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Occupational therapy and multiple sclerosis a study to determine use and perceived need of services

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Occupational Therapy and Multiple Sclerosis:
A Study to Determine Use and Perceived Need of Services

A Master's Thesis presented to the Faculty of the Graduate Program in Occupational Therapy
Ithaca College

In partial fulfillment of the requirements for the degree Master of Science

By
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August 2013

Ithaca College
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CERTIFICATE OF APPROVAL

.....

This is to certify that the thesis of

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Submitted in partial fulfillment of the requirements for the degree of Master of Science in the Department of Occupational Therapy, School of Health Sciences and Human Performance at Ithaca College has been approved.

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Abstract

Multiple sclerosis (MS) is a chronic, degenerative disease that attacks the central nervous system (CNS). The disease is disabling, progressive, and is thought to be an autoimmune disease. Nerves in the CNS are damaged or destroyed. The irreversible damage to the nerves causes people with MS (PwMS) to experience a wide variety of symptoms and limitations in their functional abilities and a decreased quality of life (QOL).

Researchers have shown that occupational therapy (OT) is beneficial for PwMS at all stages of the disease process by improving fatigue, self-efficacy, functional abilities, occupational participation and performance, and QOL. What is unknown is the number of adults with MS in the United States who use OT services as well as the perceived need for OT services among PwMS. The purposes of this study were to determine the number of PwMS across the lifespan, in the United States, and within a given sample who use OT services, to determine the perceived need for OT services among PwMS, and to determine reasons why PwMS might not use OT services including the effect of quality of life.

Forty-five PwMS responded to an anonymous, researcher designed survey either online or through the mail. Variables and data for quantitative and open-ended responses were entered into SPSS. Frequency distributions and cross-tabulation tables were created to summarize results for quantitative questions, and categories for the open-ended responses were formed according to common themes.

The majority of PwMS who responded to the survey were not using OT services as a part of their treatment for MS for reasons including a lack of knowledge of OT, limited or no health insurance coverage, and lack of referral for OT treatment. Many PwMS who have used OT in the past as a part of their treatment for MS felt that OT was helpful for them.

The results of the study suggest there is a marketing dilemma for the profession of occupational therapy. There is a strong need for occupational therapists to market, promote, and advocate for the profession of OT to PwMS and to members of MS treatment teams.

Running head: MULTIPLE SCLEROSIS

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Chapter 1: Introduction

Background

Multiple sclerosis.

Multiple sclerosis (MS) is a chronic, degenerative disease that attacks the central nervous system (CNS), which includes the brain, spinal cord, and optic nerves (Mayo Clinic, 2012a; National Multiple Sclerosis Society [NMSS], 2012). Multiple sclerosis is disabling, progressive, and thought to be an autoimmune disease, meaning that the body's own immune system attacks the nerves in the CNS (Mayo Clinic, 2012a; NMSS, 2012). The myelin, a fatty and protein-rich layer of insulation surrounding a nerve fiber, is destroyed forming scar tissue; the nerve itself can also be damaged or destroyed, and the process is irreversible (Mayo Clinic, 2012a; NMSS, 2012). When the myelin or the nerve is damaged or destroyed, the nerve impulses that travel to and from the brain and the spinal cord are interrupted, causing individuals with MS to experience a wide variety of symptoms (NMSS, 2012).

People with MS (PwMS) can face several limitations in their functional abilities (Keller & Stone, 2009; Mayo Clinic, 2012a; NMSS, 2012). Most PwMS will experience at least one type of occupational challenge that might be helped by occupational therapy services (Finlayson, Dahl Garcia, & Cho, 2008). A person with MS might experience difficulties with fine and gross motor skills (Keller & Stone, 2009). Vision problems and sensitivity to light are also common problems (NMSS, 2012). Many PwMS also experience problems with pain, headaches, memory, concentration, speech, fatigue, and bowel and bladder control (Mayo Clinic, 2012a; NMSS, 2012). All of the symptoms of MS affect functioning in ADLs and might lead to a decreased quality of life (American Occupational Therapy Association [AOTA], 2008). Since PwMS are no longer able to participate in life in ways that are normal for them, they experience

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a lack in social participation and might have feelings of worthlessness and depression (Keller & Stone, 2009; Mayo Clinic, 2012a).

Multiple sclerosis treatment and rehabilitation.

Due to the wide variety of symptoms and functional limitations, and due to the unpredictable and progressive nature of the disease, interventions for MS should be provided by a multidisciplinary team (Holland, Schneider, Rapp, & Kalb, 2011; Kesselring & Beer, 2005; Mayo Clinic, 2012b; NMSS, 2012; Smith, Costello, Halper, & Harris, 2010). The main treatment team should include the person's primary care physician, a neurologist, occupational therapists, physical therapists, speech and language pathologists, nurses, social workers, pharmacists, and other physicians as needed (Holland et al., 2011; Kesselring & Beer, 2005; Mayo Clinic, 2012b; NMSS, 2012; Smith et al., 2010). Other possible members of the treatment team include recreational therapists, nutritionists, psychologists, and clergymen (Holland et al., 2011; Kesselring & Beer, 2005; Mayo Clinic, 2012b; NMSS, 2012; Smith et al., 2010).

People with MS need rehabilitation at all stages of the disease; rehabilitation is most necessary after an exacerbation and during advanced stages of the disease (Kesselring & Beer, 2005; NMSS, 2012; Smith et al., 2010; Thompson, 2001). Researchers have shown that occupational therapy is effective for increasing quality of life (QOL) and for decreasing functional limitations in the everyday life of PwMS, and can be provided in an inpatient, outpatient, or community setting (Holland et al., 2011; Kesselring & Beer, 2005; Smith et al., 2010; Thompson, 2001). The benefits of rehabilitation often last for six to nine months after rehabilitation has been stopped due to the relapsing and progressive nature of the disease (Kesselring & Beer, 2005; Smith et al., 2010; Thompson, 2001). Given that the benefits provided by rehabilitation are temporary, it is important that rehabilitation services are available

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to PwMS whenever they might be needed (Kesselring & Beer, 2005; Smith et al., 2010; Thompson, 2001).

PwMS experience a gradual decline in function and become unable to participate in activities (Boeijea, Duijnsteeb, Gryndonckb, & Pool, 2002). Multiple sclerosis can result in severe disability, and PwMS often lose their independence, become a burden on their caregivers, and move into a nursing home (Finlayson, 2004). PwMS often move into nursing homes at a younger age, and some PwMS can spend more than 20 years of their lives in a nursing home, leading to an increase in depression (Finlayson, 2004; Northrop & Frankel, 2009). PwMS who are no longer able to participate in desirable occupations and who are unable to stay in the home lose their roles, lose their identity, and lose their sense of self (Boeijea et al., 2002).

Occupational therapy theories in treatment.

Occupational Therapy (OT) is a scientific discipline in which practitioners provide help to people whose everyday activities in life are disrupted by illness, injury, developmental problems, the aging process, mental illness, or emotional problems (Blesedell Crepeau, Boyt Schell, & Cohn, 2009). The occupational therapist uses evaluation, assessment, OT diagnosis, planning, and intervention to assist individuals in achieving an independent, productive, and satisfying lifestyle doing the day-to-day activities that the individual wishes to do (Blesedell Crepeau et al., 2009). A person with limitations in occupational skills can face several functional difficulties in performing activities of daily living (ADLs) and in participating in life in ways that are meaningful (AOTA, 2008).

Occupational therapists incorporate OT theories into treating PwMS, and one such theory is the model of human occupation. The model of human occupation (MOHO) focuses on the client's motivation and volition, on performance of the client's desired occupations, and on how

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the environment affects the client's occupational participation and ability to adapt (Kielhofner, 2009). Allowing the client to engage in desired activities, instilling a sense of self-efficacy within the client, and providing the client with the skills necessary to independently engage in occupations and life roles suggests MOHO is a model that might be used by many therapists to treat PwMS (Kielhofner, 2009).

Theory helps guide occupational therapists in their practice and interventions (Trombly Latham, 2008). Theories are used as "a way of conceptualizing the interrelatedness of the person, and his or her environments, occupations, and quality of life" (Trombly Latham, 2008). MOHO is a theoretical model that therapists can use when treating PwMS to help identify problems, create goals, and provide treatment (Kielhofner, 2009).

Research Problem

Through several studies researchers have provided evidence that occupational therapy services provide positive and effective treatment methods to improve fatigue, self-efficacy, functional abilities, occupational participation and performance, and QOL in PwMS (Baker & Tickle-Degnen, 2001; Dalgas et al., 2010; Maitra et al., 2010; Mathiowetz, Matuska, & Murphy, 2001; Rietberg, Brooks, Uitdehaag, & Kwakkel, 2006; Vantage, Gilbertson, & Mathiowetz, 2003). Studies have been performed to determine the use of OT services among the aging population with MS, but none to determine the number of PwMS of all ages in the United States who use OT services; since PwMS need rehabilitation at all stages of the disease it is important to know if and when services are being utilized (Finlayson et al., 2008; Kesselring & Beer, 2005). There is little research involving the perceived need for OT services among PwMS, and there is little research to determine reasons why PwMS might not use OT services.

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Rationale and Study Purpose

Without OT intervention as part of a multidisciplinary treatment, PwMS might be placed in a nursing home or might become homebound at a younger age, which might then decrease QOL and increase overall treatment cost (Northrop & Frankel, 2009). PwMS might experience a decrease in function, in participation, and in safety, and an increase in limitations while performing activities (Keller & Stone, 2009). Given that the symptoms of MS can cause much functional impairment, it is important for PwMS to begin OT treatment in a timely manner (Mosley, Lee, Hughes, & Chatto, 2004). People with MS who do not receive OT services as a part of their treatment within a timely manner might experience greater difficulty regaining functional abilities (Mosley et al., 2004). The purposes of this study were to determine the number of PwMS across the lifespan, in the United States, and within a given sample who use OT services, to determine the perceived need for OT services among PwMS, and to determine perceived barriers to obtaining OT services including the effect of quality of life.

Research Questions

Based on the reviewed literature, the following research questions were formed:

1. To what extent do PwMS across the lifespan living in the United States use occupational therapy services as a part of their MS treatment?
2. Do PwMS believe that they have benefited or might benefit from occupational therapy services?
3. What are the factors that influence reasons why PwMS might not use occupational therapy services?
4. How do PwMS rate their quality of life on the Global Quality of Life Scale?

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Answering these questions will provide useful information in occupational therapy practice about the need for education about OT services to insurers, PwMS, and referral sources. It has been shown to be more cost effective to get OT involved earlier rather than later in the disease process (Asche, Singer, Jhaveri, Chung, & Miller, 2010; Kobelt, Berg, Atherley, Hadjimichael, & Jönsson, 2006; McCrone, Heslin, Knapp, Bull, & Thompson, 2008; O'Brien, Ward, Patrick, & Caro, 2003; Zwibel, 2009). Early intervention, including energy conservation and joint protection education, might help prevent many of the disabling symptoms that commonly occur throughout the disease process (Asche et al., 2010; Kobelt et al., 2006; McCrone et al., 2008; O'Brien et al., 2003; Zwibel, 2009). As most of the permanent disabilities related to MS occur early in the disease process, early intervention can help restore maximum function and reduce any residual deficits (Asche et al., 2010; Kobelt et al., 2006; McCrone et al., 2008; O'Brien et al., 2003; Zwibel, 2009). Early intervention for PWMS will not occur unless clients, insurers, and referrers have an accurate understanding of the potential benefits of OT services. The research questions target the conceptions or misconceptions PwMS have about OT and the barriers to access of OT services. Insight might be gained into ways that occupational therapists need to be better advocates for PwMS in order to ensure adequate and accessible treatment (e.g., referrals, insurance companies, OT availability, family members/caregivers) to help PwMS remain independent for longer.

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Chapter 2: Literature Review

Multiple Sclerosis

The National Institutes of Health (2013) describe MS as a disease of the nervous system that damages the myelin sheaths in the brain and in the spinal cord. Without the myelin sheath the nerve is left unprotected, the nerve is damaged, and neural transmissions between the brain and the body are disrupted (National Institutes of Health [NIH], 2013). Nerve damage and disruption cause common symptoms of MS such as numbness, muscle weakness, and visual, balance, and coordination problems (NIH, 2013).

Multiple sclerosis is usually diagnosed between the ages of 20 and 50, and affects twice as many women as it does men (NMSS, 2012). Worldwide, MS affects more than 2.1 million people (NMSS, 2012). MS has been diagnosed in approximately 400,000 people in the United States, with more than 200 new diagnoses every week, but symptoms of MS can be similar to many other illnesses or diseases, and disease diagnosis takes a long time or can go unrecognized (NMSS, 2012). The Center for Disease Control and Prevention does not require physicians in the United States to report new cases of MS because it is not considered communicable or a threat to public health (NIH, 2011; Multiple Sclerosis Foundation [MSF], 2009). For these reasons, the numbers are only estimates and might be on the low side (MSF, 2009).

