Pilates Adapted for Parkinson’s Disease and Multiple Sclerosis

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Parkinson’s disease (PD) and multiple sclerosis (MS) result in disruptive physical, cognitive, and sensory complications that progress with time. These symptoms can alter muscle tone and disturb movement, which can negatively impact a person’s ability to complete activities of daily living (ADL) and participation in community activities (Lexell, Iwarrson, & Lexell, 2006; Wressle, Engstand, & Granerus, 2007). Treatment for PD and MS consists mainly of medications and occasionally surgery, (Merck Manual, 2012a; Merck Manual, 2012b) but alternative and supplemental treatments, including exercise, are also being used (National Institute of Neurologic Disorders and Stroke [NINDS], 2012; National Multiple Sclerosis Society [NMMS], 2012).

Significant improvements in walking speed and upper extremity endurance were seen in people with MS when they engaged in aerobic exercise (Romberg et al., 2004). A study by O’Brien, Dodd, and Bilney (2008), found that a successful exercise program for PD specifically addressed postural muscles, strength training and breathing exercises. It is suggested that treatment of PD should include the use of medication as well as regular exercise to manage the motor and psychosocial issues of coping with a chronic disease (Ziemssen, 2011). One possible exercise that should be considered is Pilates, which has been found to improve muscle endurance, flexibility, balance, and posture in people without neurological conditions (Kloubec, 2010).

The Pilates method can be adapted for individuals, thus allowing compensation for restrictions in movement (Owsley, 2005). It is able to meet the needs of diverse populations because the specialized equipment has features that allow an exercise routine to be adapted to individual body types. However, there is a lack of knowledge in the Pilates community about
biomechanics and the basics of functional fitness (Monroe, 2010). Therefore, the motor, cognitive or sensory disturbances associated with PD or MS is outside the basic knowledge required to become a certified Pilates instructor. This project addresses an unmet need by giving Pilates instructors the knowledge and skills to provide an accessible service that addresses some of the health and wellness needs of people with PD or MS.

**Background/Literature Review**

**Parkinson’s Disease Background**

PD is a chronic and progressive movement disorder that results from the degeneration of neurons primarily in the area of the brain called the substantia nigra (Parkinson’s Disease Foundation [PDF], 2012). The malfunction and death of these neurons affects the production of dopamine, a neurotransmitter partially responsible for the production of movement (Centers for Disease Control [CDC], 2013). Approximately 60,000 Americans are diagnosed with PD each year in the United States (PDF, 2012). Men are 1.5 times more likely to have PD than women (Merck Manual, 2012b) and the incidence of PD increases with age, but an estimated 4% of those with PD are diagnosed before the age of 50. One in every 100 people over the age of 60 has PD, and the number of people with PD in the U.S. is expected to double between 2005 and 2030 (Alliance for Aging Research, 2010).

**Symptoms and categories.** The symptoms experienced with PD vary from person to person; however, the primary motor symptoms often include rigidity, resting tremor, bradykinesia, and postural instability, though not all of these are present in every person with PD (CDC, 2013). Rigidity, which is an increased response to muscle stretch that appears in both antagonist and agonist muscle groups, usually appears initially unilaterally and proximally on an upper limb and then spreads to the other extremities and trunk (Goodman & Fuller, 2009).
Resting tremor can begin in the hand, limb or head. Generally, resting tremors can present on one side of the body and progress to both sides. They are present when the extremity is at rest or when the person is stressed (Goodman & Fuller, 2009; Mayo Clinic, 2012b). Bradykinesia reduces a person’s ability to move and can slow down movement. Postural and trunk instability is present and associated with abnormal patterns of postural responses, including excessive antagonist activity that result in co-activation of distal and proximal muscles. Kyphosis is the most common postural deformity in PD. This is characterized by flexion of the neck, trunk, hips and knees (Goodman & Fuller, 2009). Lateral postural stability is compromised by lack of trunk flexibility (Goodman & Fuller, 2009). Postural and trunk instability can lead to an increase in fall risk due to decreased balance (Wressle et al., 2007). Additional characteristics include freezing gait, which is an involuntary termination of movement, an expressionless face due to rigidity of facial muscles, low voice volume, pain, sleep disturbance, mood and cognitive changes (National Parkinson’s Foundation, 2012). PD symptoms are generally classified as tremor-dominant (TD) or akinetic dominant (AK). TD is defined as a sustained dominance of resting tremor over bradykinesia and rigidity, and AK is defined as predominantly bradykinetic motor features with no or only mild resting tremors (Selikhova et al., 2009).

