

during the control period and increased during the intervention period, while yoga experienced participant scores increased more during the control and increased only slightly during the intervention.

At each time point, FPSS scores were not significantly different between yoga practice status groups. We therefore considered the yoga practice status groups together and analyzed differences between the control and intervention periods. When considering the control period differences (*LSM difference* = 2.01, *SE difference* = .57, *d* = 2.80) and intervention period differences (*LSM difference* = 1.26, *SE difference* = .58, *d* = 1.75), there was no significant difference in FPSS score changes, $t(24) = -.75$, $p = .46$ (Table 3.7).

[Insert Figure 3.3 Near Here]

On the FMS, participants perceived ability to manage falls was significantly different across assessment time points, $F(2, 30) = 4.80$, $p = .02$. However, when considering if the differences between the control time period and intervention time period were significant, there were no significant differences on FMS scores, $t(30) = -.44$, $p = .66$. The lack of significance between the control and intervention period changes is due to the fact that FMS scores improved in both the control (*LSM difference* = 1.18, *SE difference* = .63, *d* = 1.60) and intervention periods (*LS M difference* = .70, *SE difference* = .63, *d* = .95), so the differences between the improvements was minimal. The FCS and FMBQ showed no significant differences across time points, between yoga practice groups, or between the control and intervention time periods.

Concern surrounding falls and balance confidence. There were no significant interaction effect on FES-I scores or ABC scores across yoga practice groups, or significant differences between the control group and intervention group on either assessment. Both scales

showed a slight improvement across assessment time points, with the ABC scores increasing, and FES-I scores decreasing which indicated reduced concern surrounding falls.

Balance. The Mini-BESTest demonstrated significant differences across assessment points (Table 3.6). When considering the difference in score changes between the control and intervention periods, the Mini-BESTest showed that participants had much greater changes in balance during the intervention period (*LSM difference* = 3.23, *SE difference* = .61, d = 3.63) as compared to the control period (*LSM difference* = -.47, *SE difference* = .61, d = -.52) (Table 3.7). For balance, participants had a slight decline on the Mini-BESTest during the control period and large improvement during the intervention period, $t(30) = 3.50$, $p < .01$. Improvements were seen in all outcomes following the intervention, but only the FPMQ and Mini-BESTest showed significant differences between the control and intervention periods.

[Insert Table 3.6 Near Here]

[Insert Table 3.7 Near Here]

Discussion

The purpose of this study was to explore feasibility and changes in outcome measures following the MY-OT for PD program. Related to feasibility, we measured process, resources, management, and scientific basis constructs (Tickle-Degnen, 2013). We experienced low attrition (5.6%) and high attendance (91.6%) compared to our estimations from previous interventions for PwP (L. King et al., 2015; McGinley et al., 2012). The time commitment was intensive, but with the low attrition and high attendance, we believe the time commitment was appropriate for this intervention and participants remained committed. Resources and management were primarily funded through a small foundation grant, university assistance, and donations from a community athletic center. Overall, the MY-OT for PD program was a feasible

community-based program when conducted with university support.

The scientific basis of the MY-OT for PD program was primarily established through preliminary analyses of the outcome measures. There were four fewer falls reported during the intervention period, representing a 40% decrease in self-reported falls. According to some fall prevention researchers, a decrease in self-reported falls of at least 30% represents a critical decrease in fall risk (Campbell, Robertson, Gardner, Norton, & Buchner, 1999; Clemson et al., 2004; Cumming, 2002). Additionally, the control period occurred during the summer/fall and the intervention period occurred in the fall/winter so we expected that even maintaining the number of falls during this period could be an important finding because in the winter the roads and walkways are often icy and snowy. The prevention of even one fall could result in drastically different outcomes for that individual, such as the avoidance of a severe injury or hospital admission.

We found improvements in all of our outcome measures, although not all differences were statistically significant when comparing between the control and intervention periods. Of the five fall management scales, participants experienced significant improvements on the FMS, FPSS, and FPMQ. Two of those scales (FPSS, and FPMQ) were the same two scales that showed significant improvement in the original MY-OT study (Schmid et al., 2016). Interestingly, since participants served as their own controls in this study, participants had greater improvements on the FMS and FPSS during the control period. In a previous physical activity and behavior intervention, participants who improved in the control group had similar characteristics to our sample, they were retired, and had completed secondary school (Waters, Reeves, Fjeldsoe, & Eakin, 2011). Additionally, alternative treatments (e.g. yoga) can lead to placebo effects for many participants (Ghaffari & Kluger, 2014). In PD medical and surgical

trials, up to 50% of PwP experienced placebo effects (de la Fuente-Fernández, Schulzer, & Stoessl, 2002; Goetz et al., 2008). Positive placebo responses may be seen because the brain is releasing dopamine as participants anticipate benefits (De la Fuente-Fernández et al., 2001). These anticipation benefits could potentially be experienced by all participants regardless of yoga practice status as they were anticipating the intervention during the control period.

In our study, when the FPSS results were compared between yoga status groups, the yoga novices had a greater improvement during the intervention. The initiation of yoga may have had an additional effect on fall prevention strategies, for example, perhaps participants were more mindful of fall prevention. This interaction effect could explain why in the original MY-OT study, the FPSS had significant improvements during the intervention, because in that intervention all participants were new to yoga (Schmid et al., 2016).

On the FPMQ, differences were significantly greater intervention as compared to the control period. Perhaps changes were significant on this measure because it assessed participants' perceived ability to identify risks and confidence in reducing those risks. The FPMQ did not necessary ask if the participant had enacted change so the assessment may capture the increased awareness from the program that could lead to potential change if longitudinal follow-up was completed. For example, on the FPMQ one question was, "I know how to safely increase my physical activity levels to reduce my fall risk," and they could answer from strongly agree-strongly disagree but were not asked if they had enacted actual change on their physical activity levels. Conversely, on the FPSS, participants were asked about how often participants completed certain strategies such as "when I am fatigued, I change my activities to reduce my fall risk." If a participant had not yet integrated that change they would likely indicate a low score. In some cases, the MY-OT for PD program may have increased their awareness of fall

risk, but the post-assessment time did not allow enough time to implement changes, which could be why there was no significant improvement during the intervention period.

In this study, participants also had a significant improvement in balance during the intervention, but experienced minimal improvements in balance confidence, and concern surrounding falls. Average balance scores increased 3.3 points on the Mini-BESTest during the intervention, which represented a significant increase and large effect of the program. Additionally, participants were just above the 20 point cut-off score at pre-assessment, indicating that they have a balance level that would be associated with falling (Leddy et al., 2011). On average, as a group, they then progressed to a score of 23.4 after the program, indicating a decreased risk to fall. However, the Mini-BESTest change did not reach the established minimal detectable change cut-off of 5.5 points (Leddy et al., 2011). In a meta-analysis of yoga for PwP, participants in yoga groups had improvements in Mini-BESTest scores, and the effects were moderate. In our study, there was a large effect on balance following the intervention. Perhaps, the occupational therapy portion of the program heightened the balance effects by encouraging participants to further participate in activities that improved balance.

Interestingly, despite the overall balance improvement, participants did not experience significant improvements in balance confidence or concern surrounding falls. PwP have high fall rates, and since balance confidence is significantly lower in PwP who have previously experienced a fall (Mak & Pang, 2009). The concept of low balance confidence and high concern surrounding falls is further confirmed with the FES-I scale results. Scores of 28 or greater on the FESI indicate high concern surrounding falls (Delbaere et al., 2010). At all three time points our participants had scores greater than 28 indicating that throughout the program they had a high concern surrounding falls. In the original MY-OT program (for chronic stroke) significant

improvements were seen in concern surrounding falls, and balance confidence (Schmid et al., 2016). The significant change in balance confidence and concern surrounding falls could be because individuals with chronic stroke were likely not experiencing further decline but rather adapting to life after a stroke and potentially improving in their physical health. Since PD is progressive, participants likely expect their balance to get worse over time. Yoga was meant to target balance confidence because yoga can significantly improve balance confidence more than relaxation interventions (Hamrick et al., 2017), when tested in the older adult population. However, for people with a neurodegenerative condition it may be difficult to affect change on balance confidence and concern surrounding falls in the 8-week time period. The occupational therapy sessions presented fall risk management strategies, but even with this increased knowledge PwP were still concerned about falls, and rated similar balance confidence levels.

Limitations and Future Directions

The sample size for this study was small and we used a convenience sampling method. Therefore, the study sample was homogeneous in some capacities; for example, all participants were white, and 83% were college graduates or had completed further education. If we conduct a larger trial in the future we could additionally consider covariates in the model such as age, or medication dosages. We also assessed participants at three time points, with the last assessment point occurring at the end of the 8-week program. It may be important to complete longitudinal follow-up with the MY-OT for PD program because we expect that participants may take some time to implement some of the learned strategies following the program.

On some measures, participants improved during the control period which could be due to testing threat and learning responses from the previous iteration (Bhattacherjee, 2012), benefits from weekly check-ins, or placebo effects. It is possible that participants may have actually implemented some of the fall prevention strategies just from reading them on the

baseline assessment. To reduce this risk, a larger randomized controlled trial could be beneficial to explore changes in the outcome measures with a control group. Additionally, we recommend longitudinal follow-up to capture participant changes in fall risk factor management following the program and sustainability of balance improvements. Before implementation of a larger trial it would be important to integrate participant feedback on program satisfaction, acceptability, and delivery, and adapt the program. Participant feedback and recommendations could help us form Stage II program manuals, which are refined manuals that include facilitator training plans and are essential to create before clinical efficacy trials (Carroll & Nuro, 2002).