Multiple sclerosis can range from mild to moderate to severe, and the NMSS (2012) provides information describing the four different courses of disease progression. The most common course, affecting 85% of those diagnosed with the disease, is called relapsing-remitting MS (NMSS, 2012). Relapsing-remitting MS is characterized by definable periods of neurological decline, followed by periods of partial or complete remission periods, in which disease progression stops (NMSS, 2012). The second form of MS, affecting approximately 10%

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of MS patients, is primary-progressive MS characterized by slowly worsening neurological decline (NMSS, 2012). The rate of progression may vary over time, there may be occasional increases in progression, or there may be temporary improvements, but there are no defined periods of exacerbation or remission (NMSS, 2012).

A third course of disease progression, secondary-progressive MS, follows an initial period of relapsing-remitting MS, but is characterized by a steady worsening of neurological functioning with or without exacerbations or remissions (NMSS, 2012). Prior to the introduction of disease modifying medications, about 50% of people with relapsing-remitting MS were diagnosed with secondary-progressive MS within 10 years of the initial diagnosis. There are no long-term data available to determine if the transition from relapsing-remitting MS to secondary-progressive MS is significantly delayed by treatments (NMSS, 2012). The fourth course of disease progression, occurring in about five percent of MS patients, is progressive-relapsing MS (NMSS, 2012). Progressive-relapsing MS steadily gets worse, with clear attacks of worse neurological functioning and no periods of remission (NMSS, 2012).

There is no cure for MS (NMSS, 2012). The life-span of a person with MS is usually not affected by the disease, though some might die from secondary infections or complications, such as an undiagnosed urinary tract infection or loss of function of the muscles of the respiratory system (Keller & Stone, 2009; Rasova et al., 2010). Since there is usually no loss in longevity, PwMS continue to lose neurological function for life, making it important for PwMS to manage their symptoms and limitations in occupational performance and participation (Finlayson et al., 2008; Rasova et al., 2010).

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Symptoms and limitations.

Symptoms of MS vary widely, depending on which nerves are affected. Mild to extreme fatigue is one of the most common symptoms, causing the person to take several breaks and sometimes making it difficult to get out of bed (Keller & Stone, 2009; Kesselring & Beer, 2005). Trembling, spasticity, tetany, numbness, weakness, and eventually paralysis in the hands, arms, feet, and legs can occur making it difficult to perform simple tasks such as writing, walking, brushing teeth, or using a can opener (Keller & Stone, 2009; Kesselring & Beer, 2005). People with MS could experience problems with vision, such as blurred vision, double vision, sensitivity to light, and blindness, making it difficult to function in the home, workplace, social situations, or while driving (Kesselring & Beer, 2005; NMSS, 2012). Pain, severe headaches, and speech and swallowing disorders are common (Kesselring & Beer, 2005; NMSS, 2012). Dizziness, vertigo, and balance and coordination problems cause difficulties performing most activities of daily living, including walking, driving, and eating (Kesselring & Beer, 2005; NMSS, 2012). Cognitive function might be affected causing difficulties in concentration, memory, and speech (Kesselring & Beer, 2005; NMSS, 2012). Bowel, bladder, and sexual dysfunction may also result, usually with longer progression of the disease (Kesselring & Beer, 2005; NMSS, 2012). Any of the symptoms of MS limit normal, everyday, functional activity and could lead to a decreased QOL (Keller & Stone, 2009). People with MS might lose the ability to participate in life in ways they normally would at any time during disease progression (Keller & Stone, 2009). Feelings of embarrassment, worthlessness, and the inability to perform simple tasks could cause problems in the home and at work, and might cause a lack of social participation (Keller & Stone, 2009). Depression is a common result (Keller & Stone, 2009; NMSS, 2012).

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Treatment options.

Treatments for MS include medications, physical therapy, speech therapy, and occupational therapy (NMSS, 2012). Multiple sclerosis treatment should include a multidisciplinary approach in order to address all the different aspects of the disease (Holland et al., 2011; Kesselring & Beer, 2005; Mayo Clinic, 2012b; NMSS, 2012; Smith et al., 2010).

Medications.

Medications are available to treat the symptoms and exacerbations of the disease, and to try to slow the progression of the disease (NMSS, 2012). Corticosteroids are used to reduce inflammation, ease symptoms, and shorten acute attacks. Disease-modifying drugs for relapsing-remitting MS and secondary-progressive MS are used to slow the rate and extent of MS, and are often injected medications (Keller & Stone, 2009; NMSS, 2012). Betaseron, Avonex, Rebif, Copaxone, Tysabri, Novantrone, Aubagio, Extavia, Gilenya, and Tecfidera are the disease-modifying drugs approved by the Food and Drug Administration to treat PwMS (NMSS, 2013). When used in combination, corticosteroids and disease-modifying drugs help to improve QOL in PwMS (NMSS, 2012). Though people using disease-modifying drugs might experience side effects such as flu-like symptoms and thinning hair, the medications are still recommended immediately following diagnosis as the best way to limit disease progression (NMSS, 2013).

Physical therapy for multiple sclerosis.

According to the Mayo Clinic (2012b), physical therapy can be used to increase mobility, physical fitness, and muscle strength and control. Personalized exercise programs and aerobic exercise might be used to help people regain mobility and to regain muscle strength and control after exacerbations, and might help in fatigue reduction and increased endurance (Keller &

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Stone, 2009; Mayo Clinic, 2012b). Physical therapists can also provide PwMS with mobility aids and teach PwMS how to use them properly (Mayo Clinic, 2012b; NMSS, 2012).

Speech therapy for multiple sclerosis.

Though aphagia, or difficulty swallowing, in MS is rare, dysarthria, or difficulty articulating words, is much more common, making speech therapy an important part of treatment (Kesselring & Beer, 2005). Retraining a person to swallow or training a person to swallow using reflexes will help to reduce choking and aspiration risks (Kesselring & Beer, 2005). Training the person with dysarthria to articulate will help with language skills, communication, and socialization (Kesselring & Beer, 2005). Respiratory training will help to improve articulation, increase respiratory function, and strengthen the cough reflex in order to increase language skills, decrease fatigue, and reduce the risk of pulmonary infections (Kesselring & Beer, 2005).

Occupational therapy for multiple sclerosis.

The primary purpose of OT for PwMS is to optimize functional capacities and to enable participation in activities that they need or wish to do throughout their daily lives (Steultjens et al., 2004). Occupational therapy intervention focuses on problems that are causing limitations in occupational performance and participation such as strength, coordination, spasticity and range of motion (ROM), loss of sensation, fine motor control of the upper extremities, cognition, depression, fatigue, and pain management (Keller & Stone, 2009; Steultjens et al., 2004). Occupational therapy interventions often include training clients to use selected assistive devices that might help them during everyday activities such as electronic personal aids, electronic can openers, canes, wheelchairs, and wrist splints (Keller & Stone, 2009; Steultjens et al., 2004). Exercise therapy is used to increase energy, muscle power function, exercise tolerance, and mobility-related activities (Rietberg et al., 2006). Traveling to a client's home or workplace to

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assess and make changes to the environment is common, and might include rearranging furniture for safer maneuvering throughout a room, or changing lighting situations in rooms to reduce fatigue and headaches caused by light sensitivity (Stachowiak, 2009). Providing PwMS and their families with counseling and education about the disease, disease treatments, and safety awareness is essential (Keller & Stone, 2009; Steultjens et al., 2004). Decreasing and preventing fatigue by teaching energy conservation techniques, time management, and efficient task performance are common foci of OT (Mathiowetz, Finlayson, Matuska, Chen, & Luo, 2005). Teaching efficient body mechanics and educating PwMS and their families about rest, exercise, proper use of the body, and task delegation is also a common focus for OT intervention (Mathiowetz et al., 2005). Overall the goal of OT for PwMS is to enable them to function as productively and independently as possible in all aspects and roles of their daily lives that they deem important (Finlayson et al., 2008; Keller & Stone, 2009; Steultjens et al., 2004).

The Model of Human Occupation

The science and practice of occupational therapy is guided by theory, and the model of human occupation is a theory that is applicable when treating PwMS. The model of human occupation (MOHO) was designed by Gary Kielhofner to enable occupational therapists to help clients maximize their functional abilities and adapt to their environment through participation in valued and motivating activities (Kielhofner, 2009). MOHO can be used to address a wide variety of impairments that clients might face, and it can be used during any stage of life (Kielhofner, 2009). MOHO can be used with people who have disabilities or with people who do not have disabilities and are receiving wellness services (Kielhofner, 2009). Motor, cognitive, and sensory impairments, a lack of motivation, a lack of positive involvement in

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routines and life roles, and problems with performance of tasks create difficulties in everyday life (Kielhofner, 2009).

When a person performs an activity or task, Kielhofner (2009) suggested occupational therapists examine three levels of doing. Occupational participation is a person's engagement in activities that are necessary or that are desired such as working at a job, going to school, swimming, playing a board game, or caring for oneself or others (Kielhofner, 2009).

Occupational performance is how a person actually and purposefully does an activity or task (Kielhofner, 2009). Skills are purposeful actions that a person uses to perform an activity or task including how a person moves or uses objects, how a person sequences steps or selects objects for use, and how a person communicates and interacts with other people (Kielhofner, 2009). A person who loses the skills to perform a task or activity might stop engaging in necessary, desired, and meaningful occupations which will affect physical and mental health (Kielhofner, 2009).

Assumptions of MOHO.

Included in MOHO are three main assumptions that concern participation and adaptation in everyday life activities (Kielhofner, 2009). The first assumption is that the environment influences a person's behavior, and that a person's identity and personal characteristics are influenced by interaction with the environment (Kielhofner, 2009). The second assumption is that activities in which a person chooses to engage are framed by personal characteristics and by the environment (Kielhofner, 2009). The third assumption is that personal characteristics, such as motives, are maintained and changed through a person's engagement in daily activities (Kielhofner, 2009). It is also conceptualized in MOHO that the elements of volition, habituation,

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and performance capacity all work together to form a person's inner characteristics (Kielhofner, 2009).

The concept of volition.

Kielhofner (2009) stated that "volition is the process by which people are motivated toward and choose the activities they do" (p. 150). Volition is formed by motivation to engage in activities, by life experiences, and by thoughts and feelings (Kielhofner, 2009). Thoughts and feelings occur in a cycle and include anticipating engaging in activities, choosing what to do, emotionally feeling what one does, and internally reflecting on the experience to decide how well something was performed or how enjoyable the experience was (Kielhofner, 2009). Personal causation, values, and interests are the thoughts and feelings that form volition (Kielhofner, 2009).

Personal causation is how people feel about the way they perform everyday activities including feelings of confidence or anxiety, knowing their own strengths and weaknesses, and how well they feel they performed a task (Kielhofner, 2009). Values are one's "beliefs and commitments about what is good, right, and important to do" (Kielhofner, 2009, p. 150). Values also include how a person feels an activity should be performed and what activities a person feels are worthy of commitment (Kielhofner, 2009). Engaging in activities that people value allows them to experience a sense of self-worth and a sense of belonging (Kielhofner, 2009). Interests develop from a person's enjoyment of an experience and from the experiences that are available to a person (Kielhofner, 2009).

Volition has a great impact on how people choose what they want to do, whether people see activities in the environment as challenges or as opportunities, and how people interpret experiences (Kielhofner, 2009). People who experience functional limitations or impairments

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might lose the ability to perform activities they value, might feel they perform everyday activities ineffectively, and might lose interest in activities they once enjoyed (Kielhofner, 2009). “When volition is negatively impacted, people may make decisions that worsen or amplify the impact of their impairments” (Kielhofner, 2009, p. 150) because they stop participating in activities that might increase their confidence and their functional abilities. When people stop participating in activities they begin to lose the skills necessary to perform those activities, which might also be skills that are needed to perform other activities (Kielhofner, 2009). Using MOHO, an occupational therapist must be sure to incorporate the concept of volition into treatment by identifying problems a client might have with volition and by requiring that the client chooses what activities to perform during therapy (Kielhofner, 2009).

The concept of habituation.

When people repeatedly perform activities in the same environment, they form patterns and routines which allow them to move through much of each day automatically and predictably (Kielhofner, 2009). The patterns that people use to perform activities are influenced by habits and roles (Kielhofner, 2009). Habits are the ways people learn to do tasks or activities so they can be performed automatically and without much thought (Kielhofner, 2009). Habits influence behavior, how people perform routine activities in familiar environments, and how people use time (Kielhofner, 2009).

Roles are how people identify themselves and the obligations they feel to that identity (Kielhofner, 2009). A person’s roles can be many different things and might include a mother, a brother, a student, a worker, a friend, and a volunteer (Kielhofner, 2009). People have multiple roles they fulfill, and what people do in their everyday lives is guided by those roles, the social environments of those roles, and the expectations of others in those social environments

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(Kielhofner, 2009). When using MOHO “learning a new role involves internalizing an identity, an outlook, and an expected way of behaving” (Kielhofner, 2009, p. 152). People who have functional impairments might lose the ability to perform activities in the routine and familiar manners that allowed them to easily pass the day with the least amount of stress or anxiety (Kielhofner, 2009). People lose their habits and roles when they can no longer perform or engage in activities with which they are familiar (Kielhofner, 2009). Occupational therapists using MOHO should focus on maintaining or creating new habits and roles in which people are interested so they can again participate in everyday activities with ease and with familiarity (Kielhofner, 2009).