**Treatment.** For both classifications, treatment generally consists of medications or surgery. Medications include dopamine precursors or agonists, anticholinergic drugs and MAO-B inhibitors and are intended to modulate dopamine production or absorption in the body in order to manage symptoms (Mayo Clinic, 2012b). There are a number of side effects with the medications, which can impact functioning. Dopamine agonists, which strive to increase dopamine production, can cause nausea, vomiting, orthostatic hypotension, dyskinesias, confusion, hallucinations, delirium, psychosis and sleepiness or compulsive behaviors such as
hyper-sexuality, gambling and eating (Merck Manual, 2012b; Mayo Clinic, 2012b). Dyskinesia, which is defined as diminished voluntary movement or uncontrolled movement, is an incapacitating side effect of some PD medications. Some people may manage their medications to reduce the presence of dyskinesia by planning activities before or around when the medication peaks because dyskinesia appears when the medication is strongest (PDF, 2012). Anticholinergic drugs, which work to inhibit acetylcholine, can cause dry mouth, urinary retention, constipation, blurred vision (particularly in the elderly), confusion, delirium, and impaired thermoregulation due to decreased sweating (Merck Manual, 2012b). Deep brain stimulation is a surgery that is performed on the thalamus, subthalamic nucleus and globus pallidus to alleviate fluctuations of symptoms, reduce tremors, slowness of movement and gait problems (NINDS, 2012). Possible side effects include stroke, speech problems, breathing problems, seizures and possible paralysis (Mayo Clinic, 2012b).

In addition to pharmacological or surgical interventions, management of symptoms can include diet, exercise and rehabilitation services. Exercise can be an effective complementary treatment for PD by increasing strength, putting underused or rigid muscles through the full range of motion, improving balance and increasing emotional well-being (NINDS, 2012).

Multiple Sclerosis Background

MS is an autoimmune disorder characterized by scar tissue, or sclerotic plaque, forming on the axon and myelin coverings within the central nervous system (Forwell, Copperman, & Hugos, 2008). MS is typically diagnosed between 20 to 40 years of age with women affected slightly more often than men. It is more common in temperate climates (incidence of 1/2000) than tropical climates (1/10,000). It is estimated that 400,000 people are living with MS in the United States (NMMS, 2012).
**Categories.** MS is typically categorized into four types. Relapsing-remitting type is characterized by cycles of flare-up, remission and recovery. The majority of people with MS, approximately 80%, begin with this type (Mayo Clinic, 2012a). Relapsing-remitting MS often develops into the second type of MS, secondary progressive, which involves relapses and recovery but with a steady decline in health (Mayo Clinic, 2012a). Primary progressive MS is the third type of MS and is characterized by a decline in health that is continuous throughout the disease process. The final type, progressive relapsing MS, is characterized by continuous disease progression and flare ups (Forwell et al., 2008).

**Treatment.** Primary medications for MS are not designed to aid in symptom management, and are instead meant to slow the disease course by reducing the immune system’s ability to attack myelin. They include beta interferon, glatiramer, natalizumab and mitoxantrone (Mayo Clinic, 2012a). Side effects of these medications include: liver damage, flushing, shortness of breath, increased risk of fatal neurologic infections, heart problems, and increased risk for blood cancers (Mayo Clinic, 2012a).

Other medications are intended to manage symptoms by reducing spasticity, stiffness, fatigue, depression, pain, and bladder or bowel control problems (Mayo Clinic, 2012a). Treatments specifically for MS exacerbations include corticosteroids and plasma exchange (Mayo Clinic, 2012a). Corticosteroids are used to shorten the length and severity of flare-up but are not indicated for long-term use because they may lead to osteoporosis and hypertension (Mayo Clinic, 2012a) as well as increased susceptibility to infection, diabetes, weight gain, fatigue and ulcers (Merck Manual, 2012a). Plasma exchange is used for those who have not found success with corticosteroids and have sudden, severe attacks. Plasma exchange has not
been shown to have any benefit beyond three months of onset of neurologic symptoms (Mayo Clinic, 2012a).