Conclusion

MY-OT for PD was feasible and led to improvements in all targeted outcomes for PwP. The program resulted in decreased falls during the intervention period, and improved balance and some aspects of fall risk factor management. Decreasing falls for PwP is important and a primary concern in this population (Deane et al., 2014). The MY-OT for PD program should be adapted based on participant feedback following this pilot study and trialled with a larger sample and matched control group. Following further testing, MY-OT for PD may be an efficacious option to reduce falls and improve balance for PwP.

Implications for Rehabilitation

- Multifactorial fall prevention interventions specifically designed for PwP must be further developed and explored.
- The Merging Yoga and Occupational Therapy for Parkinson's disease program is one option for community-based fall risk self-management programming that had high attendance/low attrition, reduced self-reported falls, and improved balance.
- Across the 8-week intervention, the Merging Yoga and Occupational Therapy for Parkinson's disease program showed improvements in fall risk factor management scale

scores, but only 1/5 scales demonstrated a significant improvement difference from the control to intervention period.

Figures and Tables

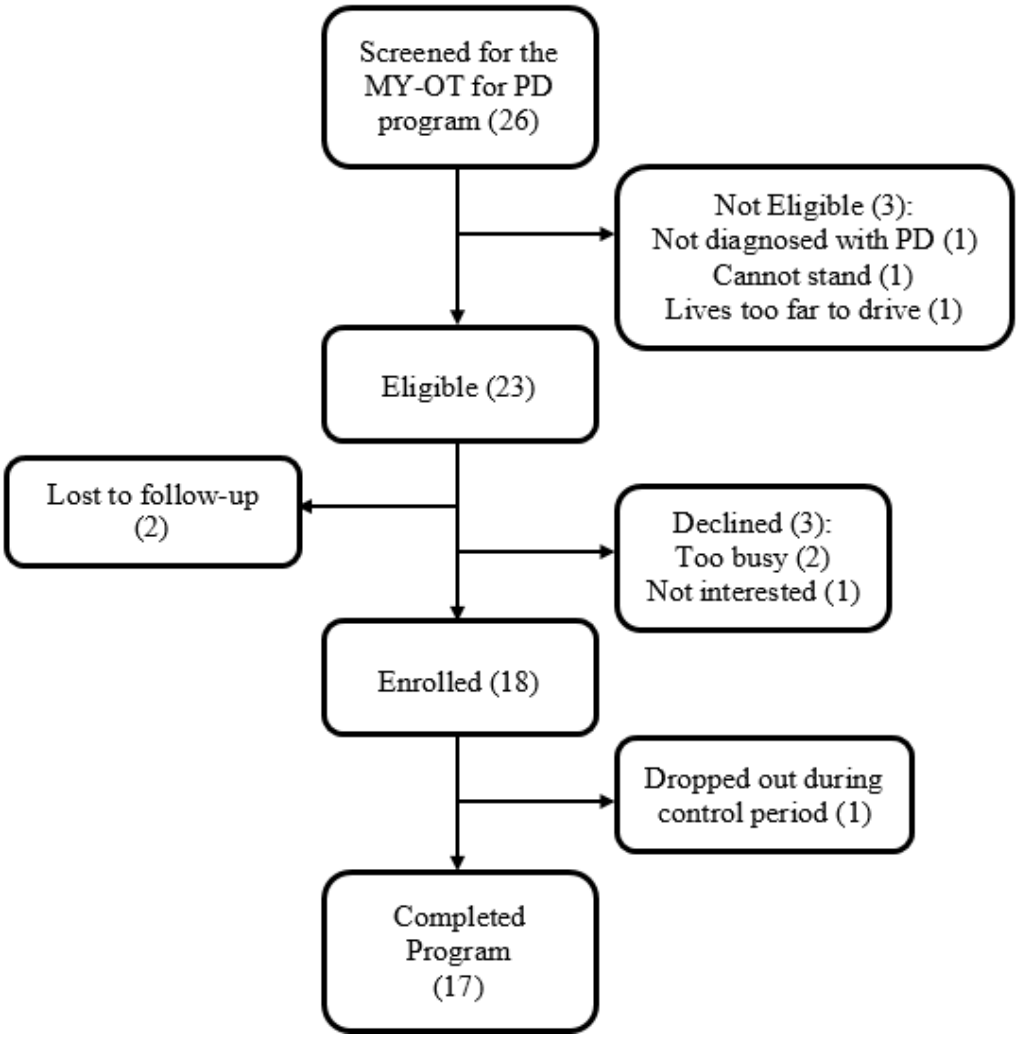

Figure 3.1. Participant Flow Diagram

Note. MY-OT for PD = Merging Yoga and Occupational Therapy for Parkinson's disease.

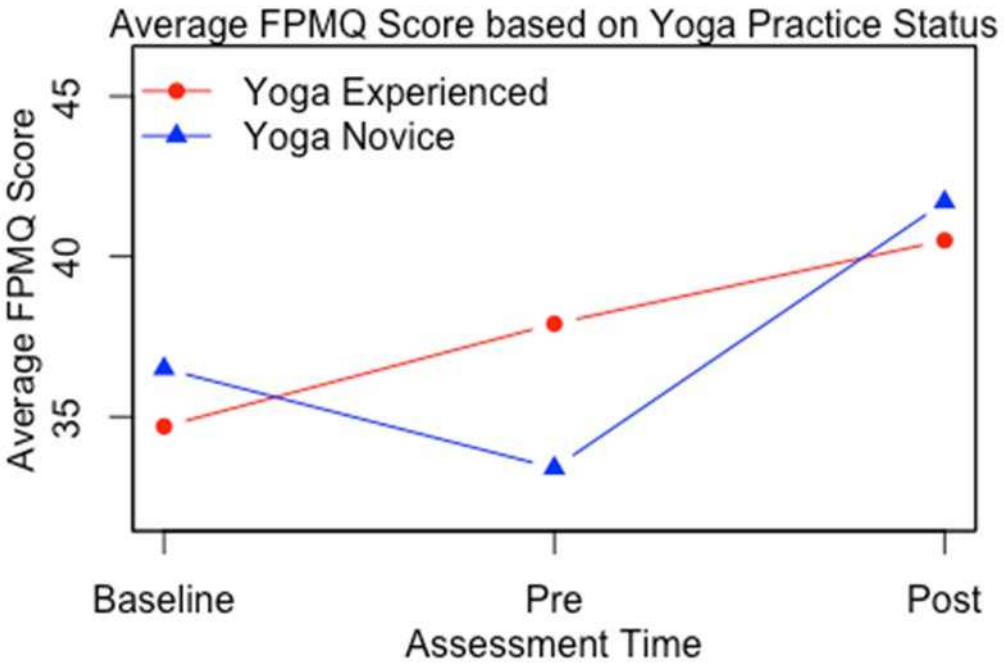

Figure 3.2. Fall Prevention and Management Questionnaire (FPMQ) scores based on Yoga Practice Status

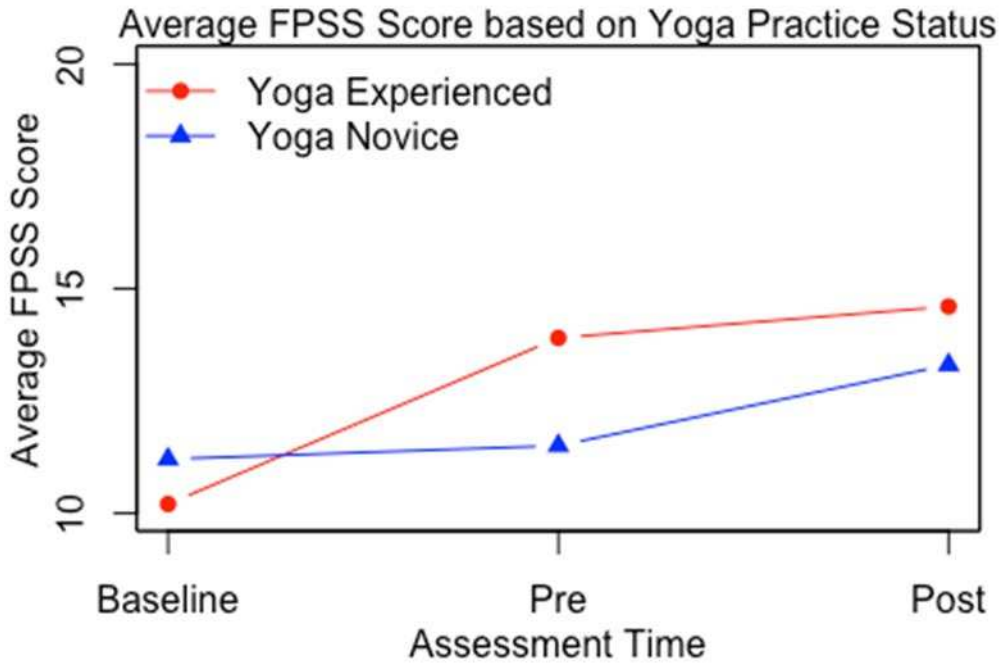

Figure 3.3. Fall Prevention and Strategies Survey (FPSS) scores based on Yoga Practice Status

Table 3.1

Yoga Focus Each Session

Session	Yoga Focus
1	Awareness of breath, moving with breath
2	Finding center of balance while changing position* Finding ease with breath and body positioning*
3	Vocalizing to enhance body awareness
4	Balance and coordination, shoulder/ankle mobility, arm strength* Neck and shoulder mobility and comfort*
5	What is mindful movement
6	Listen to and honoring body, arm strength and balance* Relaxing and releasing tension, restorative poses*
7	Vocalizing, face yoga, coordination with core strength
8	Hip flexors and walking stride* Hip opening, restorative poses, vocalizing and face activation*
9	Crossing the midline, complex movement while seated
10	Balance and smoothly changing direction* Body awareness and letting go of tension*
11	Vocal activation with face, abdominal strength
12	Balance and coordination while standing and moving* Deep stretch, hand dexterity, and facial movements of release*
	Holiday Break
13	Coordinating breath and movement, crossing the midline
14	Balance and changing standing to sitting, changing directions* Back and neck stretches, hip opening*