The concept of performance capacity.

An individual’s “performance capacity refers to underlying mental and physical abilities and how they are used and experienced in performance” (Kielhofner, 2009, p. 152). Bodily systems and abilities, such as cardiopulmonary, neurological, musculoskeletal, mental, and cognitive affect daily performance and function (Kielhofner, 2009). People who have an impairment in one or more of their bodily systems are at risk for decreased performance capacity (Kielhofner, 2009). MOHO is often used with other OT theories or models, such as biomechanical or sensory integration, in order to address performance capacity limitations while keeping treatment focused on how the individual person experiences impairment (Kielhofner, 2009).

MOHO and the environment.

It is conceptualized in MOHO that every aspect of every environment in which a person interacts affects occupational choices and performance (Kielhofner, 2009). Environments in which a person might interact include social, political, cultural, physical, economic, temporal,

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virtual, and personal contexts (AOTA, 2008; Kielhofner, 2009). The social context includes family, friends, and neighbors (Kielhofner, 2009). The political and economic contexts are societally based and help dictate the resources available to an individual to perform activities (Kielhofner, 2009). The cultural context “shapes beliefs about how one should perform and what is worth doing” (Kielhofner, 2009, p. 152). The physical context includes objects, people, and available space in the environment (Kielhofner, 2009). The temporal context includes stages of life, history, time of day, time of year, how much time is available to complete an activity, and how long it takes for something to occur (AOTA, 2008). The virtual context includes communication without physical contact, such as by telephone or by computer (AOTA, 2008). The personal context includes a person’s age, gender, educational background, and socioeconomic status (AOTA, 2008). Each context influences choices a person makes and how a person performs (Kielhofner, 2009). People might also choose their environment and modify their environment as needed to reflect their personal values, interests, and motivation (Kielhofner, 2009). Occupational therapists using MOHO should allow the client to perform activities in the environment that is the best match for the client, and allow the client compensations and environmental adaptations as necessary (Kielhofner, 2009).

The occupational being.

Each and every person has an occupational narrative, a story that has been created by experiences throughout life and affects how one perceives life (Kielhofner, 2009). A person might perceive life as something that will get better, as something in which to have fun, or as a tragedy (Kielhofner, 2009). How people think of life affects their occupational adaptation (Kielhofner, 2009). Occupational adaptation involves the steps that people take in order to make them occupationally competent and in order to create a positive identity (Kielhofner, 2009).

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Occupational competence is how well people are able to fulfill and sustain patterns in what they do, allowing them to maintain their occupational identity (Kielhofner, 2009). Occupational identity is created by people over time and is “the cumulative sense of who they are and wish to become as occupational beings” (Kielhofner, 2009, p. 153). People whose occupational narratives are interrupted by impairment might experience dysfunction in the ability to occupationally adapt, which will decrease occupational competence, which might then cause people to lose their occupational identity (Kielhofner, 2009).

People who have lost their occupational identity might no longer have motivation to engage in activities (Kielhofner, 2009). Kielhofner (2009) stated that “MOHO conceptualizes occupational therapy as a process in which clients engage in occupations that shape their abilities, routine ways of doing things, and thoughts and feeling about themselves” (p. 154). Occupational therapists using MOHO should enable clients to engage in activities in order to involve volition, habituation, and performance capacity (Kielhofner, 2009). Engaging in activities during therapy will also enable clients to practice skills, learn new habits, develop new roles, experience satisfaction, enjoyment, and accomplishment, feel competent, and regain an occupational identity (Kielhofner, 2009).

MOHO and multiple sclerosis.

Multiple sclerosis is a disease that adversely affects a person’s performance capacity (Keller & Stone, 2009). When performance capacity is adversely affected, there might be a decrease in skills, occupational performance, and occupational participation (Kielhofner, 2009). Volition might be negatively impacted, and daily habits, routines, and roles are often interrupted (Kielhofner, 2009). For example, the neurological system in PwMS is dysfunctional which can cause a dysfunction in any other bodily system (Keller & Stone, 2009). People with MS often

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have difficulty with visual sensitivity (Keller & Stone, 2009). A person who works as a secretary for a living needs to be able to efficiently maneuver through the computer's database and systems (Bureau of Labor Statistics, 2010). A person with MS who works as a secretary and who has difficulty focusing on the computer screen might lose the ability to efficiently maneuver through the computer's database and systems due to neurological dysfunction (Keller & Stone, 2009). Losing this skill will decrease job performance, which might then cause the person to participate in work less often (Kielhofner, 2009). The person might lose the work routine which is so familiar, and begin to feel incapable of performing the work, to lose interest in the work, to lose the values toward the work, and then might lose the role as a worker (Kielhofner, 2009). The person might not know how to occupationally adapt, might then lose occupational competence, and might then lose a large part of occupational identity (Kielhofner, 2009).

Use of the model of human occupation enables occupational therapists to improve a client's skills, occupational performance, and occupational engagement (Kielhofner, 2009). By using activities that a person values and finds interesting as a means of therapeutic treatment, the client might then begin to rebuild or maintain the skills necessary to perform desired occupations (Kielhofner, 2009). The occupational therapist using MOHO can enable the client to perform activities by teaching the client methods to compensate for impairments and by adapting the environment to meet the client's needs (Kielhofner, 2009). In the example of a secretary with visual sensitivities, the occupational therapist might help the client compensate by teaching the person to take frequent breaks from the computer, by teaching the person to close her eyes for a few minutes at least every hour, and by ensuring the client is positioned properly in front of the computer (Keller & Stone, 2009). The occupational therapist might adapt the secretary's work environment by reducing bright lighting in the office area around the desk, by dimming the

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brightness of the computer screen, and by positioning the computer so it has the least amount of glare (Keller & Stone, 2009). Applying Kielhofner's (2009) view, the client would be able to maintain work skills and occupational performance, and in doing so would remain occupationally engaged. The client would then be able to functionally adapt to the occupation, would feel occupationally competent, would keep the role as a worker, and would retain occupational identity (Kielhofner, 2009).

People with MS identify problems with engaging in daily and meaningful occupations (Lexell, Lund, & Iwarsson, 2009). There are many ways in which an occupational therapist using MOHO can help a client with MS remain occupationally engaged and maintain their identity (Keller & Stone, 2009; Kielhofner, 2009). When using MOHO, one must remember to enable the client to learn new habits and routines, to gain new roles, to experience satisfaction and enjoyment, to value accomplishment, to feel occupationally competent, and to allow the client to practice skills in the natural environment (Kielhofner, 2009). The therapist must learn what is important to the client, and the therapist must work collaboratively with the client to develop occupational goals which can then be used to plan appropriate occupational therapy interventions (Kielhofner, 2009).

Occupational Therapy: General Effectiveness

Baker and Tickle-Degnen (2001) performed a meta-analysis to determine the effectiveness of OT interventions for MS. The authors identified 23 articles that examined the physical, psychological, and functional effectiveness of OT-related treatments for PwMS (Baker & Tickle-Degnen, 2001). The researchers suggested that OT is effective in treating MS, with 83% of the studies having positive outcomes for capacities and abilities (e.g., muscle strength, ROM, and mood), 43% of the studies having positive outcomes for activity and task performance

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(e.g., dressing, bathing, and ambulation), and 17% of the studies having positive outcomes for life role (e.g., mother, worker, ambulatory person) performance (Baker & Tickle-Degnen, 2001). The researchers concluded that OT as part of a multidisciplinary treatment for MS is effective in improving occupational performance (Baker & Tickle-Degnen, 2001).

Maitra et al. (2010) performed a five-year retrospective study that analyzed associations between inpatient OT treatment and positive functional outcomes in PwMS. Occupational therapy interventions, frequency, and duration in the charts of 193 PwMS in an urban hospital were examined (Maitra et al., 2010). Functional Independent Measure (FIM) scores were calculated to compare functional capacities at assessment with functional capacities at discharge (Maitra et al., 2010). Researchers determined that OT treatment was effective in increasing functional independence and participation in ADLs, especially in the areas of cognitive skills, community reintegration, and self-care (Maitra et al., 2010).

Occupational Therapy Treatment: Energy Conservation

Mathiowetz, Matuska, and Murphy (2001) reported that after 19 weeks of participation in an energy conservation course taught by occupational therapists, participants with MS stated an increase in self-efficacy, a significant decrease in fatigue, and an improved quality of life. The study included 54 participants with fatigue secondary to MS and a control group (Mathiowetz et al., 2001). The study was limited because the sample was a convenience sample of PwMS living in a community (Mathiowetz et al., 2001).

In another study Vantage, Gilbertson, and Mathiowetz (2003) used the Fatigue Impact Scale (FIS) to evaluate the effectiveness of 8 weeks of controlled traditional treatment compared to an 8 week controlled energy conservation course for 37 PwMS. After the traditional treatment, there were no significant changes of FIS scores (Vantage et al., 2003). After

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participation in the energy conservation course, the average total FIS score showed a significant decrease in fatigue, which was maintained eight weeks after the completion of the course (Vantage et al., 2003). There were also significant decreases in physical, cognitive, and psychosocial subscale scores, showing that energy conservation not only allowed PwMS to feel less fatigue, but also allowed them to have better cognitive functioning and an increase in the outlook of their overall self-esteem and well-being (Vantage et al., 2003). The study was limited because evaluators and participants were not blind to group assignments, and because group assignments were based on the convenience of participants' schedules (Vantage et al., 2003).

Mathiowetz, Finlayson, Matuska, Chen, and Luo (2005) performed pre and post-tests to measure fatigue, health, and self-efficacy for performing energy conservation strategies on a randomized controlled trial of 169 PwMS assigned to either an intervention group or to a control group. Researchers found a significant reduction in fatigue and in physical and social subscales and a significant increase in vitality and in self-efficacy for performing energy conservation strategies for the intervention group when compared to the control group (Mathiowetz et al., 2005). The study was limited because results might only be generalized to PwMS who have similar characteristics to the participants, and because there was high attrition (Mathiowetz et al., 2005). Results of studies on energy conservation indicated that energy conservation courses are effective in reducing fatigue, increasing self-efficacy, and improving quality of life in PwMS (Mathiowetz et al., 2005).

Occupational Therapy Treatment: Exercise Therapy

Exercise therapy is performing physical activities including walking, aerobics, balance training, active and passive stretching, resistance training (e.g., forward lunges, chair raises, leg curls, and heel-toe raises), and weighted exercises (Rietberg et al., 2006). Exercise helps restore

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basic skills such as strength, ROM, and endurance, helps to prepare a person to perform purposeful activities, and helps promote occupational function (Flinn, Jackson, McLaughlin Gray, & Zemke, 2008). Exercise programs for PwMS can help to manage fatigue, reduce muscle spasticity, and maintain or improve muscle strength and endurance (Forwell, Copperman, & Hugos, 2008). Occupational therapists might use exercise therapy to help clients achieve optimal daily functioning (Rietberg et al., 2006).

Rietberg et al. (2006) argued that while no OT intervention has proven effective for long-term disease modification, exercise therapy proves to be an important factor in managing symptoms in and providing support for PwMS who are not experiencing an exacerbation. After conducting a systematic review, researchers found that muscle function, exercise tolerance function, mobility-related activities, and mood were all significantly improved in PwMS using exercise therapy, allowing an overall improvement in their ADL functioning and in their QOL (Rietberg et al., 2006). The researchers concluded that since researchers from multiple studies agree on the efficacy of exercise therapy for PwMS, it should be recommended as part of the OT treatment regimen to increase functional abilities, mobility, independence, and QOL (Rietberg et al., 2006).

Dalgas et al. (2010) conducted a study using a control group of 15 people and an exercise group of 16 people, all who had fatigue secondary to MS. The researchers found PwMS in the exercise group to have a decrease in fatigue and an increase in mood, muscular strength, functional capacity, and QOL after 12 weeks of progressive resistance training, with benefits maintained after a 12 week follow-up (Dalgas et al., 2010). The study was limited because people with severe MS were not included in the sample, participants and investigators were not blind to the intervention, and the intervention allowed for social interaction that might have

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influenced the effects of exercise therapy (Dalgas et al., 2010). In another study by Dalgas et al. (2009), a control group and an exercise group of 38 PwMS were used to study resistance therapy specifically applied to the lower extremities. Muscle strength and functional capacity of the lower extremities were improved with benefits maintained 12 weeks after the trial with self-guided physical activity (Dalgas et al., 2009). The study was limited because it did not include people with severe MS, and because the intervention allowed for social interaction that might have influenced the effects of exercise therapy (Dalgas et al., 2009). Dalgas et al. (2008) performed a comprehensive literature review of exercise therapy studies in PwMS. Researchers found that endurance and resistance training at low to moderate intensities has proven tolerable and beneficial for PwMS (Dalgas et al., 2008). The review was limited to longitudinal studies (Dalgas et al., 2008).