**Symptoms.** Symptoms are transient in nature and vary greatly from person to person (Burgess, 2010) but include disturbances in vision, bowel and bladder function, sensation and cognition, as well as extreme fatigue, depression, spasticity and intention tremor (NMMS, 2012). Freeman et al. (2012) suggested that people with MS have been found to have reduced trunk stability during arm movements when sitting compared to healthy subjects, which supports the widely held clinical view that many people with MS have reduced core stability (Freeman et al., 2012). A classic feature of MS is heat intolerance, resulting in a worsening of the person’s symptoms with a rise in body temperature (Multiple Sclerosis Association of America [MSAA], 2012). Fatigue is a significant issue for those with MS. In addition, fatigue can be secondary to MS symptoms such as depression or sleep deprivation due to incontinence (NMSS, 2012). In 2012, the National Multiple Sclerosis Society (NMSS) explained that one type of complementary treatment, used in conjunction with conventional treatments, is therapeutic exercise. It is used to improve overall health and mobility, reduce fatigue and stiffness, and improve bowel and bladder function and mood. The researchers state that approximately 75% of people with MS use a form of complementary and alternative medicine, such as exercise (NMMS, 2012).

**Effects on Activities of Daily Living (ADL)**

**Parkinson’s disease.** The motor symptoms of PD have a significant impact on the person’s ability to complete ADL, perform their job and engage in the community. Schenkman et al. (2011) found that those with PD had significantly reduced axial rotation and functional reach, which can have a negative impact on functional activity. In a study by van Nimwegen et al. (2011), the authors indicated that patients with PD were one-third less physically active than
those without PD. The disease decreases the amount of physical activity a person performs including cleaning, housework, shopping, leisure activities and traveling (van Nimwegen et al., 2011). This leads to a change in habits and roles because the person with PD is forced to give up meaningful occupations or rely on others (spouse, children and friends) to complete activities (Wressle et al., 2007). People with PD have also reported decreased balance and memory, fumbling, fatigue, slowness and issues with speech, writing and reading (Wressle et al., 2007).

Multiple sclerosis. The symptoms of MS can have a significant impact on an individual and contribute to limitations in participation in meaningful activities. For example, chronic fatigue is a significant factor when considering the effects of MS on activities. Between 76% and 96% of people with MS experience fatigue, and 28% to 40% list fatigue as their most serious symptom (Finlayson, Impey, Nicole, & Edwards, 1998). In addition to resulting in fatigue, MS can cause gait disturbances, poor coordination, balance problems, memory deficits, spasticity, motor control difficulty and focal muscle weakness (Brodkey, Ben-Zacharia, & Reardon 2011). These symptoms can cause limitations in ADL performance, which can, in turn, have a great impact on personal independence and quality of life (Mansson & Lexell, 2004). People with MS report difficulty with personal self-care, particularly dressing, grooming, and bathing (Lexell et al., 2006), as well as, difficulty with IADL such as community mobility and home management, work and leisure activities (Einarsson, Gottberg, Fredrikson, von Koch, & Holmqvist, 2006).

Role of Exercise and OT in Disease Management

Benefits of exercise for PD or MS management. Exercise has been shown to improve gait speed, stride length and distribution of body weight in people with PD (Fisher et al., 2008). Additionally, exercise has been shown to minimize impairments in gait and reduce fall risk (Herman, Giladi, Gruendlinger, & Hausdorff, 2007) and increase strength and balance (Goodwin
et al., 2008). This can lead to improved quality of life in the areas of physical functioning, social interactions and emotional reactions (Rodrigues de Paula, Teixeira-Salmela, Coelho de Morais Faria, Rocha de Brito, & Cardoso, 2006).

Dalgas and Stenagar (2012) note that exercise was once contraindicated for patients with MS because it was believed that it could cause exacerbations. However, exercise can improve walking speed and upper extremity endurance (Romberg et al., 2004) and has been shown to maintain physical fitness (Petajan & White, 1999) in those with MS. Petajan et al. (1996) found that exercise improved upper and lower strength, depression and anger, as well as increased the ability to participate in home management and leisure activities.