Note: * = Even numbered sessions split into morning and afternoon session focus

Table 3.2

Group Occupational Therapy Focus Each Session

Session	Key Topics
1	Introduction to program, space, falls, and action plans
2	Introduction to fall risk factor categories (biological, behavioral, environmental, and socioeconomic)
3	Practice a detailed fall analysis, introduction to participant home 'fall scenario' photos
4	Biological risk: how effects of PD can contribute to falls (e.g. freezing of gait, multi-tasking)
5	Behavioral risk: medication management, mobility aid options and alcohol use
6	Environmental risk: personal mobility aid safety check Behavioral risk: balancing increasing physical activity and fatigue
7	Behavioral risk: role of endurance, tracking steps
8	Biological/behavioral risk: logging activities, and monitoring fatigue
9	Biological/behavioral risk: modifying activities continued, getting to/from the floor
10	Biological/behavioral risk: role of strengthening, home exercise example
11	Environmental/socioeconomic risk: footwear, home/community safety tips, long-term action planning
12	Environmental risk: modifying home hazards, return to home photos
	Holiday Break Week
13	Environmental/socioeconomic risk: advocacy, creating emergency contact forms
14	Program Summary: reinforcement of interacting factors, questions, wrap-up

Table 3.3

Pilot and Feasibility Study Constructs with Feasibility Measures

Pilot/feasibility construct (considerations)	
Process (Eligibility, attrition, attendance, time commitments)	• Eligibility: 88.5% of interested participants were eligible (23/26), 78.3% of eligible participants enrolled (18/23) • Attrition: 5.6% of participants dropped out (1/18), and 94.4% of participants completed the study (17/18) • Attendance: 91.6% of classes completed on average (12.82/14) • Time commitments: assessments ranged from 1-3 hours at each assessment point, total program time commitment for participants was up to 36.75 hours (not including transportation)
Resources (Space, time required, physical equipment, software needs, administrative service needs)	• Space required for program implementation: conference room donated by a community athletic center • Equipment used during the program: tables, chairs, yoga mats, yoga bolsters, yoga blocks, and yoga blankets. • Items given to participants: nightlights, laser pointers, yoga mats, pedometers, and participant binders with handout information • Software needed for analysis: R software, Excel • Administrative services supporting the program at both the university and community athletic center
Management (PI capability, team member time, data organization, data safety and monitoring)	• Total participation time for program staff: Principal Investigator/occupational therapy facilitator (84 hours), yoga teacher (33.25 hours), and 6 occupational therapy master's student volunteers (90.5 hours total) • Fidelity checklist: >75% of fidelity checks completed each session, notes in observer manual documented for why items were missed (predominantly: time, focus on other discussion points). When items were missed they were added to the next session. • Data safety and monitoring: a secure drive for all data, double data entry completed for 20% of data.
Scientific Basis (Safety, estimated outcomes)	• Adverse events: none, falls tracked per the study protocol • Data analysis of outcome measures

Table 3.4

Fall Risk Management Scales' Characteristics

Assessment	Construct	Number of Items	Scale	Score range	Example Item
Falls Control Scale	Perceived ability to control falls	4	Strongly disagree—strongly agree	4-20	"There are things I can do to keep myself from falling"
Falls Management Scale	Perceived ability to manage falls	5	Not at all sure—very sure	5-20	"How sure are you that you can become more steady on your feet"
Falls Prevention and Management Questionnaire	Perceived ability to prevent and manage falls	12	Strongly disagree—strongly agree	0-48	"I know what questions to ask my doctor or pharmacist about my medications so that I can reduce my fall risk."
Falls Management Behavior Questionnaire	Behaviors currently used to manage falls	14	Yes/no Post-assessment follow-up: If yes: "How effective was this strategy in helping you reduce your fall risk" 1(not effective-10(very effective) If no: "Why did you answer this way, check all that apply" with options such as "didn't need to," "haven't had the opportunity," and "other, explain"		"I use grab-bars in my bathroom to reduce my fall risk."
Falls Prevention Strategies Survey	Perceived strategies employed to prevent falls	11	Never do—do regularly	0-22	"I plan what I will do in case I fall"

Table 3.5

Participant Demographics at Baseline (N=18)

Participant Demographic Construct	Mean (±SD) Or Category (Count)
Age	71.72 (±4.46)
Years since PD dx	6.93 (± 5.45)
Gender	Male (10), and Female (8)
Race	White (18)
Marital Status	Married (13), and Divorced (4), Widowed (1)
Living Status	Lives with others (16), Lives alone (2)
Highest Education	High School (1), Some College (1), College Graduate (9), Some post-graduate (3), Post-Graduate degree (4)
Work Status	Retired (16), Not working (2)
Parkinson's specific medications	Dopamine therapies (14), MAO inhibitors (1), combination of medications (3)
Recent Fall	Last 6 months (8), last month (4), last week (1), no recent fall (10)
Potential fall overall worry	Yes, very worried (3); yes, somewhat worried (6); yes, a little worried (8); no, not at all worried (0); missing (1)

Table 3.6

Linear Mixed Effects Model Results

Outcome	Assessment Time		Yoga Practice Status		Interaction of Assessment Time and Yoga Practice Status	
	F	*p*	*F*	*p*	*F*	*p*
Falls Control Scale	.93	.40	.32	.58	2.35	.11
Falls Management Scale	4.80	.02*	.76	.40	.16	.85
Fall Prevention and Management Questionnaire	12.20	<.01*	.02	.89	3.59	.04*
Fall Management and Behavior Questionnaire	1.62^{+}	$.44^{+}$	$.84^{+}$	$.58^{+}$	$.43^{+}$	$.66^{+}$
Fall Prevention Strategies Survey	17.29	<.01*	.34	.57	4.17	.03*
Falls Efficacy Scale International	1.16	.33	.46	.51	1.41	.26
Activities-Specific Balance Confidence Scale	.42	.66	.95	.34	.98	.39
Mini Balance Evaluation Systems Test	16.11	<.01*	1.31	.27	.76	.48

Note. *= significant at $p \leq .05$. Numerator degrees of freedom (df)=2, denominator df=30 except for Falls Control Scale df=29, Falls Prevention and Management Questionnaire df=25, Falls Prevention Strategies Survey df =26, differences in denominator df are due to missing observations. $^{+}$ = Fall Management and Behavior Questionnaire statistics and significance values are reported as chi-squared values

Table 3.7

Comparison of Differences in Outcomes Measures between the Control and Intervention periods

Outcome	Baseline (LS mean ± SE)	Pre-assessment (LS mean ± SE)	Post-assessment (LS mean ± SE)	d_r control (baseline to pre-assessment effect)	d_r intervention (pre-assessment to post-assessment effect)	Difference between Control and Intervention Periods (LS Mean ± SE)	
Falls Control Scale	15.9±0.64	16.2±0.65	16.8±0.64	0.42	0.79	0.28±1.08	
Falls Management Scale	15.2±0.67	16.4±0.67	17.1±0.67	1.60	0.95	-0.48±1.09	
Fall Prevention and Management Questionnaire	35.6±1.75	35.7±1.74	41.1±1.69	0.26	3.47	5.42±2.25	*
Fall Management Behavior Questionnaire average yeses (number of yes responses/total possible score)	0.59±0.22	0.69±0.22	0.88±0.23	0.03^{+}	0.07^{+}	0.08±0.38	°
Fall Prevention Strategies Survey	10.7±0.87	12.7±0.86	13.9±0.86	2.80	1.75	-0.75±1.00	
Falls Efficacy Scale International	31.4±1.97	30.0±1.97	29.9±1.97	-0.79	-0.06	1.31±2.36	
Activities-Specific Balance Confidence Scale	78.7±3.06	79.8±3.06	81.4±3.06	0.30	0.44	0.52±5.70	
Mini Balance Evaluation Systems Test	20.6±1.17	20.1±1.17	23.4±1.17	-0.52	3.63	3.70±1.06	*

Note. *=significant at p≤.05. LS mean = least squares mean, SE = standard error. $^{+}$ = Cohen's h values reported. ° = estimates reported as a log odds ratio

CHAPTER FOUR: HEALTH-RELATED QUALITY OF LIFE CHANGES AFTER THE MERGING YOGA AND OCCUPATIONAL THERAPY FOR PARKINSON'S DISEASE PROGRAM: A MIXED-METHODS STUDY

Introduction

Parkinson's disease and Quality of Life

Parkinson's disease (PD) is a neurodegenerative condition, affecting physical, cognitive, emotional, and social domains of everyday life (The American Occupational Therapy Association & Parkinson's Disease Foundation, 2015). Historically, PD was classified as a movement disorder, due to cardinal clinical physical features including bradykinesia, tremor, and rigidity; however, PD is now increasingly considered a multi-system brain disease with both motor and non-motor features (Alves, Forsaa, Pedersen, Gjerstad, & Larsen, 2008). PD prevalence is growing, worldwide, 2.5 million people had PD in 1990 and that number has increased to 6.1 million people with PD in 2016 (Dorsey et al., 2018). In the United States alone, an estimated 930,000 people over 45 in the United States will be diagnosed by 2020 (Marras et al., 2018). With a growing population, and currently no cure for PD, it is imperative to explore supportive treatment approaches that improve day to day living for PwP. As the disease progresses, many PwP report decreased health-related quality of life (HRQoL) (Karlsen, Tandberg, Årsland, & Larsen, 2000). Part of the decline in HRQoL may be due to worsening symptoms related to PD, as well as decreased participation in meaningful activities (Elliott & Velde, 2006).