Occupational Therapy Treatment: Assistive Devices

As the disease progresses, it might become necessary for PwMS to use assistive devices in order to maintain functional abilities and independence (Finlayson, Guglielmello, & Liefer, 2001). In their study on the use of assistive devices and MS, Finlayson et al. (2001) reported that out of 427 PwMS, 61.1% used a manual wheelchair, 50.1% used grab bars, 44.7% used crutches or canes, 39.1% used walkers, and 7.3% used orthoses. One of the largest predictors of owning and using an assistive device was seeing an occupational therapist as part of the MS treatment, indicating that OT is an important part of MS treatment and maintaining independence (Finlayson et al., 2001).

Early Treatment for Multiple Sclerosis

It is believed that most of the permanent disabilities seen in PwMS due to neurological damage and degeneration occur early in the disease process (Fernandez & Vermersch, 2011;

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Lublin, 2011). Early intervention is important to regain maximum functional abilities and to keep any residual deficits caused by an exacerbation stable (Lublin, 2011). Prevention of symptoms is of critical importance, making lifestyle interventions after disease diagnosis a necessity (Ziemssen, 2011). Teaching and encouraging PwMS to reduce fatigue by using energy conservation, exercise, diet management, and healthy sleep habits might help prevent many of the disabling symptoms that commonly occur throughout the MS disease process (Ziemssen, 2011). Teaching and encouraging PwMS to use exercise and conditioning programs to maintain mobility and to use cognitive training to maintain cognitive function might also help prevent the disabling symptoms that are associated with MS (Ziemssen, 2011).

Many PwMS are referred to therapy after they have lost important functions, such as walking, transferring, or loss of upper limb function (Thompson, 2001). Physicians fail to realize the importance of managing MS through more than medication, and people lose function throughout the disease process rather than regaining maximum functional capacity after each exacerbation (Thompson, 2001). Early management of functional losses due to MS is essential, and should be available even to those with minimal or moderate impairments who have the potential to improve (Thompson, 2001). Beginning a multidisciplinary treatment early in the disease process could limit neurodegeneration and prevent the development of long-term disabilities, and many studies are being conducted to support the efficacy of early intervention (Fernandez & Vermersch, 2011).

As PwMS gradually lose function, they also lose their independence and might be placed in a nursing home (Boeijea et al., 2002; Finlayson, 2004). While only 5-10% of PwMS require nursing home care, the MS nursing home resident tends to be younger, more mentally alert, more physically dependent, have more symptoms of depression, and require a longer length of stay as

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compared to the average nursing home resident (Northrop & Frankel, 2009); some PwMS might spend more than 20 years of their lives in a nursing home (Finlayson, 2004). Early intervention is important to allow PwMS to maintain maximum physical, cognitive, and mental functioning, and to reduce the likelihood of entering a nursing home (Northrop & Frankel, 2009; Thompson, 2001).

Economic costs.

Worldwide, the economic costs of MS treatment are substantial (Asche et al., 2010). Asche et al. (2010) found that within one year of being diagnosed with MS in the United States, medical treatment for PwMS was on average 4.7 times more costly than medical treatment for a healthy control group. O'Brien et al. (2003) conducted a study in the United States on third-party payer records over a 90-day period to determine the direct costs of medical care for MS relapses. The category of high intensity management was assigned to those who required hospitalization, and the category of low intensity management was assigned to those who required physician visits and medications to manage symptoms (O'Brien et al., 2003). With a high level of managing a relapse averaging \$12,870 and a low level of managing a relapse averaging \$243, researchers concluded that a reduction in the frequency and severity of relapses will substantially impact economic costs (O'Brien et al., 2003).

Other researchers have performed studies to determine how the severity of MS and the level of disability in PwMS affect QOL, functional capacity, and treatment costs (Kobelt et al., 2006; McCrone et al., 2008; Zwibel, 2009). Symptoms of MS impacted daily function and daily participation in activities in 44% of PwMS (Zwibel, 2009). Researchers found that as disease severity increased and functional capacity decreased, QOL substantially decreased while costs substantially increased (Kobelt et al., 2006; McCrone et al., 2008; Zwibel, 2009).

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Identified Needs or Wants of PwMS

Holland, Schneider, Rapp, and Kalb (2011) designed a study to determine the needs of people with primary progressive MS in order to aid in developing programs to meet those needs. Data was collected from three online self-report databases and from a MS focus group (Holland et al., 2011). The authors identified that a need for information and a need for medical management are important to PwMS (Holland et al., 2011). Help with decreased mood, with decreased cognition, with decreased QOL, and support for families and caregivers were also important factors in treating the participants (Holland et al., 2011). Occupational therapy is effective in providing disease education, physical and cognitive rehabilitation, improving mood, improving QOL, and providing support and resources for families and caregivers (Baker & Tickle-Degnen, 2001; Keller & Stone, 2009).

Sweetland, Riazi, Cano, and Playford (2007) performed an international study to determine what PwMS need from vocational rehabilitation services. By interviewing four focus groups of employed PwMS, the researchers determined that employed PwMS need support in managing work performance, managing work expectations, counseling, and advocacy and education to help their employers understand the nature of MS (Sweetland et al., 2007). Treating symptoms of MS through physical rehabilitation, changing the work environment, educating about proper body mechanics, and altering the demands of the job are ways that occupational therapists can help PwMS manage work performance (Baker & Tickle-Degnen, 2001; Keller & Stone, 2009; Sweetland et al., 2007). Occupational therapists also educate clients and employers about MS, and can advocate for the client so the employer has realistic work expectations (Baker & Tickle-Degnen, 2001; Sweetland et al., 2007).

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In a qualitative study performed among 10 participants by Lexell, Lund, and Iwarsson (2009), the experiences of the participants' daily engagement in occupations was examined. The participants reported that their lives were constantly changing because of their MS (Lexell et al., 2009). Common concerns for participants were decreasing engagement in meaningful occupations, constantly struggling for engagement in occupations, being a different person, and living life differently (Lexell et al., 2009). The researchers also found that societal regulations and attitudes highly influenced the ability of PwMS to engage in desired occupations (Lexell et al., 2009). The authors concluded that rehabilitation professionals need to focus on occupational performance, occupational engagement, the individual client's self-identity, and changing the attitude and regulations held by society (Lexell et al., 2009).

Johansson et al. (2007) performed a cross-sectional study involving 219 patients from an outpatient MS clinic in order to determine the rate of disability among PwMS and the perceived physical and psychological impact of those disabilities. Within the sample, 80% of patients were found to have 2 or more disabilities, and 24% of patients were found to have 6 or 7 disabilities (Johansson et al., 2007). Per the Expanded Disability Status Scale, 59.5% had mild disabilities, 17% had moderate disabilities, and 23.5% had severe disabilities (Johansson et al., 2007). Within the participant group, 49% of participants were found to have a cognitive disability, 76% had a disability in manual dexterity, 43% had a disability in walking, 67% had a disability in energy level, 29% had a disability with mood, 44% had a disability with ADLs, and 48% had a disability with social/lifestyle activities (Johansson et al., 2007). Disabilities in manual dexterity, walking, energy, mood, and ADLs were significantly associated with a perceived high physical impact, and disabilities in energy and mood were significantly associated with a perceived high psychological impact (Johansson et al., 2007). Researchers concluded that all of the identified

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areas of disability should be addressed during treatment in order to increase function, occupational participation, and quality of life (Johansson et al., 2007).

Changes in Employment Status for PwMS

PwMS often face changes in employment status due to symptoms associated with MS, potentially causing them to lose a large part of their personal identity (Julian, Vella, Vollmer, Hadjimichael, & Mohr, 2008; Kielhofner, 2009). In one study of employment among PwMS, researchers investigated the relationship of patient and disease characteristics with unemployment (Julian et al., 2008). Researchers performed a cross-sectional study of 8,867 PwMS over approximately a 17 month time period, and performed two assessments of job and disease status during that time (Julian et al., 2008). At both assessments 56-58% of participants were unemployed (Julian et al., 2008). At the time of the first assessment participants who had greater disability, greater functional limitations, a form of progressive MS, and longer exacerbation periods were more likely to be unemployed (Julian et al., 2008). At the time of the second assessment participants who experienced an increase in MS symptoms in the past six months or who had difficulties with fatigue, mobility, hand function, or cognition were more likely to be unemployed (Julian et al., 2008). The authors concluded that there are specific physical and mental functional limitations that increase the risk of PwMS becoming unemployed (Julian et al., 2008). Researchers also stated that rehabilitative interventions should focus on the specific limitations of MS in order to reduce the likelihood of PwMS experiencing a change in employment status (Julian et al., 2008).

Smith and Arnett (2005) used a cross-sectional design to compare employment status among 50 PwMS with their demographics and disease variables and symptoms. Participants were divided into a working full-time group, a reduced hours group, and an unemployed group

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(Smith & Arnett, 2005). The unemployed group had significantly more fatigue and physical disability than the other two groups (Smith & Arnett, 2005). The reduced hours group had significantly higher education levels and occupational prestige than the unemployed group, and the full-time group had significantly greater mood disturbances than the unemployed group (Smith & Arnett, 2005). In the reduced hours group, 90% of participants reported that fatigue was the main reason for their employment status change, and 86% of the unemployed group reported a broad range of physical and neurological symptoms as the main reason for their employment status change (Smith & Arnett, 2005). The researchers found no significant relationship between employment status change and age, gender, IQ, diagnosis duration, disease duration, or cognitive function (Smith & Arnett, 2005).

In another study researchers evaluated 184 PwMS in order to examine the relationship between self-rated health and employment status (Krokavcova et al., 2010). Researchers found that regardless of age, gender, functional disability, education, disease duration, and depression, the participants who rated their health as good were 2.46 times more likely to be employed than participants who rated their health as less than good (Krokavcova et al., 2010). Participants without anxiety were 2.64 times more likely to be employed than participants with anxiety (Krokavcova et al., 2010). The researchers concluded that self-rated health might be used as a prognostic tool to predict a change in employment status (Krokavcova et al., 2010).

Access to Adaptive Equipment and Rehabilitation Services

Bingham and Beatty (2003) performed a study to determine the rate of access to adaptive equipment (AE), such as walkers, reachers, and sock aids, and rehabilitation services among people with MS, spinal cord injuries, and cerebral palsy. After surveying 500 adults, researchers found that over half of the people needed AE in the past 12 months, but approximately 1/3 of the

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people that needed AE did not receive it every time it was needed due to costs and insurance coverage (Bingham & Beatty, 2003). Within the 3 months prior to the study, approximately 40% of the sample group needed rehabilitation services, but 52% of those who needed rehabilitation services did not do so due to costs and insurance coverage (Bingham & Beatty, 2003). The researchers concluded that the lack of access to necessary equipment and rehabilitation services is directly related to costs and insurance coverage limitations (Bingham & Beatty, 2003).

Without access to AE and rehabilitation services, the rate of disability among PwMS will be higher, which has been directly linked to increased healthcare costs (Bingham & Beatty, 2003; Zwibel, 2009). Improved access to AE and rehabilitation services for preventative and maintenance care will decrease disability and functional limitations in PwMS and decrease overall costs for MS care throughout the course of the disease (Bingham & Beatty, 2003).

By reviewing the Multiple Sclerosis Registry in Germany, Ziemssen (2011) found that half of the PwMS did not receive treatment for frequent symptoms including fatigue, spasticity, cognitive impairment, and bowel and bladder management. Treatment rates for fatigue and cognitive impairment were as low as 20% of PwMS (Ziemssen, 2011). Non-pharmacological treatments were the most limited (Ziemssen, 2011). Ziemssen (2011) stressed the fact that Germany is a country with national health care and with few barriers to health care access and reimbursement, yet still so few PwMS receive appropriate treatment.

Occupational Therapy Use

Mosley, Lee, Hughes, and Chatto (2004) performed a study in the United States to determine the client factors that influenced personal physicians to make referrals for PwMS to occupational therapists as a part of their treatment. Researchers found that 70% of PwMS who were surveyed were never referred to an occupational therapist (Mosley et al., 2004). For the

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30% who had been referred to an occupational therapist, the progression and/or the severity of the disease was much higher than those who were not referred (Mosley et al., 2004). People with MS who had little disease progression or few limitations in ADLs were not likely to be referred, even though OT treatment would still be highly beneficial in helping them to function in their everyday lives and in maintaining their sense of self and their sense of independence (Mosley et al., 2004). Researchers stressed the need for more education of those health care professionals who might be a part of an MS treatment team by teaching them about how OT can be effective in reducing fatigue, increasing functional independence, and improving quality of life during all stages of the disease (Mosley et al., 2004).

Freeman and Thompson (2000) performed a study in the United Kingdom to investigate the level of outpatient services received by PwMS across a wide range of disease severity. Using a questionnaire, the researchers interviewed 150 adults with MS and found that 45% of those interviewed had never received services other than from their primary care physician (Freeman & Thompson, 2000). Only 21% of the people had ever received OT services (Freeman & Thompson, 2000). Of those who had been seen by an occupational therapist, 41% had been identified as severely disabled by MS (Freeman & Thompson, 2000). The authors concluded that a small percentage of PwMS receive OT treatment, and that the greater the level of severity of the disease, the more likely an individual is to be referred for OT services (Freeman & Thompson, 2000).