For people with either diagnosis, impairments in trunk control can include weakness and loss of stability and may lead to an increased risk of falls and potential for spinal deformity or contractures (Gillen, 2011). Core stability training is popular for managing the symptoms of MS and PD because it improves balance, trunk flexibility and reduces fall risk. (Freeman, Fox, Gear, & Hough, 2012; King & Horak, 2009). Specifically, Pilates has been recommended for those with MS because of its ability to increase flexibility and strengthening, factors that can cause functional problems for people with MS (Bowling, 2006). Pilates focuses on strength, core stability, flexibility, muscle control, posture and breathing (Wells, Kolt, & Bialocerkowski, 2012). No research was found dealing directly with Pilates and MS or PD; however, exercise is advocated as a form of alternative treatment for both disorders (NINDS, 2012; NMMS, 2012) and is a precise and controlled form of exercise that uses the stabilizing muscles of the body (Kilber, Press, & Sciascia, 2006).

Benefits of OT in MS or PD management. Occupational therapists are experts in adapting the environment to support function and are also highly proficient in activity analysis.
“Occupational therapists are the ultimate adaptors; the profession has flourished because of our ability to incorporate social change and assimilate the challenges presented in a new client populations and treatment settings” (Weinstock-Zlotnick & Hinojosa, 2004, p. 597).

Occupational therapy (OT) interventions are often based on practical application of current motor control theories and the use of a task-oriented approach as a guiding frame of reference (Gillen, 2002). Effective treatment interventions are partly aimed at increasing postural stability and decreasing multi-joint movement with the goal of improving mobility and functional performance for people with neurodegenerative disorder (Gillen, 2002).

Meek et al. (2010) found that occupational therapy (OT) effectively treated clients with PD in the areas of ADL retraining, home safety, mobility, transfers, environmental adaptations and referral for other services. Elliot and Velde (2005) identify the need for the people with disabilities to maintain function and participate in meaningful activities. OT treatment for MS generally consists of providing adaptive equipment, range of motion exercises, splinting, cognitive rehabilitation, energy conservation and fatigue management with the most improvements seen in ADL interventions including toileting, bathing and dressing (Maitra et al., 2010).

Pilates as a Beneficial Occupation for MS or PD

The Pilates method. There are four aspects of Pilates that make the method noteworthy (Kopitkze, 2007). First, it offers a mind-body connection and philosophy towards function in everyday living. Joseph Pilates created his method based on his studies of eastern religion and derived some of the concepts from yoga principles (Siler, 2000). The Pilates method asks participants to be aware of their “powerhouse,” or postural control muscles, in everyday activities in order to increase body awareness during movement (Pilates & Miller, 1998).
Second, the method is performed on specialized Pilates apparatuses that utilizes spring resistance to increase strength and muscle lengthening to improve flexibility. The spring resistance builds strength through eccentric and concentric contraction, and promotes lengthening of muscles (Coleman-Brown & Haley-Kanigel, 2003). The main pieces of apparatuses include the reformer, cadillac and ladder barrel. The design of Joseph Pilates’ apparatuses allows for changing the center of gravity, shortening the length of levers, changing the base of support and instructor assistance (Anderson, 2001).

Third, the entire system of 500 exercises focuses on the trunk or postural muscles. The postural muscles are the basis for all movement in the Pilates method (Anderson & Spector, 2000). The postural muscles are called the “powerhouse” and consist of the trunk muscles that extend from the lower ribcage to the upper pelvis, anterior, lateral and posterior spine (Siler, 2000). In a study by Bird, Hill and Fell (2012) strengthening postural control muscles by participating in Pilates was an effective strategy to improve static and dynamic balance for older adults.