The World Health Organization (WHO) QoL Group defined QoL as "an individual's perception of his/her position in life in the context of the culture and value systems in which

he/she lives and in relation to his/her goals, expectations, standards, and concerns" (WHOQOL Group, 1998, p. 1405). HRQoL more narrowly focuses on QoL related to the disease process, including both subjective perceptions and objective functioning related to the disease and treatment (Den Oudsten, Van Heck, & De Vries, 2007). Specifically, HRQoL addresses how mental, physical, social, and emotional domains impact health status and functioning (Office of Disease Prevention and Health Promotion, 2018).

Falls and Quality of Life for PwP

Falls negatively impact HRQoL (Michalowska et al., 2005) and are a primary concern for PwP (Deane et al., 2014). Part of the negative impact on HRQoL may be due to severe fall consequences (i.e. injury and hospitalization); as well as fear of future falls and subsequent activity avoidance (M. King & Tinetti, 1995). Additionally, according to authors of a systematic review, many PwP fall; 60.5% of PwP reported a fall during reporting periods (average reporting period = one year) (Allen et al., 2013). Of those PwP who reported more than one fall, they experienced an average of 21 falls each year (Allen et al., 2013). With this high fall frequency, PwP may experience high levels of fear of falling (FoF) which can affect HRQoL even more than falling itself (Grimbergen, Schrag, Mazibrada, Borm, & Bloem, 2013) by avoiding previously meaningful activities (M. King & Tinetti, 1995). For example, PwP who had reported a fall had significantly lower HRQoL scores than PwP who have not fallen in all HRQoL domains; the greatest differences were seen in mobility and activities of daily living domains ($p < .01$) (Michalowska et al., 2005).

Fall risk management programming and Quality of Life

Fall risk management programming might simultaneously improve both fall risk factor management and HRQoL in PwP (Lamb et al., 2005). Over 30 fall risk factors have been

identified for PwP, and most of the fall risk factors have not been addressed in fall prevention interventions (Canning et al., 2014; Fasano et al., 2017; van der Marck et al., 2014). Multifactorial programs (i.e. programming with multiple components) provide an opportunity for individuals to identify fall risk factors and learn strategies to manage those specified fall risk factors in everyday life. Specifically, existing multifactorial fall prevention programming for older adults has led to improvements in HRQoL (Vaapio et al., 2007). Because there are limited multifactorial programs designed for PwP to reduce fall risk (Morris et al., 2017), Fasano and colleagues (2017) recommended using aspects of successful existing fall prevention programs to develop PD-specific programs. Therefore, we adapted a preexisting multifactorial intervention—Merging Yoga and Occupational Therapy (MY-OT)—that was originally designed to improve fall risk factor management for individuals with chronic stroke (Schmid et al., 2016).

The MY-OT program was adapted to meet the needs of PwP and their unique fall risk factors. This adaptation led to the creation of the Merging Yoga and Occupational Therapy for Parkinson's disease (MY-OT for PD) program (Swink et al., 2019, April). MY-OT for PD was based on a multi-component model for fall risk. During the MY-OT for PD program, the facilitator guided participants (i.e., PwP) and encouraged them to examine behavioral, biological, environmental, and socioeconomic risk factors, and create individualized action plans for fall risk management. The occupational therapy portion of the program was aimed at education for self-management of fall risk factors, and the yoga portion was designed to target balance and balance confidence. Considering that multifactorial fall prevention programming improved aspects of HRQoL in older adults (Vaapio et al., 2007), we thought a multifactorial intervention may also improve HRQoL in PwP. In addition, the Prevention of Falls Network Europe, recommended that HRQoL should be assessed in fall prevention programming because it "is

likely to capture unanticipated effects of an intervention in terms of general, emotional, and social health" (Lamb et al., 2005, p. 1619). Therefore, the purpose of this study was to integrate quantitative and qualitative methods to explore changes in HRQoL following the 8-week MY-OT for PD program. We were guided by the following research question: how does HRQoL change following the MY-OT for PD program?

Methods

Design

For this study, we utilized a mixed-methods convergent design (Creswell & Clark, 2018). Prior to initiation of the study, all procedures were approved by the University's Institutional Review Board. Participants served as their own controls, therefore quantitative data were collected at three different assessment points: baseline assessments 8-weeks prior to the program, pre-test assessments just before the program, and post-test assessments at the completion of the program. Qualitative data were collected via two focus groups at the completion of the program. Both sets of data (quantitative and qualitative) were analyzed separately, and results were then merged together to enhance understanding of changes in HRQoL following the 8-week MY-OT for PD program. Although quantitative and qualitative data were not collected at the same time, both occurred during the same phase of research. The research team discussed the collection of both data types concurrently and conferred regarding how the results related together—exemplifying a mixed-methods convergent design (Creswell & Clark, 2018).

Participants

We used a convenience sampling method to recruit participants into the MY-OT for PD program. Participants were recruited through three announcement routes: at a community adaptive yoga program, at a county support group for PwP, and with flyers or online publications

in the community. In order to be included in the study, participants met the following inclusion criteria: were at least 18 years old, had a self-reported diagnosis of PD, scored at least 4/6 on the short Mini Mental Status Exam (Callahan et al., 2002), agreed to set-up their own transportation to the program location, agreed to pay $5/yoga class or receive a scholarship, and had the ability to stand with or without an assistive device.

Intervention

The MY-OT for PD intervention consisted of two parts: adaptive community yoga programming for individuals with Parkinson's disease, and group occupational therapy designed to manage general and PD-specific fall risk factors. The community yoga program was led by a certified yoga instructor who had 20 years of yoga practice experience and facilitated adaptive yoga for PD classes for over four years. Adaptive yoga consisted of seated, standing, and supine postures, which were modified incrementally with props (bolsters, blocks, or straps), personal assistance (visual, verbal, or manual), or alternative posture options each class. All participants completed the same yoga class once a week, and then either completed a power yoga for PD class or a restorative yoga for PD class once a week (Table 4.1).

The group occupational therapy portion was facilitated by a registered and licensed occupational therapist with five years of clinical practice experience. The occupational therapy portion included lectures, guided discussions, and activities designed to identify and manage fall risk factors for individuals with PD. The occupational therapy session manuals were based on the original MY-OT program (Schmid et al., 2016), and adapted to meet the needs of PwP (Swink et al., 2019). Fall risk factors were explained based on a guiding model adapted from the WHO Risk Factor Model for Falls in Older Age (referred to as the PD Fall Risk Model) which identified four areas of potential fall risk: behavioral risk factors, biological risk factors,

environmental risk factors, and socioeconomic risk factors (World Health Organization, 2007). At the baseline assessment period, participants chose the morning or afternoon occupational therapy sessions. Participants then remained in either the morning or afternoon group throughout the program. See Table 4.1 for content of the yoga and group occupational therapy sessions.

[Insert Table 4.1 Here]

Measures and Data Collection

Participants were asked to complete an assessment at each time point that included multiple self-report measures: demographic surveys, health related information, and standardized assessments. Demographic and health information included questions related to: age, years since PD diagnosis, gender, race, and education level.

Quantitative data collection. The Parkinson's Disease Questionnaire—8 (PDQ-8) is an 8-item self-report measure used to assess eight HRQoL domains and was specifically designed for PwP (Jenkinson, Fitzpatrick, Peto, Greenhall, & Hyman, 1997). The PDQ-8 is a shortened version of the original Parkinson's Disease Questionnaire—39 and the 8-item version includes one question related to each of the following eight domains: mobility; activities of daily living; emotional well-being; stigma; social support; cognition; communication; and bodily discomfort (Jenkinson et al., 1997). Each item is scored on a five-point Likert scale ranging from "never" to "always", with always indicating that a participant always has difficulty with that item; therefore, lower scores reflect greater HRQoL. The PDQ-8 has demonstrated excellent internal consistency, excellent criterion validity, and adequate construct validity when used in the United States (Jenkinson & Fitzpatrick, 2007). According to the Parkinson's Evidence Database to Guide Effectiveness (PDEDGE) task force, the PDQ-8 is recommended for use in all stages of

PD (Kegelmeyer et al., 2014). Participants completed the PDQ-8 at all three assessment points: baseline assessment, pre-assessment, and post-assessment.

Qualitative data collection. Qualitative data were elicited through the use of two semi-structured focus groups conducted one week after completion of the MY-OT for PD program. Focus group questions were formed by a qualitative research and intervention research expert panel. We used neutrally worded questions and utilized accessible language to maximize comprehension and input (Merriam, 2009). The focus groups were led by an occupational therapist with experience on multiple qualitative research studies and who was not part of the MY-OT for PD program. Since the facilitator was not involved in the study implementation, this allowed for reduction in bias and provided an opportunity for participants to freely discuss in an open and honest manner their experiences with the program. A trained research assistant who helped with the intervention once a week was present to take notes and assist with focus group set-up. Each focus group lasted one hour, was audio recorded, and transcribed verbatim. Topics of focus group questions included: acceptability, satisfaction, overall health impact, and impact on participation. See Table 4.2 for the specific questions related to HRQoL and examples of follow-up questions asked during each focus group.

[Insert Table 4.2 Here]

Data Analysis

Quantitative data analysis. All data were imported into SPSS for analysis (IBM Corporation, 2017). Demographic data and participant characteristics were analyzed using descriptive statistics (e.g. means, standard deviations, frequencies, percentages). A PDQ-8 summary index score (PDQ-8 SI) was calculated using the following equation: $PDQ-8\ SI = \frac{Sum\ of\ PDQ-8\ item\ scores}{total\ possible\ score} * 100$. Participants scores were therefore each provided from 0-100, with

higher scores indicating decreased HRQoL. PDQ-8 SI scores at each time point were then assessed for normality using the Shapiro-Wilk Test (Field, 2018). Data were not normally distributed and therefore visually inspected; the same participant was an outlier at each assessment time point. Data from that participant were removed and the Shapiro-Wilk Test was conducted again. With the participant outlier removed, the data were normally distributed, and the interpretation of the results did not change. Therefore, the participant outlier was retained in the analysis and parametric statistics were employed. A Repeated Measures Analysis of Variance (RM-ANOVA) was conducted to determine differences between PDQ-8 SI scores at the three assessment time points. Sphericity was assessed based on Mauchly's Test of Sphericity, and effect sizes were calculated using partial η^2 estimates.