A study by Finlayson et al. (2008) was designed to determine how PwMS in Atlantic Canada aged 45-90 years used OT services. The researchers found that the majority of PwMS (61.8%) had never received OT services, and that among those who had never received services, the perceived need for OT is low (Finlayson et al., 2008). The authors reflected that this might

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be due to a lack of knowledge of the type of services that OT provides (Finlayson et al., 2008). Of those who had received OT services, the amount of people who continued to seek OT services after the initial contact was small (Finlayson et al., 2008). The PwMS who did not continue with treatment also believed that there is no need for OT treatment (Finlayson et al., 2008). This might also reflect a lack of knowledge of OT services (Finlayson et al., 2008). The authors also wrote that other explanations for not using OT services might be that patients felt the problems were solved with the initial visit, that problems were not solved with the initial visit, that additional therapy would not be beneficial, or that the referring physician felt that additional therapy would not be beneficial (Finlayson et al., 2008). The participants who continued to use OT services as a part of their MS treatment felt strongly that the services were important, and they were also satisfied with the services, though the authors did not go into detail as to why participants felt this way (Finlayson et al., 2008). This study was limited in that it only included people with higher disease progression even though OT can be beneficial for PwMS during all stages of the disease (Finlayson et al., 2008). The study was also limited because it only included PwMS who were between the ages of 45 and 90 (Finlayson et al., 2008).

Conclusion

Multiple sclerosis can be a devastating disease for which there is no cure, though symptoms and exacerbations might be limited and/or slowed through available treatment options (NMSS, 2012). The treatment of multiple sclerosis should be a multi-disciplinary approach, including occupational therapy as part of the treatment team (Holland et al., 2011; Kesselring & Beer, 2005; Mayo Clinic, 2012b; NMSS, 2012; Smith et al., 2010). Researchers have shown that occupational therapy treatment increases muscle strength, function, and mobility (Baker & Tickle-Degnen, 2001; Maitra et al., 2010). Occupational therapy treatment also reduces fatigue

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and increases mood, self-efficacy, independence, and self-esteem (Baker & Tickle-Degnen, 2001; Maitra et al., 2010). Multidisciplinary treatment leads to an increased quality of life by allowing PwMS to actively participate in the areas of life that are important to them (Baker & Tickle-Degnen, 2001; Keller & Stone, 2009; Kielhofner, 2009; Maitra et al., 2010). Increased function and increased quality of life lead to a decrease in overall cost for multiple sclerosis care, and early treatment intervention for people with multiple sclerosis is important to decrease the cost of care and to increase functional independence (Asche et al., 2010; Lublin, 2011; Thompson, 2001; Ziemssen, 2011). By determining occupational therapy use and the perceived need for treatment among people with multiple sclerosis, occupational therapists might discover a need to better promote their services. Occupational therapists might also discover a need to educate people with multiple sclerosis, referring physicians, and insurance companies about the scope, efficacy, and necessity of occupational therapy treatments, and of the importance of rehabilitation at all stages of the disease process. This will help in allowing people with multiple sclerosis the ability to maintain maximum function and the best possible quality of life.

Included in Chapter 2 was a review of the relevant literature related to MS and occupational therapy. The methods and procedures of the study are presented in Chapter 3.

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Chapter 3: Methods and Procedures

Chapter 3 presents the study design, assumptions and limitations, subjects and selection methods, and operationalization of concepts into variables. The measurement instruments and procedures are identified, and the data entry, analysis, and interpretation are explained.

Study Design

The study was a non-experimental, descriptive survey design consisting of quantitative and open-ended questions. In order to fill in gaps in available research, the research questions were as follows:

1. To what extent do PwMS across the lifespan living in the United States use occupational therapy services as a part of their MS treatment?
2. Do PwMS believe that they have benefited or might benefit from occupational therapy services?
3. What are the factors that influence reasons why PwMS might not use occupational therapy services?
4. How do PwMS rate their quality of life on the Global Quality of Life Scale?

Delimitations, Assumptions, and Limitations

Any people with MS who were over the age of 18 and who were able to supply their own answers to the survey questions were eligible for the study. Anyone under the age of 18 was excluded as people under the age of 16 with a diagnosis of MS would have been diagnosed with juvenile-onset or early-onset MS (Etemadifar, Nasr-Esfahani, Khodabandehlou, & Maghzi, 2007). The symptoms experienced by people with early-onset MS can vary considerably from the symptoms experienced by people with adult-onset MS and information would not be generalizable to the larger population of PwMS (Etemadifar et al., 2007). PwMS under the age

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of 18 were also excluded as parental consent would have been required. Any surveys for which the person with MS did not supply his or her own answers to the questions were excluded in order to ensure accurate and valid responses.

Based on previous research it was assumed that OT is a positive and beneficial form of rehabilitation for PwMS (Baker & Tickle-Degnen, 2001; Maitra et al., 2010). It was assumed that all participants responded truthfully and accurately. It was assumed that participants thoroughly read all survey questions.

The study was limited by time and money as well as by geographic location as the majority of the surveys were completed by PwMS living in the Central New York State (CNY) area. The study was limited because it was a convenience sample and because concurrent medication use while receiving OT was not surveyed and was not controlled. Medications the participants might have used at the same time as receiving OT treatment could have allowed the participants to experience a more positive outcome with occupational therapy treatment. The cognitive status of participants was not assessed and could have impacted survey responses. Another limitation was that the survey was dependent on participants' recall regarding service use, diagnosis, and number of exacerbations. Many respondents left large sections of their returned survey blank so collected data might be less valid and less generalizable. The study was also limited due to the large number of respondents who indicated they had relapsing-remitting MS. Although this is the most common type of MS and although some respondents indicated having other forms of MS, the information gathered from survey responses might not be generalizable to people who have forms of MS other than relapsing-remitting MS.

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Subjects and Selection Methods

A convenience sample was collected by providing PwMS in the CNY area with an anonymous survey. Volunteers were recruited through support group members of Multiple Sclerosis Resources of CNY Inc., through a link on the NMSS website, and through a link provided on several Facebook MS support group pages. To be eligible for the study respondents had to be at least 18 years of age and had to be able to supply answers to survey questions. Participants were informed in the cover letter that the completion and returning of the survey indicated informed consent and that they were over the age of 18 (Appendices B and C). The study was approved by Ithaca College's Human Subjects Review Board.

Operationalization of Concepts into Variables

1. A person who benefited from OT services is any person who identified that occupational therapy enabled them to cope, be more independent, gain function, feel more normal, feel less pain, have more energy, participate in life, have hope, and/or feel like themselves again.
2. Knowledge of OT is the level of correct information that people have regarding what OT services provide.
3. Perceptions of OT are the beliefs that people have about OT services.
4. A person who was currently using or who had used OT services in the past is any person who had been evaluated or treated by an occupational therapist as a part of his or her treatment for MS.
5. A person's level of independence with certain activities is how much help they need performing the activities.

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6. Survey completion is how a person completed the survey including independently, with a loved one writing the answers and the PwMS supplying the answers, or a loved one supplying the answers.
7. QOL is the level of satisfaction a person feels with his or her life (AOTA, 2008).

A survey of 20 questions was developed in order to answer the research questions.

Multiple variables were addressed using a variety of question formats (Appendix D). The variable of knowledge of OT was addressed in Question 1, included a Likert scale format, and yielded numerical data. Numerical data was obtained from questions 2 and 3 which addressed the variable of OT use. The variable of independence was addressed in Question 4, included a Likert scale format, and produced numerical data. Numerical data was collected from questions 5 and 6 which addressed the variables of OT use and perception of OT through a Likert scale. The variable of benefits of OT was the focus of question 7, and it yielded numerical and string data. Numerical and string data were yielded from questions 8 and 9 which focused on the variable of reasons for not using OT. Questions 10-19 addressed demographic variables such as type of MS, gender, age, and living situation; these questions yielded numerical and string data. Question 20 was used to address the variable of survey completion, and yielded numerical data. The Global Quality of Life Scale (GQOLS) was used to focus on the variable of QOL, and it yielded numerical data.

Measurement Instruments

Researcher-designed survey.

The survey was designed by the researcher to determine how many PwMS had ever used or currently used OT services as a part of their treatment for MS, whether PwMS who had received OT services believe that they benefited from OT, and reasons why PwMS might not

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have used OT as a part of their treatment for MS. Face validity of the survey was established through a review by occupational therapy professors and practitioners experienced with research methods, some of whom had extensive experience working with individuals with neurological conditions. Occupational therapists provided their feedback individually to the researcher, and questions were clarified, changed, and added based on responses. Field testing of the survey was performed with a group of three individuals with MS who had diverse cultural and educational backgrounds. The survey was discussed and minor changes were made to the wording of survey questions for clarification and for content validity based on the group's responses.

The survey consisted of 20 quantitative and open-ended questions and gathered information regarding (1) knowledge of OT; (2) use of OT; (3) level of independence when performing daily activities; (4) for what reasons respondents have used OT and whether they would use OT for specific reasons such as mobility, performing ADLs, fatigue, depression, cognition, environmental adaptations, muscle dysfunctions, and joint range of motion; (5) what areas of OT have or have not been beneficial; (6) reasons why OT was beneficial; (7) reasons for not using OT; (8) type of MS; (9) number of exacerbations; (10) mobility needs; (11) occupational status and change in occupational status; (12) how respondents spend the majority of their time; (13) and demographic information such as age range, gender, and living situation (Appendix D).

A variety of question forms were included on the survey including four and five level Likert scales. Some questions included several choices and required the respondent to check all that apply, and other questions required the respondent to select one choice out of a group of choices. Participants were informed that they could refuse to answer any questions and that they could stop taking the survey at any time.

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Global Quality of Life Scale.

The GQOLS (Appendix E) is a standardized, single scale measurement instrument designed by Hyland and Sodergren in order to directly evaluate QOL (Hyland & Sodergren, 1996). Clients are asked to rate their QOL on a scale of 1 (no quality of life) to 100 (perfect quality of life) by writing down the number that best describes their QOL (Hyland & Sodergren, 1996). The scale designers performed three different studies in order to determine placement of QOL quantifiers, scale performance, and scale-type preference (Hyland & Sodergren, 1996).

The first study of QOL determined placement of quantifiers, included 202 people divided into 7 different focus groups, and the quantifiers were arranged on the 1-100 scale according to the median preference of participants (Hyland & Sodergren, 1996). The second study was to determine the type of response scale preferred and to have participants self-rate on several different QOL scales, and included 95 people divided into 2 groups (Hyland & Sodergren, 1996). Researchers found that participants preferred a 100-point scale over a 20-point scale with 100, as opposed to 0, being perfect quality of life (Hyland & Sodergren, 1996). For self-rating, researchers found that responses on H scales, the new GQOL scale created by Hyland and Sodergren, were more consistent than responses on category rating (CR) and visual analog (VA) scales (Hyland & Sodergren, 1996). The third study was to determine scale performance using QOL scenarios and included 50 people (Hyland & Sodergren, 1996). Researchers again found that H scales had more consistency in rating than VA scales (Hyland & Sodergren, 1996).

Procedures

The study was approved by Ithaca College's Human Subjects Review Board. The researcher designed survey and the GQOLS were made available online and also mailed to a MS support group leader who had previously agreed to distribute surveys to support group members.

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Approximately 200 surveys in hard-copy form were distributed by the support group leader to support group members in the CNY area over a 6-week time period. A link to the Qualtrics survey was posted on the National Multiple Sclerosis Society web page, and the survey was advertised with a link on multiple MS support group Facebook pages. The MS support group leader reminded support group members to complete the survey, and a second message was posted to MS support group Facebook pages requesting response to the survey. Respondents who received the hard-copy form were asked to respond to the survey within two weeks, and the Qualtrics survey online remained open for approximately six weeks.

Data Entry, Analysis, and Interpretation

The researcher entered variables and data for the categories into SPSS Version 20 for analysis. Univariate analyses were conducted to eliminate entry errors, and entry errors were corrected as necessary. Single and multiple descriptive frequency distributions were created for all quantitative questions and were then used to summarize results. Categories for the open-ended responses were formed according to common themes gleaned from responses to questions about what respondents spend the majority of their time doing and reasons for not using occupational therapy services. The mean was calculated for QOL. Cross-tabulation tables were created to determine if there was a correlation between respondents who used a device for mobility purposes and the use of OT services, and to compare the type of MS that respondents had with those who have used OT.

Scope and Limitations of Study

The scope of this study was to determine the amount of OT use among PwMS across the adult lifespan in the United States, the level of satisfaction with OT services among Pw MS, and possible reasons PwMS might not use OT services. The scope of the study included PwMS from

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the CNY area who responded to the survey within the prescribed time frame. This study was limited by time, money, geographic location, concurrent medication use while receiving OT services, possible limitations in participants' cognitive status, and strength of participants' recall memory.

Included in Chapter 3 was a review of the methods and procedures of the study. The study results are presented in Chapter 4.