Fourth, Pilates is becoming popular and studios are providing private instruction and group mat classes, making this form of exercise available in many neighborhoods. Lange, Viswanath, Larkam, and Latta (2000) note that there has been a significant increase in the popularity of Pilates-inspired exercises. The increased popularity of Pilates has allowed the industry to be applied in rehabilitation, physical therapy and other medical areas. STOTT Pilates, a large manufacturer of Pilates equipment, exercise videos and teacher training certification programs, offers a “Rehab Program Specialty Track” that includes post rehabilitation conditioning in spinal, pelvic, scapular, and peripheral joint stabilization (STOTT Pilates, 2012).
The Pilates method is an exercise program that offers many benefits. The method appears to be effective in improving flexibility, dynamic balance and muscular endurance in healthy people (Cruz-Ferreira et al., 2011). It is low impact, low weight-bearing, and postural restrictions can be accommodated (Owsley, 2005).

**Benefits of Pilates exercise in disease management with PD or MS.** Using Pilates as an exercise method may specifically benefit disease management for people with PD or MS by providing a tool for an efficient way to strengthen proximal trunk musculature. Proximal strength, in turn, may facilitate distal control and allow for improved use of arms and hands in manipulative and purposeful activities (Case-Smith, Fisher, & Bauer, 1989). The Pilates method allows movements to be broken down into components using springs and changing body orientation to gravity. By successfully evaluating a client’s needs and accessing the desired movement outcome, exercises can be adapted to the appropriate level. (Anderson, 2000).

Pilates apparatuses are used by rehabilitation professionals and are highly adaptable, making them better able to accommodate people with limitations due to neurological deficits (STOTT Pilates, 2012). Pilates provides a promising method for dynamic spinal stabilization exercises and increasing core strength. It teaches full body, multi-plane control and is a disciplined system of exercise that has value in the rehabilitation profession (Coleman-Brown & Haley-Kanigel, 2003).

**Bridging the Gap**

**Pilates can benefit from OT expertise.** The certification requirements to become a Pilates instructor focus on the specific movement modality of Pilates. Certified Pilates instructors are qualified to offer exercise training only within that specific method. The certification requirements are not standardized, and many certification programs vary widely in curriculum.
(STOTT Pilates, 2012). However, most instructors agree on two ideas: inadequate instructor training is an issue in Pilates today, and more comprehensive education is going to be needed in the future (Monroe, 2010). For example, instructors need to understand the biomechanics of human movement and basics of functional fitness to be most effective (Monroe, 2010).

Occupational therapists have a medical background, including knowledge about PD and MS, and are skilled at activity analysis and adaptation of tasks, including exercise. Therefore, occupational therapists are uniquely qualified to teach Pilates instructors how to adapt their studio and exercise regimes for the benefit of clients with PD or MS. The popularity of Pilates has resulted in making Pilates studios a common neighborhood establishment and they represent an untapped resource for accessible programs within an already established exercise method. Combining OT and Pilates could help to fill a void in the management of symptoms for people with PD or MS.

**Purpose Statement**

The purpose of this project was to create a manual that educates Pilates instructors on the disease processes of PD and MS and provides them with strategies that allow them to safely use the Pilates exercise method and specialized apparatuses with these populations.

**Procedures**

To complete this manual, many factors were required. The project began by focusing on adapting Pilates exercise for people with neurodegenerative disorders which included Alzheimer’s disease, Huntington’s disease, Amyotrophic Lateral Sclerosis, MS and PD. Through research on disease process and prevalence, the focus became PD and MS in order to narrow the scope of this project. The steps of the project are listed below.
● A trend assessment was conducted to gather more information on the current trends associated with Pilates and Pilates studios, as well as the certification requirements for Pilates instructors. Trends were also researched concerning current PD and MS research, treatment and the connection to therapeutic exercise.

● PSI was selected. The owner, Lauren Stephen, was contacted to see if she would be interested in being a home for this project. PSI was selected because the facility offers physical therapy and an instructor training program. An hour long interview was conducted with Ms. Stephen to start to determine the studio’s needs.

● An interview with Sharon Jung, a registered nurse who has been running a PD support group in the Tacoma area for 10 years, was conducted to determine the current use of exercise in PD treatment. Additionally, one PD support group was attended to inform on the lived experience of having PD and what concerns and strategies people with PD currently have. Due to time constraints, a support group for MS was not attended.