Exploratory post-hoc analyses. We completed two exploratory post-hoc analyses to assess for quantitative differences between groups. During the control period and intervention period, participants were emailed or called weekly to ask about potential falls and yoga class attendance. For the purposes of these analyses, fallers were classified as participants who reported at least one fall during the control or intervention, and non-fallers were those who reported no falls during the control or intervention periods. Regarding yoga, if participants practiced yoga before or during the control period, they were classified as starting "yoga experienced" or if they did not they were classified as "yoga novice." We compared PDQ-8 SI scores at each time point between fallers and non-fallers and also between yoga experienced and yoga novice groups. Between-group comparisons were considered significant at $p < .017$ given the Bonferroni correction for three comparisons in each exploratory post-hoc analysis (Gliner, Morgan, & Leech, 2017).

Qualitative data analysis. Focus group transcripts were imported into NVivo 12 for qualitative analysis (QSR International Pty Ltd., 2018). Each of the eight domains of the PDQ-8 (i.e. mobility, activities of daily living, emotional well-being, stigma, social support, cognitions, communication, and bodily discomfort) were used as deductive codes to analyze the focus group data. The first author (LS) and fifth author (TK) independently coded each focus group separately in NVivo using the deductive codes (the eight domains of the PDQ-8). The independent coders then reviewed coded data together to facilitate consensus regarding supportive quotes in each deductive theme area and reached consensus that no further themes emerged related to HRQoL. Given that the PDQ-8 domains represented HRQoL well in this sample, and no further categories related to HRQoL emerged, the coders discussed the utility of maintaining the PDQ-8 codes as final themes. Both coders agreed that the PDQ-8 domains were appropriate to represent the research question, and the participants' perspectives. We additionally completed peer review with a faculty mentor in the design phase during focus group question development, examination of the utility of the deductive coding schema, and analysis of data representation within themes (Merriam, 2009).

Integration procedures. Quantitative and qualitative data were collected and analyzed separately but the data were compared and integrated into related results using overall HRQoL and the PDQ-8 domains. According to Creswell and Plano Clark (2018), one method for merging quantitative and qualitative data using a convergent design is to "identify differences and similarities within one set of results based on dimensions within the other set" (p. 70). Therefore, overall quantitative HRQoL results were presented and qualitative results were coded and presented within the domains of the quantitative measure. Together, qualitative and quantitative

data were integrated to create a more comprehensive understanding of the HRQoL changes seen over the course of the MY-OT for PD program.

Results

Participant Characteristics

Seventeen participants completed the program, and one dropped out during the control period. Additionally, one participant was unable to attend the focus group due to illness, therefore, 16 people participated in the focus groups (11 people in the first focus group, 5 people in the second focus group). All available demographic data were reported from the baseline assessment period, which included the participant who dropped out during the control period (n = 18). The majority of participants were male (55.6%), married (72.2%), white (100%), college graduates (44.4%), and retired (88.9%) (Table 4.3). Participants were, on average, 71.72 years old (range = 64-82 years old) and had been diagnosed with PD for 6.93 years (range = 9 months-18 years).

[Insert Table 4.3]

Quantitative Results

We considered quantitative and qualitative results in order to comprehensively answer the research question: how does HRQoL change following the MY-OT for PD program? The three mean PDQ-8 SI scores (±SD) were: baseline (31.25±14.78), pre-assessment (27.57±19.74), and post-assessment (28.31±16.99). There was no significant main effect on PDQ-8 SI overall scores between time points, $F(2, 32) = 1.60$, $p = .22$, partial $\eta^2 = .09$. The partial η^2 value indicated a medium-large effect on HRQoL over the course of the control and intervention periods, with specifically a large control period effect (partial $\eta^2 = .13$) and small intervention period effect (partial $\eta^2 = .01$) (Cohen, 1988).

Exploratory post-hoc results. The exploratory post-hoc results were used to examine between-group differences in PDQ-8 SI scores between fall groups (fallers, or non-fallers) (Table 4.4), and yoga practice experience (yoga experienced, or yoga novices) (Table 4.5). The only between-group difference was PDQ-8 SI scores at post-assessment, where fallers had significantly higher (i.e. lower HRQoL) scores, $t(15) = -2.85$, $p = 01$.

[Insert Table 4.4]

[Insert Table 4.5]

Qualitative Results

During the focus groups, participants discussed changes they noticed in relation to HRQoL in each of the 8 domains of the PDQ-8. This section is organized from the HRQoL domain that was mentioned by the greatest number of participants, to the HRQoL domain that was mentioned by the least number of participants. Participants were each assigned a pseudonym to report qualitative results. See Table 4.6 for a full description of focus group participants, including demographic information and corresponding HRQoL domains mentioned by that participant. Selected quotes are represented under each PDQ-8 HRQoL domain.

[Insert Table 4.6]

Social support. Six participants reflected on the importance of social support over the course of the program. Earl was newly diagnosed with PD and frequently struggled with noticing symptoms, but following the program he reflected on the social support aspect:

> I think what I liked the best was the group and seeing myself in everybody else and having that reflected back to me and seeing the kindness of the humanity of the group and what they're going through and… that's what was the best for me.

David expanded that sentiment:

> there's a lot of societal support [for PwP] and it couldn't be a better illustration of that then this very class. It's really something very wonderful…I would say what what- what is some simple thing well it it's that we're human beings and we care about each other. That's it.

Experiencing the class together in person seemed to be a powerful aspect of the program, John reported on how the program would have been much different if it was not in person, as a group:

> I also enjoyed the comradery of the group I think it was very good. You know we could have done the same kind of thing as a home study. Read these things and draw the stoplights and all that and do yoga by yourself and the video finding a CD or something like that. But having the group here makes it a lot better.

Mobility. Five participants discussed changes in mobility they had noticed over the course of the MY-OT for PD program. Douglas reflected on changes in motivation and mobility:

> I've been forcing myself to go out and walk more….I'd go out to a certain bridge and I'd turn back, took me 10 minutes the first time, well I broke 9 minutes just the other day, so I'm getting more of a workout…so now I've gotta go further…that has encouraged me to go out and do more.

Other participants agreed that mobility was a positive change following the program, and some participants targeted mobility areas like walking for their action plans as part of the program requirements. Another participant discussed increased mobility in the form of walking. Barb stated, "in my walking…it took me about an hour to do 6 blocks. I now go over 22 blocks in an hour." Joan saw improvements from many of her community-based classes, with the MY-OT for PD program adding to her overall improved mobility as one of those classes:

> "Well I think these folks know that I sat for a year after I was diagnosed and then I couldn't get out of the chair. And so I'm doing six [community-based] classes now, six classes a week…that's made all the huge difference—all the difference in the world."

Bodily discomfort. When discussing bodily discomfort, participants mentioned the specific benefits of yoga. When probed for changes in bodily comfort issues, Pam stated, "yoga really helps me a lot with the muscle tightness…yoga's a great solution." She went on to discuss how PwP are greatly impacted by muscle tightness, and yoga reduces that symptom. David agreed that yoga was important to promote comfort in the body. Barb then discussed changes in joint discomfort related to her knees:

> They used to just kill me…I still have pain but um, oh pain say, 1 to 10, 10 being the highest. I used to be an 8, 9, 10 most of the time. I'm down now about 2, 3…I have pain and I have it all the time but it's not like it was.

Throughout the program may participants underscored the muscle stiffness associated with PD. Multiple participants felt that yoga was a safe and progressive option to focus on prolonged stretch and slowly address muscle stiffness. Ken explained that yoga can release "a lot of tension" and "it helps in learning to relax." Some participants cited other community classes they enjoyed for cardiovascular fitness, or strengthening, but most agreed that yoga was the best class they attended for gentle and effective stretching.

Activities of daily living. Three participants mentioned changes in activities of daily living over the course of the program. During yoga practice, certain exercises were designed to promote coordination and engage both sides of the brain. For example, the yoga teacher included exercises crossing midline, postures that required complex bilateral coordination, and alternating intricate fine motor tasks. When discussing some of the yoga exercises designed to engage both

sides of the brain, Douglas stated, "that helps me…pick up silverware and grab the salt and…you struggle picking up the salt shaker, you know, when you do that same motion 5 times a week, you know it's easier to pick up the salt shaker." Ann also noted that repetition of certain exercises and confidence in movement had improved her ability to do everyday activities—"instead of it taking you 45 minutes to make the bed you can make it in 15." Participants frequently tied changes in everyday life back to movements that were practiced in yoga, and the occupational therapy portion additionally facilitating increased awareness and mindfulness.

Stigma. David discussed the stigma associated with being reliant on the help of others due to a diagnosis of PD, and how that has changed with participation in the MY-OT for PD program. He stated:

> One of the things that I think is really great about this is that, you know we're used to being needy. With PD you have a lot of needs, but I like the idea that this is a research project to do your PhD and that's gonna really contribute something and we can contribute to that educational process. We're not just taking, we're giving too.

He frequently discussed the benefits of being able to talk to other people with PD in a dedicated program, and contribute to science at the same time. When the facilitator clarified that it is nice to be part of a program where you're involvement is essential, David stated, "we are all human beings," further supporting the idea that no one should be discredited. Joan also discussed how the group had helped her reframe stigma during their time together:

> Can't tell if it's the class or if it's just where we are as a support group. It's kind of what we encourage each other to do. People who view us in one way, it's their problem it's not our problem. I know, it's like the parent who says to the child 'don't stare, don't stare',

then they're saying to the child there's something wrong with this person and you know there's nothing wrong with me.