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Chapter 4: Results

Contained in Chapter 4 are detailed descriptions of the results of the study. Information about participants, use of occupational therapy services, use of occupational therapy and mobility purposes, reasons for not using occupational therapy services, level of independence when performing activities, and quality of life are included. Also included is information regarding knowledge of occupational therapy services, occupational therapy use for specific activities, perceptions of occupational therapy services, reasons occupational therapy was helpful, and how PwMS spend the majority of their time.

Participant Demographics

Respondents returned hard-copy surveys via mail with a response rate of approximately 20%. Thirteen people took the survey and GQOLS online. A total of five surveys and nine GQOLSs were excluded from analysis due to the respondents leaving too many responses incomplete or responding that a loved one supplied answers for the questions, leaving a total sample of $N = 40$ for the surveys, and a total sample of $N = 36$ for the GQOLS.

The average age of respondents was between 40 and 59 years and 33 of the 40 respondents (82.5%) were female. The majority (67.5%) of respondents lived in a small urban or suburban area, and the majority (65.0%) of respondents also lived with a spouse or significant other. Twenty-nine of the 40 respondents (72.5%) had a diagnosis of relapsing-remitting MS, and the majority (62.5%) of all respondents had less than 10 exacerbations since their diagnosis. Twenty-one respondents (52.5%) were either retired or not working, nine respondents (22.5%) worked full-time, and six respondents (15%) worked part-time. Twenty-one respondents (52.5%) changed their primary occupation at some point due to complications from MS. Fourteen respondents (35%) used a wheelchair for mobility purposes, 27 respondents (67.5%)

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used a cane or walker, and 15 respondents (37.5%) did not use any mobility aids. The average QOL was 69, indicating a good QOL. Table 1 illustrates the demographic information of respondents.

Use of Occupational Therapy Services

One respondent (2.7%) was currently using OT services as a part of treatment for MS, and 14 respondents (37.8%) had used OT services in the past for treating complications from MS. Twenty-seven respondents (79.9%) indicated that they have never used OT services as a part of their treatment for MS, though 11 respondents (29.7%) indicated that they might use OT services in the future for the treatment of MS. Of those who have received OT treatment for MS, six (15.0%) used OT during an exacerbation, five (12.5%) used OT after an exacerbation, and four (10.0%) used OT between exacerbations. Table 2 details these results.

Use of Occupational Therapy and Mobility Purposes

Of the 14 people who have used OT in the past, 10 of those people (71.4%) use a wheelchair for mobility purposes, 5 (35.7%) use a cane, and 7 (50.0%) use a walker (see Table 3). Of the 14 people who have used OT in the past, 1 participant (7.1%) did not use a device for mobility purposes. The one respondent who currently uses OT services as a part of treatment for MS also has a type of MS other than relapsing-remitting MS. Of the 10 respondents who indicated having a type of MS other than relapsing-remitting MS, 8 of those respondents (80.0%) have also used OT in the past, as compared to 5 out of 29 respondents (17.2%) with relapsing-remitting MS having used OT services.

Reasons for Not Using Occupational Therapy Services

The primary reason for PwMS not using OT services in the past was that they did not know what OT was (17.5%). Other major factors included: their function was not affected

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(15.0%), they felt OT was not needed (15.0%), they had too much to deal with already (12.5%), and they had no insurance coverage (12.5%). The two primary reasons for PWMS not currently using OT services were they did not know what OT was (17.5%) and their function was not affected (17.5%). Other major factors included their health insurance limited the number of OT visits allowed (15.0%), they felt OT was not needed (12.5%), and they had no referral for OT (12.5%). There were also four open-ended responses that OT has never been suggested or mentioned for the treatment of MS. See Table 4 for results.

Level of Independence when Performing Activities

When engaging in ADLs (grooming 16.0%; bathing/showering 16.5%; dressing 18.4%; toileting 13.9%; mobility 17.8%; transfers 16.1%), IADLs (leisure activities 22.8%; communication 19.3%; work 15.2%), and cognition (17.8%) most respondents indicated they were either independent or required minimal assistance with the activities. The only exceptions were with housekeeping and with cooking. When engaging in housekeeping tasks 9.4% of respondents were independent or required minimal assistance, 17.5% required moderate assistance, and 49.7% required maximum assistance or were completely dependent on someone else to complete the activities. When engaging in cooking 16.3% of respondents were independent or required minimal assistance, 12.5% required moderate assistance, and 28.2% required maximum assistance or were completely dependent. Several respondents (41.0%) required some degree of assistance performing paid or unpaid work.

Quality of Life

The mean QOL rated on the GQOLS was 69 (good QOL). Even though the average QOL was 69, 27.5% of people rated their QOL at 85 (very good QOL). The average QOL among

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PwMS who had a form of MS other than relapsing-remitting MS was also 69 (good QOL), indicating no correlation between a more severe form of the disease and a poor QOL.

Knowledge of Occupational Therapy Services

Respondents were asked in the first survey question to indicate on a Likert scale their agreement or disagreement with statements about what OTs do in treatment. The majority of respondents agreed that occupational therapists address fatigue (28.0%), joint protection (20.8%), ROM (21.2%), cognition (26.4), ADLs (28.8%), and use of AE (26.8%). 30.4% of respondents disagreed that occupational therapists address stress management, and 23.1% of respondents disagreed that occupational therapists address communication and socialization. Two categories were included in the question that contained areas that occupational therapists do not address as a means of further testing the respondents' knowledge of OT; 66.5% of respondents disagreed that occupational therapists will do their grocery shopping for them, and 40.9% of respondents disagreed that occupational therapists will take care of their pets or children for them. Table 5 illustrates these results.

Occupational Therapy Use for Specific Activities

Respondents were provided with a list of certain activities and asked to select an activity if they had used OT for the activity in the past, if they were currently using OT for the activity, if they would not use OT for the activity, and if they would use OT for the activity. Respondents were only permitted to select one option per activity (a person who responded that they would use OT for an activity, for example, did not also select that they would not use OT for an activity). Respondents had primarily used OT in the past for ADLs/IADLs (16.3%) and for arranging the living environment (11.6%). Respondents indicated they would not use OT to arrange the living environment (10.1%), access the computer (12.8%), deal with depression

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(14.9%), and participate socially (13.5%). Respondents would use OT to perform ADLs/IADLs (10.6%), feel less fatigue (12.7%), help with mobility (13.2%), manage pain (9.5%), manage muscle weakness/spasticity (10.6%), increase ROM (11.1%), and to manage cognitive deficits (9.5%). This question was limited by the large number of respondents not completely answering the question. See Table 6 for results.

Perceptions of Occupational Therapy Services

Respondents were provided with a list of certain activities and asked to select an activity if OT had been helpful for the activity, if they thought OT might be helpful for the activity, if OT had not been helpful for the activity, and if they did not think OT would be helpful for the activity. Respondents were only permitted to select one option per activity (a person who responded that OT had been helpful for performing ADLs, for example, is a person who had used OT in the past for performing ADLs; a person who responded that OT might be helpful for performing ADLs is a person who has likely not used OT for performing ADLs). Respondents indicated that OT had been helpful for performing ADLs (18.4%), feeling less fatigue (13.2%), mobility (13.2%), and increasing ROM (15.8%). Respondents thought OT might be helpful for arranging the living environment (11.2%), accessing the computer (10.1%), performing ADLs (11.7%), feeling less fatigue (9.5%), mobility (9.5%), and increasing ROM (9.5%). Respondents indicated OT had not been helpful for arranging the living environment (20.8%), accessing the computer (12.5%), dealing with depression (12.5%), and managing cognitive deficits (12.5%). Respondents did not think OT would be helpful for dealing with depression (15.5%), managing pain (13.4%), participating socially (11.3%), managing muscle weakness/spasticity (10.3%), and increasing cognitive deficits (10.3%). This question was limited by the large number of respondents not completely answering the questions. Table 7 details these results.

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Reasons Occupational Therapy was Helpful

When asked reasons that OT has been helpful, the most common reason was that it helped PwMS gain function (25.0%). Coping (22.5%) and feeling more independent (22.5%) were the second most common reasons. Other common reasons included OT helped to feel more normal (15.0%) and to have more energy (12.5%). Twenty-three respondents (57.5%) indicated not using OT. See Table 8 for results.

How PwMS Spend the Majority of their Time

Respondents were asked what they spend the majority of their time doing, and categories were formed according to common themes in the responses. Fourteen out of 39 people (35.9%) indicated they spend most of their time doing hobbies or leisure activities, with 7 of these responses (18.0%) including reading. Eleven people (28.2%) spend their time doing housework with cooking, cleaning, laundry, and money management being a common part of housework. Resting or sleeping (25.6%), using the computer (23.1%), working (18.0%), watching television (18.0%), and spending time with family and friends (18.0%) were common responses. Caring for children or others (10.3%), exercise or walking (7.7%), medical appointments or health management (7.7%), and volunteer work (7.7%) were other common themes. See Table 9 for results.

Included in Chapter 4 was a review of the results of the study. Chapter 5 includes a discussion of the results of the study.

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Chapter 5: Discussion

Contained in Chapter 5 is a discussion of the study results. Study results are also compared to prior research.

Occupational Therapy Use for PwMS

The majority of PwMS included in the study are not using OT services as a part of their treatment for MS. Of those PwMS who have used OT services, most of them only used OT during or after an exacerbation. While during and after exacerbations is when function is most impaired and it makes sense to use OT during or after an exacerbation, PwMS are not seeking OT services to take preventative measures against losing function and maintaining QOL. Of the PwMS who have used OT services, more than half of them use a wheelchair for mobility purposes, indicating that PwMS are not being referred to OT unless they have an obvious disability. Almost every respondent who indicated having a type of MS other than relapsing-remitting MS had used OT services as a part of their treatment, likely indicating that people who have more severe forms of MS are being referred to OT as opposed to people who have relapsing-remitting MS. These results are similar to results of other studies in which the researchers found that a large number of people are not using OT and those who had used OT had greater disease severity and greater functional limitations (Bingham & Beatty, 2003; Finlayson et al., 2008; Freeman & Thompson, 2000; Mosley et al., 2003).

Reasons PwMS are not Using Occupational Therapy Services

There are many factors that influence the reasons why PwMS are not using OT services as a part of their treatment for MS. PwMS do not know what OT is, and many either have had no health insurance coverage or their insurance company limits the number of visits for OT services. PwMS already have too much to deal with so they are not seeking OT services, and,

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similar to results found by Mosley et al. (2003), PwMS do not have referrals for OT services. Also, OT has never been suggested or mentioned as a form of treatment for PwMS, possibly indicating that medical service providers, social workers, and support group leaders do not know enough about OT services to recommend OT for treatment. Many PwMS feel their function is not affected or they feel OT is not needed indicating that many PwMS might feel satisfied with their current level of function and have no need for OT services. Another reason that PwMS might not be using OT services as a part of their treatment for MS is that they feel they have a good to very good QOL. PwMS might not feel any need to seek OT services if they are overall satisfied with their QOL.

For ADLs, most IADLs, and cognition the majority of PwMS indicated that they are either independent or require minimal assistance when performing activities. Half of the respondents reported requiring maximum assistance or were completely dependent with housekeeping activities. Close to half of the respondents reported requiring moderate to maximum assistance or were completely dependent with cooking, and close to half of the respondents required some form of assistance when performing paid or volunteer work. A possible reason that PwMS need more assistance with housekeeping, cooking, and work is that these activities might take more energy to perform than other activities. The activities might also be more taxing on the body, or perhaps the activities take more cognitive focus than the ADLs and IADLs that have become habit and are performed without much thought, indicating that OT services providing education involving joint protection and energy conservation would be beneficial for PwMS. Other researchers have found that energy conservation is effective for allowing PwMS to feel less fatigue, to have an increase in vitality, to have better cognitive

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functioning, and to have an increased sense of self-efficacy (Mathiowetz et al., 2005; Mathiowetz et al., 2001; Vantage et al., 2003).

When combined with the information that PwMS know that occupational therapists address ADLs and IADLs, it is surprising that more PwMS are not seeking OT services to help with housekeeping and cooking activities. Perhaps the reason is that PwMS are more independent with other aspects of ADLs and IADLs and they feel that their function is not affected enough to use OT services. The reason might also be related to limited insurance coverage or not having a doctor referral for OT. Even though almost half the respondents indicated that they need assistance when performing work, not a single person indicated that they would use OT services to help them when performing work. A possible reason for this is that PwMS might not know that occupational therapists address work-related issues.

Conceptions and Misconceptions about Occupational Therapy Services

Most PwMS knew that OT addresses fatigue, joint protection, ROM, cognition, ADLs, IADLs, and the use of AE, but many PwMS did not know that occupational therapists also address stress management, cognition, and communication. PwMS indicated they will use OT services for performing ADLs/IADLs, for feeling less fatigue, and to help with mobility. PwMS also indicated they will use OT for managing pain, for managing muscle weakness/spasticity, to increase ROM, and for managing cognitive deficits. PwMS indicated they will not use OT to arrange the living environment, to access their computer, to deal with depression, or for participating socially. Perhaps it is that the areas for which PwMS indicated they will use OT services are more challenging for PwMS, or maybe those areas affect their overall function more than the areas for which they indicated they will not use OT. Another possible reason is that it is simply a matter of not knowing all areas that occupational therapists address. Even though

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respondents indicated that they thought OT might be helpful for arranging the living environment and for accessing their computer, they also indicated that they would not use OT for these activities. A possible reason for this is that people might not fully understand how occupational therapists would address these areas, or possibly because they feel they have a greater need for OT services in different areas. People with MS also might underestimate the importance of arranging the living environment in order to reduce fatigue and use energy conservation techniques.