● A needs assessment was conducted to determine the best approach to creating a manual and implementing this project. Current research was reviewed, and discussion with the owner of the studio revealed that a gap in understanding existed on how to adapt the Pilates method to create an accessible Pilates lesson for clients with PD or MS.

● The needs assessment concluded that the Pilates instructors would benefit from education on the disease process and symptoms for both PD and MS as well as education on ways in which to adapt the Pilates exercise method.

● A project proposal, which included an outline of topics and sections of the manual was created and submitted to the project chair. After approval, these sections of the manual were created (described below).
• The owner of PSI reviewed and provided feedback on the manual. She provided feedback on clarity of the manual as well as input on the adaptations of the exercises in the Pilates method.

• A pretest survey was created to assess the Pilates instructor knowledge of the disease process and symptoms for both PD and MS. The pretest was given before the manual was delivered.

• A post-test survey was given after the manual was delivered to measure the effect of the information provided in the manual.

In creating similar projects in the future, it will be important to consider the specific wants and needs of the program home. The livelihood of the business and its current clientele must be taken into account when considering which adaptations and modifications are appropriate. Additionally, the functional mobility of the clients would need to be considered. Clients who require assistance in and out of a wheelchair may not be appropriate for this kind of program because Pilates instructors are not educated on safe handling techniques and this could present danger to them and the clients.

Specific skills and knowledge are vital to creating this type of project including when considering its viability and sustainability. These include: knowledge of Pilates method and philosophy, the marketing and culture of the organization, experience and knowledge of the targeted disease (including pathology, etiology, symptoms, side effects, research, statistics), knowledge of basic occupational therapy principles (including activity analysis, adaptation skills, the Occupational Therapy Practice Framework, occupational models, therapeutic use of self), Additionally, knowledge of anatomy and physiology, leadership and teaching skills, graphic design/layout for manual development, organization skills, interpersonal skills, writing skills,
and knowledge on funding sources is essential. The necessary materials and equipment for this project include access to Pilates equipment and apparatuses, use of computer design program (such as Microsoft Publisher) and the resources to develop a bound manual.

**Final Product**

The manual, called *Pilates for Parkinson’s Disease and Multiple Sclerosis*, has three main sections. One section is dedicated to MS and one to PD and each has with nine subsections, described below. A third section is dedicated to appendices.

The first section, on Parkinson’s disease, and the second section, on multiple sclerosis, follow the same format with nine subsections each. The first subsection is titled *Background* and includes information about the cause, prevalence and incidence of the disease. The second subsection is titled *Symptoms* and gives detailed information about each of the symptoms associated with the disease. *Treatment* is the third subsection and discusses the different types of medical treatment available for the disease. The fourth subsection is *Medication & Side Effects* and includes the different types of medications used to treat these diseases, what their intended effect is and side effects that are common and may affect a Pilates session. The fifth subsection is *Exercise Guidelines* and provides information from the National Center for Health, Physical Activity and Disability on the recommended type and amount of exercise for each diagnosis. Subsection six is *Precautions while Teaching* and includes a list of issues that may arise during exercise and possible solutions and accommodations. The seventh subsection is *Adaptations* and provides a classification system (Grade I, II and III) created to categorize the client based on ability so that the instructor can decide which exercises are the most appropriate. Subsection eight is *Pilates Based Exercises* and provides specific exercises for each symptom associated with MS and PD as well as modifications that can be made based on the client’s ability. The
ninth subsection is *Beneficial Apparatuses* and provides considerations and exercises for each apparatus.

The appendix section provides intake forms to determine what symptoms and difficulties the client is experiencing as well as a glossary of terms. An electronic copy of the manual was provided as well.

**Outcome**

The overall goal of this project was to increase the participation of people with MS and PD in Pilates classes. The desired outcome for this project was to educate the Pilates instructors employed at PSI on the common characteristics of these disorders and provide modification techniques to support changes in motor function, cognition and sensation of client’s with PD or MS. The owner did not respond to the request to take a post-test, however, based on conversations during review of the first copy of the manual, Lauren expressed satisfaction with the product and desire to share this information with instructors.

**Goal 1:**

Upon reading the Symptoms subsections of the manual, instructors at Pilates Seattle International will be educated on the physical, cognitive and sensory limitations that are present for people with Parkinson’s disease or multiple sclerosis.