Communication. Communication was addressed by three participants in the focus group. Many of the communication examples related back to aspects of social supports and interacted with that HRQoL domain. However, a couple of participants reflected on communication-specific changes. Barb revealed her thoughts on proactive communication:

> My husband every once in a while, he's a good man, he does a lot of things to take care of me right. But once in a while he'll come out and he'll speak and it'll be in angry voice and I learned to say 'hey wait a minute I did not like the way that sounded, that hurts my feelings, you know can you rephrase that and don't take your anger out on me.'

Joan reiterated the overall sentiment and responded to Barb and said:

> Be sensitive to the fact that you're more sensitive to hearing that and it might not be angry at all it's just what you're interpreting. That's your Parkinson's hearing it. That's what I know about myself anyway cause he'll say 'I didn't say it that way- what're you talking about' and you have to understand I interpret it that way.

Cognition. Participants did not naturally bring up cognition during the focus group. However, when prompted, a couple of participants discussed changes noticed in cognition. Barb experienced an increased sense of peace with her cognitive processes:

> I think it has [in the past] but [now] it doesn't bother me if I can't come up with the things right away. I will think about something and it takes a little while before the words will come up, and I don't feel bad about it anymore it's like, this is normal.

Judy specifically recalled a cognitive strategy from the MY-OT for PD program, and stated "[what I learned was] not multi-tasking when I do things. When I'm walking or when I'm getting

in and out of the car…to make sure I pay attention and I'm alert to all of the factors around me." A few other participants mentioned that higher level thinking and planning is something that has become so difficult for them. Some of the conversation centered around difficulty with cognition for PwP.

Emotional well-being. Two participants discussed changes in emotional well-being when prompted regarding this domain. Shirley remarked, "having the [occupational therapy] class and being quiet and thinking and then going in and doing the yoga…it kind of got your mind relaxing and, after all the thinking, and I think that was a nice follow through for the whole class." The merging of the two classes was helpful to this participant. Returning to her concept of peace, Barb, discussed emotional well-being in terms of being at peace: "I feel like I'm in such peace…before I used to be very anxious about things and worrying. I don't do that too much now….I just have kind of a peace over me that, you know, I'm going to be ok."

Discussion

In this study, we used mixed methods to create a comprehensive understanding of participants' perceived HRQoL changes after a fall risk self-management program. We combined quantitative and quality methods to answer the question: how does HRQoL change following the MY-OT for PD program? Our inquiry was in part guided by recommendations from the Prevention of Falls Network Europe (ProFaNE). ProFaNE recommended that HRQoL should be measured because it may be an unintended improvement from fall prevention programming (Lamb et al., 2005). Following the MY-OT for PD program, quantitative results showed no significant differences in HRQoL at the three assessment points, although overall, participants rated higher HRQoL scores at post-assessment than baseline. Interestingly, participants rated the highest HRQoL scores following the control period (i.e. before the

intervention). While significant changes in the quantitative data did not occur, in the focus group, many participants discussed improvements seen in HRQoL across the 8 domains of the PDQ-8 following the intervention.

Improvements during the control period could partially be attributed to the fact that, although they were not receiving the intervention, participants were still participating in a research study. As one participant expressed, there was a sense of purpose associated with signing up for the study, and in many cases, participants signed up in an effort to give back to academia and science. In a trial promoting health behavior-change, researchers similarly found that participants frequently cited "to help science" as a reason they decided to participate (Lakerveld et al., 2008). Consciously, or subconsciously, with the goal of helping the researchers, participants may have altered PDQ-8 responses in an attempt to "improve," creating a potential socially desirable response bias (Van de Mortel, 2008). However, participants were not familiar with the study design (i.e. participants serving as their own controls), and therefore the potential response bias was lessened, but may have resulted in better HRQoL scores at pre-assessment. Additionally, some of the positive results seen during the intervention period could be due to positive placebo reactions. Up to 50% of PwP experience placebo effects during trials (de la Fuente-Fernández et al., 2002; Goetz et al., 2008), which can occur because dopamine is released when participants anticipate positive outcomes (De la Fuente-Fernández et al., 2001). Especially with the weekly check-ins, participants in our study could have experienced control period improvements in HRQoL from positive placebo effects.

Conversely, participants may have truly experienced HRQoL improvements during the control period. In a physical activity intervention, researchers found that participants who improved in the control group were predominantly retired, and had completed secondary school

(Waters et al., 2011), characteristics that are consistent in the current sample. Additionally, participants' responses on the PDQ-8 could be reflective of their condition in that specific point in time, rather than the past month as the assessment instructions directed. Additionally, PD is progressive and dynamic and changes in function may be related to HRQoL. For example, the weekly check-ins during the control period could have resulted in a sense of social connection and increased HRQoL even though the MY-OT for PD intervention had not yet begun.

Rehabilitation or exercise interventions for PwP have shown mixed results regarding HRQoL changes, with some trials showing no significant changes in HRQoL (Clarke et al., 2016; Laupheimer, Härtel, Schmidt, & Bös, 2011; Westheimer et al., 2015), while others have promising results for significant improvements in HRQoL (Dereli & Yaliman, 2010; Tickle-Degnen, Ellis, Saint-Hilaire, Thomas, & Wagenaar, 2010; Yousefi, Tadibi, Khoei, & Montazeri, 2009). Consistent with our findings, a 3-month physical and occupational therapy trial showed no change on HRQoL for individuals with mild to moderate PD (Clarke et al., 2016). Since HRQoL typically declines overtime for PwP, results that show no change in HRQoL could be meaningful (Karlsen et al., 2000). Our intervention was not long enough to determine if HRQoL continued to remain steady, but an intervention like MY-OT for PD can potentially help PwP maintain current HRQoL levels and lessen potential declines. Thus, seeing no decline in HRQoL scores may be important, but a follow-up assessment would be necessary to track these changes and establish a clear relationship between HRQoL changes over time. A longitudinal follow-up may have been a better design to see the implications of participants implementing fall management strategies and yoga practice in a way that improved HRQoL.

Although rehabilitation and exercise trial results are mixed, many yoga interventions have shown improvements in HRQoL following yoga-based trials (Bega et al., 2016; Ni et al.,

2016; Walter et al., 2019). For example, in an 8-week yoga intervention for PwP, PDQ-8 scores significantly improved in the yoga group (p = .03) indicating that the 8-week timeline could affect HRQoL for PwP (Walter et al., 2019). Interestingly, in our study, there were no significant differences in HRQoL regardless of yoga practice status (yoga experienced, or yoga novice). Based on literature from previous studies, we hypothesized that yoga improves HRQoL, but in our sample, there were not significant differences in HRQoL quantitative improvements depending on yoga group.

We assume the PDQ-8 questions did not fully capture each participant's HRQoL changes during the MY-OT for PD program because of the rich focus group descriptions of HRQoL improvements despite the minimal changes in PDQ-8 results. In the focus group, participants particularly illuminated the strong social environment of the program, which was defined as part of HRQoL and can impact HRQoL improvements. Decreased social support has been associated with greater anxiety and depression in PwP (Simpson, Haines, Lekwuwa, Wardle, & Crawford, 2006), which speaks to the need for programs that foster social participation. Both the group occupational therapy and group yoga could contribute to participants' reports of a strong social support system within the program. Although group interaction was not explicitly promoted during the yoga portion, yoga could have played a role. In an 8-week study of yoga alone, PwP in focus groups discussed improvements in social relationships through the development of a PD-specific support system and engagement in yoga as a shared experience (Hawkins et al., 2018). Participants discussed the benefits of group conversations during occupational therapy, and then participating in yoga together even though they were not talking during yoga. Likely, the merger of the two interventions resulted in the strong perceived social interactions.

When discussing changes in mobility, and activities of daily living, participants often considered being able to do things quicker or more efficiently. Bradykinesia (i.e. slowed movements) is a cardinal feature of PD and individuals are likely greatly impacted by these slowed movements and has been associated with decreases in HRQoL (Lyons, Pahwa, Troster, & Koller, 1997). In our study, participants' reports of being able to complete intentional tasks more efficiently could have a profound impact on their HRQoL. Similar results were found in a 3-month yoga study, participants experienced reduced bradykinesia in their limbs, and decreased rigidity scores, as well as significantly improved HRQoL following the yoga intervention (Ni et al., 2016). The researchers noted that participants had the greatest improvements in physical domains of HRQoL (i.e. mobility and ADL), which were consistently the areas our participants brought up in the focus groups without additional prompting. Participants' examples in our study of walking more quickly and making the bed faster can all lead to substantial changes in their lifestyle and perceived HRQoL. Participants highlighted improvements in all HRQoL domains during the focus group. However, given the nature of a community-based intervention, these improvements could also be, in part, due to other changes that occurred over the time period in their everyday life or activities.

Limitations and Future Directions

We had a small sample size in this intervention and cannot assume that HRQoL changes seen in this group are representative of all PwP. Additionally, participants were relatively homogenous. All participants were white, the majority had completed college or higher levels of education, and all lived in a small city in the Western United States.

If we completed a similar study design in the future, we would add participant focus groups at baseline and at pre-assessment or conduct individual interviews. If we had additional

focus groups or interviews we may have been better able to capture qualitative changes in HRQoL and determine specifically when during the program, or in relation to which content participants perceived HRQoL changes. Since we only completed focus groups after the program, participants may have considered the weekly check-ins during the control period as part of the intervention. Additionally, quieter participants did not speak as much, and participants who experienced less benefit from the program likely did not contribute as much to the focus group. Individual interviews may capture broader insight to the MY-OT for PD program and potential HRQoL changes.