Reasons Occupational Therapy was Beneficial

Similar to findings by Finlayson et al. (2008) who reported that PwMS were satisfied with the OT services they received, PwMS in the current study who had utilized OT services felt that OT services were helpful for them as well. It was indicated that OT has helped PwMS to gain function, cope, feel more independent, feel more normal, and have more energy. Of the 14 PwMS who had used OT services in the past, 12 of them also indicated that they would use OT again. PwMS have not only felt that OT was helpful for treating MS, but they were also satisfied enough with the results of their OT treatment that they would use OT again.

How Respondents Spend their Time

Many PwMS indicated spending a majority of their time doing hobbies and leisure activities. Several PwMS also indicated spending a majority of their time doing housework, resting or sleeping, using the computer, working, watching television, and spending time with family and friends. While many PwMS are spending time with hobbies and leisure activities, it is disheartening to see that many PwMS spend much of their time resting, sleeping, or doing activities that involve sitting (computer and television). While resting and sleeping might help to conserve energy, too much sedentary activity can cause muscles to weaken, and rest, sleep, and

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sedentary activities might not reflect an occupation that a person with MS would choose to do if not for their diagnosis. This might also indicate that PwMS would greatly benefit from energy conservation strategies.

Included in Chapter 5 was a discussion of the study results. The study implications for practice are presented in Chapter 6.

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Chapter 6: Implications for Practice

Chapter 6 contains a discussion of the implications the study results have for the practice of occupational therapy. The primary findings were occupational therapists need better marketing of services, occupational therapists need to educate PwMS about the full scope of the practice of OT, and OT can be beneficial for PwMS.

Occupational therapists need to better market their services in order to promote OT services for treating PwMS. Most PwMS are not using and have never used OT as part of their treatment, and those who have used OT have primarily used it only during or after an exacerbation. Occupational therapists need better marketing to promote the use of OT services for treating PwMS at any point during the course of the disease. Many PwMS indicated that they have not used OT services because they have no referral from a health care provider or because OT had never been mentioned to them. The profession of OT can also benefit from increasing awareness about the potential benefits of OT services to people who might be a part of the treatment team for PwMS including the primary care physician, neurologist, social worker, and support group leader. Occupational therapists also need to better promote the use of OT services for all PwMS since most PwMS are only being referred to OT once they have an obvious dysfunction or if they have a more severe form of MS. Early referral to learn energy conservation techniques and other strategies for managing life activities could make a significant difference in long term independence for PwMS (Mosley, Lee, Hughes, & Chatto, 2004).

Better awareness of the benefits of OT services is also needed by health insurance companies. One of the top reasons that PwMS have not used OT for treatment is because their insurance company limited the number of visits allowed for OT. Occupational therapists need to educate insurance companies about the numerous ways in which OT treatment can benefit

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PwMS, and occupational therapists need to advocate for their clients in order to get them better coverage of OT services for their treatment of MS.

There are many misconceptions about what OT is and what services occupational therapists provide. Occupational therapists need to better educate clients about the types of services that occupational therapists provide. Occupational therapists need to promote their services to PwMS in the areas of stress management, cognition, environmental adaptation, accessing technology, and communication. Promotion of OT services is also needed for managing depression, social participation, pain management, work performance, and managing muscle dysfunction. For those PwMS who feel that their function has not been affected or that OT is not needed, promoting OT services for teaching energy conservation, joint protection, and medication and disease management would be beneficial for the profession of OT and for the client. Educating PwMS that OT can be beneficial at any stage of the disease would be worthwhile in order to help prevent dysfunction and to maintain satisfaction with levels of functioning.

OT has been beneficial for the majority of PwMS who have accessed OT. This potentially means that occupational therapists are treating the needs and wants of PwMS. Since PwMS who have benefited from OT services also indicated that they will use OT services again, occupational therapists can look forward to treating more PwMS in the future as it appears likely those PwMS will access more OT services. This does not take away the need for the marketing and promotion of services, nor does it take away the need for educating people about OT. Insurance companies will still need to provide appropriate levels of coverage for OT services and medical practitioners will still need to write referrals for OT services. The large majority of PwMS are not using OT as a part of their treatment, so educating PwMS about OT is still needed

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in order to create a new client base of PwMS and in order to help ensure that PwMS will continue to benefit from OT treatment.

Chapter 6 discussed the implications of the study results for the practice of OT.

Contained in Chapter 7 is the conclusion.

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Chapter 7: Conclusion

Multiple sclerosis affects more than 2.1 million people worldwide (NMSS, 2012).

Multiple sclerosis has been diagnosed in approximately 400,000 people in the United States, and there are more than 200 new diagnoses every week (NMSS, 2012). People with multiple sclerosis experience a wide variety of symptoms that can be extremely disabling and that can severely limit functional abilities (NMSS, 2012). There is no cure for multiple sclerosis, and people with multiple sclerosis continue to lose neurological function for life, making it important for people with multiple sclerosis to manage their symptoms and limitations in occupational performance and participation (Finlayson et al., 2008; NMSS, 2012; Rasova et al., 2010).

Occupational therapists possess the knowledge and the skills necessary to provide treatment for people with multiple sclerosis, and to help people with multiple sclerosis manage their functional deficits, maintain the highest level of function possible, and maintain a healthy quality of life (Keller & Stone, 2009; Stachowiak, 2009; Steultjens, 2004). Occupational therapists have been trained to treat people with physical, cognitive, and mental disabilities (Blesedell Crepeau, 2009; Keller & Stone, 2009). Occupational therapists are highly skilled at analyzing environments and components of tasks and at adapting those environments and tasks in order to optimize occupational performance (Blesedell Crepeau, 2009; Keller & Stone, 2009). Occupational therapists can help people with multiple sclerosis manage their symptoms and limitations in occupational performance and participation, and maintain their functional independence (Keller & Stone, 2009; Stachowiak, 2009; Steultjens, 2004).

This study was completed to determine to what extent adults with multiple sclerosis are using occupational therapy services in their treatment, the factors that influence the use of occupational therapy services by people with multiple sclerosis, and if people with multiple

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sclerosis believe they have benefited from occupational therapy services. Based on study findings, people with multiple sclerosis are generally part of a healthy, functional population with a good quality of life, but they have a narrow view of occupational therapy services. People with multiple sclerosis are unsure what occupational therapy is, they have mixed opinions about whether occupational therapy will be helpful, depending on the activity, and the majority of people with multiple sclerosis are not using occupational therapy as a part of their treatment for multiple sclerosis. Medical practitioners are not providing referrals for people with multiple sclerosis to occupational therapy, and insurance companies limit coverage for occupational therapy services. People with multiple sclerosis who have used occupational therapy as a part of their treatment have found occupational therapy to be beneficial.

There is a marketing dilemma for the profession of occupational therapy. When searching for multiple sclerosis on the American Occupational Therapy Association (AOTA) website, no information was found for consumers about occupational therapy and multiple sclerosis (February 19, 2013). There is a strong need for occupational therapists to market, promote, and advocate for the profession of occupational therapy to people with multiple sclerosis, to members of multiple sclerosis treatment teams, and to health insurance companies to ensure that people with multiple sclerosis are getting the assistance needed to maintain independence as long as possible. Similar studies are needed using a nationwide sample of people with multiple sclerosis. Research needs to be performed to determine the conceptions and misconceptions that medical practitioners have regarding occupational therapy services, and to determine reasons why medical practitioners are not referring people with multiple sclerosis for occupational therapy services.

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Table 1

Demographic Information of the Sample

Survey Item	n	%
Age		
18-29	1	2.5
30-39	2	5.0
40-49	11	27.5
50-59	14	35.0
60-69	9	22.5
70 or over	3	7.5
Gender		
Female	33	82.5
Male	7	17.5
Living community		
Large urban	4	10.0
Small urban	16	40.0
Suburban	11	27.5
Rural	9	22.5
Living situation		
Alone	9	18.0
Spouse/significant other	26	52.0
Child	12	24.0
Sibling	2	4.0
Parent	1	2.0
Other	3	7.5
Type of multiple sclerosis		
Relapsing-remitting	29	72.5
Primary-progressive	3	7.5
Secondary-progressive	6	15.0
Progressive-relapsing	1	2.5
Not sure	1	2.5
Number of exacerbations		
1-4	9	22.5
5-9	11	27.5
10-14	5	12.5
15-19	2	5.0
20 or more	5	12.5
Not sure	3	7.5
Work Status		
Full-time	9	22.5
Part-time	6	15.0
Retired	9	22.5
N/A	12	30.0
Change in primary occupation		
Yes	21	52.5
No	16	40.0

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Mobility purposes	14	35.0
Wheelchair	11	27.5
Walker	16	40.0
Cane	2	5.0
Other	15	37.5
None		
Quality of life		
Good (mean)		69 (mean)
Quality of life		
Very good	11	27.5

Notes. N= 40. Some total percentages do not equal 100% as some questions allowed for more than one response or respondents left the question blank.

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Table 2

Use of Occupational Therapy (OT) Services

Survey Item	n	%
Currently use OT	1	2.70
Used OT in the past	14	37.84
Never used OT	27	72.97
Might use OT in the future	11	29.73
	N= 37	
Used OT during an exacerbation	6	15.0
Used OT after an exacerbation	5	12.5
Used OT between exacerbations	4	10.0
Never used OT	26	65.0
	N= 40	

Note. N totals add up to more than 37 and 40 and percentages do not equal 100 as the questions allowed for more than one response.

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Table 3

Use of Occupational Therapy and Mobility Purposes

Mobility Device	Use of OT Services	%
Wheelchair	n= 10	71.429
Walker	n= 7	50.0
Cane	n= 5	35.714
None	n= 1	7.143

Notes. N= 14. Total adds up to more than 14 as some people indicated using more than one device.

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Table 4

Reasons for Not Using Occupational Therapy (OT)

For not using in the past	n	%
Did not know what OT was	7	17.5
Function was not affected	6	15.0
Felt OT was not needed	6	15.0
Had too much to deal with	5	12.5
No insurance coverage	5	12.5
Did not want help	4	6.2
Did not know how to ask for help	4	6.2
No referral for OT	4	6.2
Cost too much	4	6.2
No transportation	3	4.6
Just wanted to be normal	3	4.6
Too afraid	2	3.1
Too embarrassed	2	3.1
Insurance limited number of visits	2	3.1
Felt no one could help	2	3.1
Too depressed	1	1.5
Did not understand what OT is	1	1.5
Did not want to be labeled	1	1.5
Did not want to lose independence	1	1.5
Was too angry	1	1.5
No OT available close to home	1	1.5
For not using currently	n	%
Do not know what OT is	7	17.5
Function is not affected	7	17.5
Insurance limits number of visits	6	15.0
Feel OT is not needed	5	12.5
No referral for OT	5	12.5
Have no insurance	4	6.6
Have no transportation	4	6.6
Costs too much	4	6.6
Want to be normal	3	4.9
No OT available close to home	3	4.9
Do not know how to ask for help	2	3.3
Too afraid	2	3.3
Feel no one can help	2	3.3

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Do not want help	1	1.6
Too angry	1	1.6
Do not want to lose independence	1	1.6

Notes. N= 40. Values do not add up to N= 40 as not all responses were included in this table and respondents were permitted to select multiple answers.

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Table 5

Knowledge of Occupational Therapy Services

Area	% Agree	% Disagree	% Unsure
Dealing with stress	15.6	30.4	17.6
Managing fatigue	28.0	10.3	6.6
Communication and socialization	16.8	23.1	13.2
Do grocery shopping for me	3.2	66.5	12.1
Joint protection	20.8	8.8	11.0
Range of motion	21.2	14.5	11.0
Cognitive skills	26.4	12.8	6.6
Take care of my pets or kids	12.3	40.9	11.0
Activities of daily living	28.8	5.1	5.5
Adaptive equipment	26.8	5.1	5.5

Note. N= 40.

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Table 6

Occupational Therapy (OT) Use and Specific Activities

Variable	Have used OT for this	Will not use OT for this	Would use OT for this	N
Arranging living environment	11.6%	10.1%		32
Accessing computer		12.8%		33
Performing activities of daily living	16.3%		10.6%	36
Dealing with depression		14.9%		37
Feeling less fatigue			12.7%	37
Helping with mobility			13.2%	37
Managing pain			9.5%	35
Participating socially		13.5%		36
Managing muscle weakness/ spasticity			10.6%	38
Increasing range of motion			11.1%	37
Managing cognitive deficits			9.5%	36

Note. Percentages indicate the majority of responses for each activity.