**Objective 1:** After instructors have read the Symptoms subsections of the manual, they will be able to define two physical symptoms associated with both PD and MS.

**Objective 2:** After instructors have read the Symptoms subsections of the manual, they will be able to recognize one cognitive symptoms associate with both PD and MS.
Objective 3: After instructors have read the Symptoms subsections of the manual, they will be able to identify two ways the physical, cognitive and sensory symptoms may affect participation in Pilates exercises.

Goal 2:
Upon reading Medications and Side Effects subsections of the manual, instructors at Pilates Seattle International will be educated on the typical side effects of medications that occur in people with Parkinson’s disease (PD) and multiple sclerosis (MS).

Objective 1: After instructors have read the Medications and Side Effects subsections of the manual, they will be able to describe two side effects associated with the medications for both PD and MS.

Objective 2: After instructors have read the Medications and Side Effects subsections of the manual, they will be able to recognize two medication side effects that may affect function in both PD and MS.

Goal 3:
Upon reading the Adaptations, Pilates Based Exercises and Beneficial Adaptation subsections of the manual, instructors will be able to identify specific adaptations to apply to the Pilates method to individualize the Pilates lesson for a person with Parkinson’s disease or multiple sclerosis.

Objective 1: After instructors have read Adaptations, Pilates Based Exercises and Beneficial Adaptation subsections of the manual, they will identify five modifications that can be utilized while working on the “reformer” Pilates apparatus in order to increase participation in the Pilates occupation.

Objective 2: After instructors have read Adaptations, Pilates Based Exercises and Beneficial Adaptation subsections of the manual, they will be identify five modifications that can be
utilized while working on the “Cadillac” Pilates apparatus order to increase participation in the Pilates occupation.

**Objective 3:** After instructors have read Adaptations, Pilates Based Exercises and Beneficial Adaptation subsections of the manual, they will identify five modifications that can be utilized when instructing a client with Parkinson’s disease or multiple sclerosis while working with the “mat” work order to increase participation in the Pilates occupation.

The method to measure the effects of this program included a pretest with 10 questions focusing on PD and MS symptoms as well as possible adaptations to the Pilates program. Eight instructors returned the pretest form which is a 72% response rate. Although the instructors were instructed to “take your best guess” if they were unsure of an answer, many of the questions were left blank, specifically questions regarding cognitive symptoms, emotional symptoms and medication side effects. The instructors scored the highest (between 50 and 75%) when asked to choose the correct common symptom of MS or PD. They scored between 0 and 25% when asked to choose the correct motor symptom. This indicates that many of the instructors were aware of common symptoms of MS and PD, heat intolerance and flat affect respectively, but less aware of the motor, cognitive and emotional symptoms associated with each diagnosis and what effect prescribed medications have on the client’s ability to perform the Pilates program. Interestingly, seven out of eight instructors were able to provide possible adaptations that could be made to the Pilates program including: “slow, smooth movements,” “cool environment,” “stretching exercises,” and “slower directions.” Most of their answers were appropriate but were broad suggestions not specifically targeted to reducing certain symptoms to increase the effectiveness of the Pilates program.
Implications for OT

This program was developed using the Model of Human Occupation (MOHO) as a guide. MOHO seeks to describe the inter-related phenomena inherent in occupations. It states that many factors, including physical abilities, contribute to engagement in activities of everyday living and meaningful occupations. This model states that a person’s inner characteristics and external environment are linked together into a dynamic whole (Kielhofner, Forsyth, Kramer, Melton, & Dobson, 2009). People pursue occupations because they want to explore and master their environment. Volition (a person’s motivation), habituation (a person’s habits, roles and routines) and performance capacity (the ability to perform an occupation) are interacting elements that exist in a recursive process or circular nature. These phenomena influence the extent in which occupations are established or reinforced. These elements also contribute to people’s sense of who they are and what roles they identify with, thus establishing their occupational identity. This is supported by occupational competence, which is the degree to which people can achieve and sustain their occupational identity. They are often negatively affected by disability causing disruptions in performance capacity. MOHO is concerned with the extent to which occupations establish and reinforce identity. This basic assumption proposes that positive participation in occupations can change abilities, thoughts and motivations. The model is ultimately concerned with the extent to which individuals can participate in life occupations. MOHO conceptualizes OT as a process in which practitioners support client engagement in occupations in order to promote occupational competency by creating an occupational identity using volition, habituation and performance capacity (Kielhofner et al, 2009).