We also did not analyze any notes taken during the MY-OT for PD program, such as field notes to capture the participants' discussion. The addition of field notes during the classes could capture group discussion in the moment and lead to a more comprehensive understanding of participant perceived HRQoL changes. Future trials should consider the addition of field notes during the intervention program and triangulate these data with focus group or interview data. In addition, we did not complete a longitudinal follow-up. Following up with participants to determine sustained HRQoL changes is important to consider in future trials.

Conclusion

Although quantitative results showed no significant improvement during the study time, participants in the MY-OT for PD program spoke to improvements in HRQoL over the course of the intervention. Social support was a main contributor to perceived HRQoL improvements during the MY-OT for PD program. The program did not specifically target HRQoL, but perceived HRQoL improvements were evident in qualitative results. Further research is needed to explore multifactorial fall prevention programming for PwP and the effect on HRQoL.

Figures and Tables

Table 4.1

Merging Yoga and Occupational Therapy for Parkinson's Disease: Program Outline

Week	Occupational Therapy Session 1	Yoga Session 1	Occupational Therapy Session 2	Yoga Session 2
1	Program Introduction Fall Statistics	Breath awareness	Introduction to using the PD Fall Risk Model: behavioral, biological, environmental and socioeconomic fall risk factors	(1) Maintaining balance with position changes (2) Awareness of breath with changing body positions
2	Personalized Fall Stories Individualized Action Plans	Vocalizations to improve body awareness	**Biological** risk (PD symptoms) and the role in falls	(1) Mobility: shoulder and ankle Strengthening: arms Balance and coordination, (2) Mobility: neck and shoulder within comfortable range of motion
3	**Behavioral** risk (medication management, and mobility aid use)	Basics of mindful movement	**Behavioral** risk (physical activity levels) and **environmental** risk (mobility aid use)	(1) Honoring the body Arms: strength and balance (2) Restorative poses to release tension
4	**Behavioral** risk (endurance)	Core strength, coordination, face yoga	**Biological** risk (fatigue) and **behavioral** risk (modifying activities)	(1) Hip flexion with mindful walking stride (2) Restorative focus on hip opener postures, vocalizations, and face yoga
5	**Biological** risk (fatigue) and **behavioral** risk (modifying activities and personal application)	Complex seated postures, mindful crossing midline	**Biological** risk (weakness) and **behavioral** risk (physical activity, strengthening, getting up from the floor))	(1) Coordination of movement while changing direction, dynamic balance (2) Guided release of tension
6	Action plans for the home and community	Vocalizations and core strength	**Environmental** risk (home hazards)	(1) Balance through dynamic standing movement

				(2) Prolonged stretch, fine motor dexterity
		Week 7 Holiday Week		
8	**Environmental** risk (community hazards) and **socioeconomic** risk (advocacy)	Coordination of movement and breath	Program Summary	(1) Challenging balance through dynamic position changes (2) Prolonged back and neck stretches
9		**Scheduled Focus Groups**		

Table 4.2

Focus Group Guide with Targeted Health-Related Quality of Life Questions

Primary Question	Prompt Options	Example of How Prompt was Used
How has coming to this program changed your overall health?	If not mentioned the following probes were used, how has this program changed your (insert any of the following): mobility, activities of daily living, emotional well-being, stigma, social support, cognition, communication, and bodily discomfort?	Facilitator during FG1: "So ___ also mentioned balance there at the end she was talking about her balance improving. What else have people noticed, that their health has benefited, and both your mental health and physical health, what has this program helped in your ***daily life***?" Facilitator during FG1: "So we've talked about kind of mobility, getting around, um trying to set up your day where you're doing stuff, how about maybe your ***emotional well-being*** or your ***ability to think clearly*** [cognition]?" Facilitator during FG2: "In terms of the classes too, we've talked a lot about the physical aspects and being able to do more things in your home. Um how do you feel about your ***emotional well-being*** or your ***ability to think*** [cognition]?" Facilitator during FG2: "You had mentioned it bothered your wife more, we talked a little bit earlier to about kind of the ***stigma*** of having Parkinson's…Are there things that you've been able to do in these last several weeks to calm that, to think differently to shift your perspective on that [stigma related to Parkinson's disease]?"

Table 4.3

Demographic Characteristics

Category		Frequency (n=18)	Percentage
Gender	Male	10	55.6
	Female	8	44.4
Marital Status	Married	13	72.2
	Divorced	4	22.2
	Widowed	1	5.6
Race	White	18	100
Education	High school graduate	1	5.6
	Some college	1	5.6
	College graduate	9	50.0
	Some post-graduate	3	16.7
	Post-graduate degree	4	22.2
Work Status	Retired	16	88.9
	Not working	2	11.1

Table 4.4

Faller Group Differences

	Faller (n=8) or Non-faller (n=9)	Mean	Standard Deviation	p-value
PDQ-8 total baseline	Non-faller	25.69	11.46	.10
	faller	37.50	16.28	
PDQ-8 total pre-assessment	Non-faller	17.71	8.12	.02
	faller	38.67	23.44	
PDQ-8 total post-assessment	Non-faller	19.10	6.34	.01*
	faller	38.67	19.55	

Note: *= significant at p <.017 considering Bonferroni correction for three comparisons.

PDQ-8 = Parkinson's Disease Questionnaire—8

Table 4.5

Yoga Group Differences

	Yoga Practice Status (Yoga Experienced [n=10], or Yoga Novice [n=7])	Mean	Standard Deviation	p-value
PDQ-8 total baseline	Yoga Experienced	29.69	11.24	.63
	Yoga Novice	33.48	19.58	
PDQ-8 total pre-assessment	Yoga Experienced	23.75	11.14	.43
	Yoga Novice	33.04	28.18	
PDQ-8 total post-assessment	Yoga Experienced	25.94	11.51	.51
	Yoga Novice	31.70	23.42	

Note. PDQ-8 = Parkinson's Disease Questionnaire—8

Table 4.6

Participants in Focus Group: Demographic Information and Identified Health-Related Quality of Life Domains

Pseudo	Age	Sex	Years since PD dx	Marital Status	Highest Education	Health-Related Quality of Life Domain Discussed in Focus Group							
						ADLs	Mobility	Emotional Well-being	Stigma	Social Support	Cognitions	Communication	Bodily Discomfort
Harry	74	M	13	Married	Some post-grad								
John	70	M	6	Married	Post-grad degree					X			
David	82	M	5	Married	Post-grad degree				X	X		X	X
Barb	68	F	7	Married	College grad	X	X	X	X		X	X	X
Ken	71	M	3	Married	College grad								X
Judy	71	F	14	Widowed	Post-grad degree		X			X	X		
Shirley	78	F	1	Married	High School			X					
Larry	77	M	18	Married	Some post-grad		X						
Joan	72	F	4	Married	Some post-grad		X		X	X		X	X
Brenda	69	F	9	Divorced	College grad								
Steve	66	M	1	Married	College grad								
Douglas	74	M	10	Married	College grad	X	X			X			
Ralph	69	M	15	Married	Some College	Participant's voice did not record (hypophonia) and therefore his sentiments were difficult to capture in terms of health-related quality of life							
Ann	70	F	1.5	Divorced	College grad	X							
Pam	64	F	2.5	Married	College grad								X

Earl	73	M	.75	Married	College grad	X

Note. Pseudo=pseudonym. PD dx= Parkinson's disease diagnosis. ADLs=Activities of Daily Living. M=Male. F=Female. Grad=graduate

CHAPTER FIVE: OVERALL DISCUSSION

Major Findings

This dissertation is a necessary and important contribution to community-based fall prevention programming because we created and tested a fall risk self-management program for PwP. We developed Stage 1 manuals for the MY-OT for PD program using a focus group of PwP and experts in related fields of practice and research. Prior to pilot and feasibility testing, we incorporated the majority of suggested changes related to the guiding model, content, and delivery. Some revisions were related to the inclusion of PD-specific content (e.g. tips surrounding multi-tasking, freezing of gait strategies), while other revisions were related to reinforcing general content that was already somewhat present in the manuals (e.g. medication management, emotional feelings with mobility aid use).

Participants completed testing eight weeks before, immediately before, and after the 8-week (14 sessions) MY-OT-PD interventions. Participants experienced improvements in all outcome measures following the MY-OT for PD program, and fewer falls during the intervention period. Specifically, participants experienced significant improvements in their perceived ability to prevent and manage falls, and in balance when comparing differences from the control and intervention periods. Other fall management scales showed improvements across time points, but the differences were not significant between the control and intervention periods. We expected HRQoL to improve due to the addition of the community-based MY-OT for PD program where participants were provided with opportunities for discussion, activities, resources, and yoga practice. HRQoL did change, although the change was not significant. In relation to perceived

HRQoL changes, the participants commonly discussed improvements related to social support, mobility, and bodily discomfort following the program.

Discussion

Overall, we hypothesized that the MY-OT for PD program would reduce falls, improve fall risk factor management, reduce concern about falls, and improve balance and balance confidence. We assumed that, similar to the original MY-OT program (Schmid et al., 2016), group occupational therapy could improve fall risk factor management through a combination of group education, guided activities, and individualized action planning. Additionally, we thought yoga would improve balance and balance confidence. Ultimately, the MY-OT for PD program reduced falls, significantly improved aspects of fall prevention and management, significantly improved balance, and participants qualitatively described positive changes in HRQoL.

Most importantly, during the intervention period participants reported an overall 40% reduction in self-reported falls as compared to the control period. According to fall prevention researchers, a 30% reduction in falls represents a critical reduction in fall risk (Campbell et al., 1999; Clemson et al., 2004; Cumming, 2002). Because of the short-time period of the follow-up assessments, the small sample size, and participants serving as their own controls, we cannot assert that this difference was significant. Yet the prevention of even one fall could have an immense impact on an individual's life, and it bears to reason that the MY-OT for PD program should be further investigated.