The model provided a strong foundation of concepts related to the person. Examining the individual’s internal environment or motivations served as a useful tool in developing this
project. It was especially important to address the personal factors involved in these diseases when providing adaptations and modifications. MOHO provided a context for why people choose to explore and master an activity and how personal causation, values and interests, habits and roles, and performance capacity influence this. These concepts may provide the instructors at PSI an opportunity to understand the lived experience of managing a chronic disorder and allow the instructors an opportunity to tailor a Pilates lesson that provides a positive experience. This facilitates participation and mastery of the activity of Pilates. MOHO stresses the importance of also paying attention to the experience of performance and, in particular, the experience of having limitations in performance (Kielhofner et al, 2009).

The overarching goal of OT, “supporting health and participation in life through engagement in occupation,” (American Occupational Therapy Association [AOTA], p. 626, 2008) encompasses all areas of occupations that people do in daily life including but not limited to: ADL, IADL, rest and sleep, education, work, play, leisure and social participation (AOTA, 2008). Creating a positive relationship between occupation and health is essential in clients’ abilities to engage in the occupations necessary to their life. OT does not just focus on individuals as clients but also on organizations and populations within a community by consulting on modifications to the environment to increase accessibility, educating on health and occupation and empowering clients to obtain resources. Through knowledge in activity analysis, adaptation techniques and the complex and interdependent nature of performing tasks, occupational therapists support clients in performing the occupations they want and need to do (AOTA, 2008).

This project focused on increasing the client’s ability to perform the instrumental activity of daily living (IADL) of health maintenance through participation in exercise. By developing
concepts about movement and its relation to their body’s individual needs, participants may develop new habits and routines that promote better physical function. Promoting these healthy performance patterns may cause an improvement in body functions and increase function in health maintenance. This Pilates program demands that the participants engage their physical bodies, use sequencing and timing skills and attend to the space and objects used in order to perform the required actions.

In order to promote participation, the occupation of Pilates must be accessible. It is a prevalent form of exercise found in most cities with numerous private studios and classes available throughout the day. Due to its availability, Pilates is a resource that could be utilized by people with MS and PD in maintaining health. It behooves the profession of OT to explore a variety of non-traditional settings and it is the responsibility of all occupational therapists to advocate for the profession by identifying areas that can benefit from activity analysis, adaptive techniques and neurologic disorders and provide quality service.

**Limitations**

One limitation for this project is the difficulty in communicating with the Pilates instructors at PSI directly. They are autonomous within the organization and given the freedom to come and go as needed, which often made it difficult to ensure that information was accessible to them. Using the staff break room as a place to leave important information was more effective than communicating with instructors via email. Due to the difficulty in communicating with instructors, as well as limited access to people with MS and PD, this manual was not able to be piloted with people with PD or MS. Due to time constraints, the home was only in possession of the manual for one week, therefore, data on the efficacy of the manual was not collected. This
would have given further insight into useful exercises and adaptations specific to these populations.

**Future Steps and Sustainability**

**Sustainability**

To enhance the sustainability of the project, the manual was made to be easily accessible, concise and designed for quick reference. The manual was given to Lauren Stephen, owner/director of PSI and be made easily available to all instructors. There was an electronic version of the manual provided as well, again to ensure that the manual was readily available to instructors.

**Future Steps**

Lauren Stephen has expressed an interest in having an in-service for the apprentice instructors during the October 2013 instructor training seminar. Future steps for this project could include the creation of an in-service to be presented to the apprentice instructors during their seminars or for certified instructors who would like to gain more knowledge on the diseases. Two amendments could be created for the manual to include a list of additional websites and resources for PD and MS for instructors to reference for additional information, as well as a section that allows instructors to add techniques they find helpful through their experience. Other populations that could be addressed in future projects include Amyotrophic Lateral Sclerosis, adults with cerebral palsy and fibromyalgia.
References


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