Following the MY-OT for PD program, participants experienced improvements on all outcomes, but significant improvements were different than those of the MY-OT (for chronic stroke) program. Two main differences between the programs could account for these changes: (1) the design was different and in MY-OT for PD participants served as their own controls, and

(2) over half of the participants in MY-OT for PD were already practicing yoga during the control period. With participants serving as their own controls, some participants experienced improvements during the control period. Part of this difference could be due to a testing bias because participants learned the questions or participants implemented the strategies they read during baseline assessments (Bhattacherjee, 2012). Participants could have also experienced improvements due to positive placebo effects during the control period. For PwP, placebo effects are thought to function by increasing dopamine levels when participants expect positive outcomes and are anticipating benefits (De la Fuente-Fernández et al., 2001).

Additionally, in MY-OT for PD program 10 participants were already involved in yoga during the control period as compared to MY-OT where all participants were new to yoga (Schmid et al., 2016). In the MY-OT study, significant improvements were seen on the FPSS, whereas in MY-OT for PD the significant improvements on the FPSS were attributed to changes during the control period. Therefore, it is possible that in this study, yoga contributed to the control group improvement on strategies to manage falls. Interestingly, whether or not participants practiced yoga during the control period did not significantly impact balance. Balance significantly improved comparing the control period and intervention period, despite yoga practice status. With this population, the group occupational therapy portion may have also affected balance, and the yoga portion may have also affected fall risk factor management. During the occupational therapy portion we discussed balance and participants reinforced methods to reduce biological fall risk by improving balance and strength. Therefore, the occupational therapy content may have contributed to balance improvements. Additionally, yoga may improve neural connectivity, memory, and executive functioning (Eyre et al., 2016; Gothe, Kramer, & McAuley, 2014) which can increase participants' ability to absorb occupational

therapy content and implement self-management strategies. Fall risk factor management content was discussed during the occupational therapy portion, but yoga may have helped participants retain this knowledge and better integrate the strategies.

We assumed that MY-OT for PD would improve HRQoL. Participants described improvements most frequently in the HRQoL domains of social support, and mobility. The group nature of the program likely increased social support. Additionally, yoga may improve muscle strength, endurance, and flexibility for PwP (Roland, 2014), which could lead to their reported changes in mobility (one HRQoL domain). Despite recommendations that HRQoL should be captured as an outcome in fall prevention programming (Lamb et al., 2005), it did not significantly change following MY-OT for PD. Perhaps for PwP, maintaining or slightly increasing HRQoL is an important finding because, naturally with a neurodegenerative condition, HRQoL typically declines over time (Elliott & Velde, 2006; Karlsen et al., 2000).

Limitations and Future Directions

We were not able to integrate all changes from Study One into Stage 1 manuals for the MY-OT for PD program. For example, due to space limitations we did not include caregivers in this iteration. Prior to future trials, the MY-OT for PD program should be adapted based on participant feedback following the program. Additionally, we should create Stage 2 manuals to guide program implementation which includes therapist training information (Carroll & Nuro, 2002). Within Stage 2 manuals, revisions mentioned in Study One should be revisited.

We did not complete field notes during the program, or use information from participant manuals for data analysis. Program field notes would have created a more comprehensive understanding of the MY-OT for PD program. Participant manuals also included weekly action plans that targeted something participants wanted to change related to fall risk factor

management. Formal analysis of participant action plans in the future could help us identify potential areas of occupation where participants are targeting change. Additionally, we could assess whether or not participants are meeting their goals and if that outcome was associated with fall risk factor management outcomes.

The sample size for the MY-OT for PD program was small, and outcomes are not intended to represent all PwP. Our sample was 100% white, and the majority were highly educated. Therefore, results seen in this specific sample of participants cannot be generalized to all PwP. Participants also served as their own controls, which potentially led to testing bias, and could have contributed to the improvements seen in the control period. In future programs, a two-group comparative design could reduce this potential bias.

We completed the last assessment just after program completion. Without longitudinal follow-up we may not have given participants enough time to enact changes in fall risk as suggested in the program. Many of the fall risk factor management scales ask about strategies that take time to integrate. For example, questions addressed whether a participant checked with their doctor about reducing medications, or if a participant used grab bars in the bathroom. Even though a participant may be planning to do this behavior, the change may not be implemented by the end of the program. Future trials would greatly benefit from longitudinal follow-up after the program to capture integrated and sustained changes.

Relation to Occupational and Rehabilitation Science

This dissertation was completed towards completion of a PhD in occupation and rehabilitation science. In the development and implementation of the MY-OT for PD program I was informed by both occupational science (OS) and rehabilitation science (RS). The program was based more explicitly in concepts from RS because RS is a science which “encompasses

basic and applied aspects of the health sciences, [and] social sciences…related to restoring functional capacity in a person and improving their interactions with the surrounding environment" (Brandt Jr & Pope, 1997, p. 5). Specifically, RS is used to "examine[s] physical, behavioral, environmental, and societal factors" that interact and influence enablement and functioning of the whole person (Seelman, 2000, p. 79). In parallel, MY-OT for PD was designed to educate participants about biological fall risk factors (i.e. physical factors), behavioral fall risk factors, environmental fall risk factors, and socioeconomic fall risk factors. Beyond the focus on identifying and improving specific factors, rehabilitation scientists assert that individuals function as a whole person and in a complex context (Seelman, 2000).

Ultimately, the MY-OT for PD program was designed to help participants identify factors that they could self-manage to change their overall function and support quality of life. In the MY-OT for PD program, participants were asked to create action plans each week that targeted fall risk factors they could change. Problem-solving and action planning was an important piece of how participant integrated changes into their everyday life to potentially improve overall functioning. Additionally, yoga practice is designed to consider the whole person in a holistic manner because yoga is practiced using the body, mind, and breath (Taylor, 2003). Together yoga and occupational therapy likely lead to changes in many factors that influence the whole person's functioning, which cannot all be captured in the assessment of this program.

In complement, OS is a "social science focused on the form, function, and meaning of human occupation" (Clark, 2000, p. 125). Within this definition, occupation is understood as "chunks of activity within the ongoing stream of human behavior which are named in the lexicon of a culture" (Yerxa et al., 1990, p. 5). In a sense, OS researchers attempt to understand how humans structure those chunks of activity and the meaning behind that structure, all which

contribute to participation in daily life. Occupation can improve well-being using occupation as a means (part of the therapeutic process) or occupation as an ends (the desired outcome) (Dickie, 2014). In the MY-OT for PD program, occupation was not specifically utilized during the sessions; however, using the action plans, participants frequently identified fall risk self-management goals that included occupational outcomes (i.e. occupation as an ends). Although the delivery was not occupation-based, participants frequently translated the discussion content to engagement in occupation. Additionally, the adaptive yoga component can be seen as a modality to improve balance, but as individuals' may ascribe value to the activity and find participation more meaningful yoga, resulting in yoga becoming an occupation for participants (Venthan J. Mailoo, 2005; Venthan J Mailoo, 2006).

Conclusion

The purpose of this dissertation was to develop a fall risk self-management program for PwP (MY-OT for PD), and analyze the program through feasibility and pilot testing. We identified improvements in all outcome measures following the program, yet note that many were not significant and ongoing adaptation should be integrated into the MY-OT for PD program. Although there is more research to be done, I am hopeful that this dissertation was one step towards filling the need of fall management intervention options for PwP.

Clinical Implications

- MY-OT for PD is a feasible fall risk self-management program that could reduce self-reported falls and improve balance
- The MY-OT for PD program should be adapted, and additional assessment points added for longitudinal follow-up in future iterations

- An occupational therapist can address multiple fall risk factor categories when explaining fall risk to their clients. It is important that occupational therapists consider the interactive nature of fall risk and prompt the individual to consider certain risk factors he/she can change.

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GLOSSARY

Parkinson's disease: "A neurodegenerative disorder that affects predominantly dopamine-producing neurons" and is characterized by four primary clinical features: tremor, bradykinesia, rigidity, and postural instability (Parkinson's Foundation, 2017).

Fall: "an unexpected event in which the participants come to rest on the ground, floor, or lower level" (Lamb et al., 2005, p. 1619).

Feasibility study: "any sort of study that can help investigators prepare for full-scale research leading to intervention" (Bowen et al., 2009, p. 452).

Measuring feasibility: "The outcomes [process, resources, management, and scientific basis] of most feasibility and pilot studies should be measured with descriptive statistics, qualitative analysis, and the compilation of basic data related to administrative and physical infrastructure" (Tickle-Degnen, 2013, p. 172).

Occupational therapy (OT): "the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of enhancing or enabling participation in roles, habits, and routines in home, school, workplace, community, and other settings" (American Occupational Therapy Association, 2014, p. S1).

Yoga: Yoga is an ancient practice that combines "physical postures (*âsanas*), breathing practices (*prânâyâma*), ethical disciplines (*yâmas* and *niyâmas*), chanting, concentration techniques, and meditation" (Douglass, 2007, p. 35). Traditional yoga practice includes eight paths to personal improvement and wellbeing (Taylor, 2003). Typically, western yoga, focuses on merging body (postures), mind (meditation), and breath (breathing practices). Postures are steady body positions that focus on prolonged stretch and gentle strengthening (Nayak & Shankar, 2004).

Meditation facilitates awareness of the body, while reducing anxiety and depression (Smith, Greer, Sheets, & Watson, 2011). Breathing practices foster maximal respiratory capacity, self-awareness, and decreased negative autonomic responses (Nayak & Shankar, 2004). Hatha yoga is the branch of yoga most commonly practiced in western cultures (Smith et al., 2011) that focuses primarily on physical postures and breath control (Smith, 2007), and was referred to as 'yoga' throughout the dissertation.