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Table 7

Perceptions of Occupational Therapy (OT) Services

Variable	OT has been helpful for this	OT might be helpful for this	OT has not been helpful for this	Do not think OT would be helpful for this	N
Arranging the living environment		11.2%	20.8%		30
Accessing computer		10.1%	12.5%		31
Performing activities of daily living	18.4%	11.7%			33
Dealing with depression			12.5%	15.5%	30
Feeling less fatigue	13.2%	9.5%			32
Helping with mobility	13.2%	9.5%			31
Managing pain				13.4%	30
Participating socially				11.3%	29
Managing muscle weakness/spasticity				10.3%	30
Increasing range of motion	15.8%	9.5%			31
Managing cognitive deficits			12.5%	10.3%	32

Note. Percentages indicate the majority of responses for each activity.

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Table 8

Reason Occupational Therapy (OT) was Helpful

Survey Item	n	%
Gained function	10	25.0
Coping	9	22.5
More independent	9	22.5
Feel more normal	6	15.0
Have more energy	5	12.5
Have not used OT	23	57.5

Notes. N= 40. Values do not add up to N= 40 as respondents were permitted to select multiple answers.

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Table 9

How People with Multiple Sclerosis Spend the Majority of their Time

Survey Item	n	%
Hobbies/leisure activities	14	35.9
Reading	7	18.0
Housework (cooking, cleaning, laundry, money management)	11	28.2
Resting/sleeping	10	25.6
Using the computer	9	23.1
Working	7	18.0
Watching television	7	18.0
Spending time with family/friends	7	18.0
Caring for children or others	4	10.3
Exercise/walking	3	7.7
Medical appointments/managing health	3	7.7
Volunteer work	3	7.7

Notes. N= 39. Values do not add up to N= 39 as respondents were permitted to select multiple answers.

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Appendix A: Human Subjects Proposal Materials**Principle Investigator:** Jaime Seamans**Title:** Graduate Student**Faculty Advisor:** Dr. Melinda Cozzolino**Department:** Occupational Therapy**School:** HSHP**Email:** jseaman1@ithaca.edu**Project Title:** Occupational Therapy and Multiple Sclerosis: A Study to Determine Use and Perceived Need of Services

Abstract: Multiple sclerosis (MS) is a chronic, degenerative disease that attacks the central nervous system (CNS). The disease is disabling, progressive, and is thought to be an autoimmune disease. Nerves in the CNS are damaged or destroyed. The irreversible damage to the nerves causes people with MS (PwMS) to experience a wide variety of symptoms and limitations in their functional abilities and a decreased quality of life (QOL).

Researchers have shown that occupational therapy (OT) is beneficial for PwMS at all stages of the disease process by improving fatigue, self-efficacy, functional abilities, occupational participation and performance, and QOL in PwMS. However, there has been a lack of research performed to determine the percentage of PwMS who use OT services and to determine the perceived need for OT services among PwMS. The purposes of this study are to determine the percentage of PwMS who use OT services, to determine the perceived need for OT services among PwMS, and to determine reasons why PwMS might not use occupational therapy services.

A researcher designed survey will be available online through Qualtrics, and the survey will also be available in hard copies provided to local support groups. Participants will also be asked to complete the Global Quality of Life Scale. Participants will be recruited online through the Upstate New York Chapter of the National Multiple Sclerosis Society and through Facebook, and through support from group leaders during MS support group meetings. Variables and data for the quantitative and open-ended responses will be entered into SPSS and frequency distributions will be used to summarize results.

The information gained through this study will provide useful information in OT practice for PwMS and should be used as a tool for occupational therapists to provide services to PwMS, and to educate and promote their services to PwMS and to their health care practitioners.

Additional Researchers:

-Dr. Melinda Cozzolino, Chair Graduate Program, Occupational Therapy, mcozzoli@ithaca.edu

-Dr. Diane Long, Chair of Department, Occupational Therapy, dlong@ithaca.edu

Funding: No

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Location of Study: local Central New York MS support groups, online

Proposed Implementation start date: November 1, 2012

Duration of Project: one year

Expected outcomes:

1. Complete my Master's Thesis
2. Gain knowledge about the role of occupational therapy in MS
3. Submit for presentation at OT meetings for local/national conferences
4. Possible submission for publication

Related Experience of Researchers:

-Jaime Seamans: I am a second year Graduate student. I have had the following classes that provide experience related to research, occupational therapy, and multiple sclerosis: neuroscience, research methods, research seminar, adult clinical conditions, occupational therapy theory. I also have a sister with multiple sclerosis and have spent much time since her diagnosis learning and studying the disease.

-Dr. Melinda Cozzolino: I received my Bachelors of Science from Keuka College in Occupational Therapy in 1990 and have worked as a licensed and registered Occupational Therapist for 16 years. My work experience has included both inpatient and outpatient settings in orthopedic, neurological and psychiatric rehabilitation. I received my Masters of Science from Scranton University in 1996 in Rehabilitation Counseling, and have been a Certified Rehabilitation Counselor since 1997. I hold a Board Certification from the American Occupational Therapy Association in Neurological Rehabilitation (1999).

I began work at Ithaca College's Department of Occupational Therapy as a Clinical Assistant Professor in 1999 where my job responsibilities included teaching and developing and running the Adult Occupational Therapy portion of the OT/PT clinic on campus. In 2001 I was Principal Investigator of a funded Health Resources and Service Administration (HRSA) grant to support the Interdisciplinary Program, The Center for Life Skills. In 2004 I completed my Post Professional Doctorate in Occupational Therapy from Creighton University and subsequently transferred into a full time Academic Position and became Graduate Chair.

-Dr. Diane Long: School-based and pediatric occupational therapy have been the primary focus of Professor Long's clinical career and she brings more than 20 years of hands-on experience to the classroom. Since joining Ithaca College as a full-time faculty member in 1998, she has coordinated and taught courses about human development, pediatric theory and treatment, and school-based practice. Dr. Long supervises graduate students in group research and individual thesis projects. Her doctoral work focused on clinical reasoning of occupational therapy students.

Number of Participants: 200

Salient Characteristics: People with MS over 18 years of age with at least one exacerbation of symptoms since initial diagnosis

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Description of Participation: Subjects will complete a researcher designed survey and standardized Global Quality of Life Scale. The survey will take no more than 20 minutes of time. Participants will have the option of completing the survey through a written hard copy or online through Qualtrics.

Recruitment Procedures: 1. Post links on the National Multiple Sclerosis Society website for web-based support. 2. Post links through Facebook for web-based support. 3. Recruit support group leaders of local chapters who will make the survey available to interested parties in hard copy or through a web-based link.

Debriefing: Not necessary

Compensatory Follow-up: Not necessary

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Appendix B: Participant Information Sheet for Hard-copy Version

Dear Participant,

My name is Jaime Seamans and I am a graduate occupational therapy student at Ithaca College. Thank you for your interest in my thesis research study entitled *Occupational Therapy and Multiple Sclerosis: A Study to Determine Use and Perceived Need of Services*.

The purpose of my thesis is to survey people with multiple sclerosis (MS) in order to determine reasons why people with MS might or might not use occupational therapy (OT) as a part of their treatment. This information can serve as a guide for providing knowledge about the roles of occupational therapists that are treating people with MS.

If you are over the age of 18 years, have a medical diagnosis of MS, and are able to supply your own answers then you are eligible for this study. You will be asked to complete a survey and a quality of life scale that will take no longer than 20 minutes of time. The survey consists of questions and statements about the following:

1. Demographic information
2. Your level of independence when completing daily activities
3. Your diagnosis of MS
4. Your knowledge of and experience with OT

Your participation is voluntary. You can refuse to answer any question or stop taking the survey at any time.

YOUR COMPLETION AND RETURNING OF THIS SURVEY INDICATE INFORMED CONSENT AND THAT YOU ARE OVER THE AGE OF 18 YEARS. PLEASE SAVE THIS COVER LETTER FOR YOUR RECORDS.

Please read and follow the directions in order to complete the survey. After completion place the survey and quality of life scale in the enclosed, addressed, stamped envelope and mail it. If you would prefer to complete the survey online, it is available online at...(will fill in once link is created).

In order to preserve confidentiality, please **do not** include any identifying information on or with the returned survey.

If you have any questions or would like to receive a copy of the study results please contact:

Jaime Seamans- jseaman1@ithaca.edu or Dr. Melinda Cozzolino- mcozzoli@ithaca.edu
Ithaca College Occupational Therapy Department Associate Professor and Graduate Chair
953 Danby Road Department of Occupational Therapy
Ithaca, NY 14850
(315) 447-5382

MULTIPLE SCLEROSIS

Appendix C: Participant Information Sheet for Online Version

Dear Participant,

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Appendix D: Survey Instrument

Please place a check mark in the box next to correct response or write an answer as needed. Please answer truthfully and to the best of your knowledge.

Occupational therapists support health and participation in life through engagement in occupation (Occupational Therapy Practice Framework, 2008). Occupation is defined as meaningful work, tasks, or activities that people perform throughout their lives.

1. Indicate how much you agree or disagree with the following statements. Occupational therapists will...

	Strongly Agree	Somewhat Agree	Neither Agree nor Disagree	Somewhat Disagree	Strongly Disagree
Teach me how to deal with stress					
Find ways to help me not feel so tired					
Help me communicate/socialize					
Do grocery shopping for me					
Teach me how to protect joints					
Help me keep my joints moving					
Teach me how to be safe and to problem solve					
Help me take care of my children or pets					
Help me find different ways to do the things I want/need to do					
Teach me how to use adaptive devices (walkers, canes, reachers, planners, electric can openers, GPS devices)					

2. Please select all that apply.

- I am currently using occupational therapy (OT) as part of my MS treatment.
- I have used occupational therapy in the past as part of my treatment for MS.
- I have not used occupational therapy as part of my treatment for MS.
- I might use occupational therapy in the future as part of my treatment for MS.

3. An exacerbation is a period of time when symptoms associated with MS get markedly worse. When I have used occupational therapy it was (*Check all that apply.*)

- During an exacerbation After an exacerbation Between exacerbations
- I have not used occupational therapy as part of my treatment for MS

MULTIPLE SCLEROSIS

4. How much help do you need to do the following activities? Please place a check mark in the boxes that best describe your situation.

	I need help with 0% of the task	I need help with 25% of the task	I need help with 50% of the task	I need help with 75% of the task	I need help with 100% of the task	I would use OT to help me in this area
Cooking						
Housekeeping						
Grooming (ex. brushing teeth, shaving, hair)						
Bathing/Showering						
Dressing						
Toileting						
Walking/Using wheelchair						
Transfers						
Performing Leisure Activities						
Cognition						
Communication						
Performing Paid or Unpaid Work						

5. Please place a mark for all that apply.

	I have used OT for this in the past	I am currently using OT for this	I will not use OT for this	I would use OT for this
Arranging my living environment				
Accessing my computer				
Finding ways to help me perform daily activities (ex. bathing, cooking, driving, shopping, school, dressing, toileting,...)				
Dealing with depression				
Feeling less fatigue				
Helping me with mobility				
Managing pain				
Participating in social activities				
Managing muscle weakness/spasticity				
Increasing range of motion in my joints				
Managing cognitive deficits				
Other _____				

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9. I might **not currently use OT because... (Check all that apply.)**

- | | |
|---|--|
| <input type="checkbox"/> I do not want any help | <input type="checkbox"/> I am having no difficulties functioning |
| <input type="checkbox"/> I do not know how to ask for help | <input type="checkbox"/> I have too much to deal with already |
| <input type="checkbox"/> I am afraid to ask for help | <input type="checkbox"/> I do not want anyone to take advantage of me |
| <input type="checkbox"/> I do not understand MS | <input type="checkbox"/> I do not want to be labeled |
| <input type="checkbox"/> I am angry | <input type="checkbox"/> I do not think anyone can help me |
| <input type="checkbox"/> I am too embarrassed | <input type="checkbox"/> I feel like I might lose my independence |
| <input type="checkbox"/> I just want to be normal | <input type="checkbox"/> I just do not care anymore |
| <input type="checkbox"/> I have no insurance coverage | <input type="checkbox"/> I feel like I do not need occupational therapy |
| <input type="checkbox"/> I have no doctor referral for OT | <input type="checkbox"/> I am unsure what occupational therapy is |
| <input type="checkbox"/> Limited transportation/accessibility | <input type="checkbox"/> Cost of treatment without insurance is too high |
| <input type="checkbox"/> Insurance limits number of visits | <input type="checkbox"/> No occupational therapy close enough to my home |
| <input type="checkbox"/> Other (please specify) _____ | |

10. With what type of MS have you been diagnosed?

- | | |
|---|---|
| <input type="checkbox"/> Relapsing-Remitting MS | <input type="checkbox"/> Primary-Progressive MS |
| <input type="checkbox"/> Secondary-Progressive MS | <input type="checkbox"/> Progressive-Relapsing MS |
| | <input type="checkbox"/> Not sure |

11. Number of exacerbations (a period when symptoms of MS get noticeably worse or more severe) since diagnosis?

- 0 1-4 5-9 10-14 15-19 20 or more Not sure

12. For mobility purposes do you use a (Check all that apply) Cane Walker

Crutches Wheelchair I do not use a walking aid Other _____

13. What is your current occupation (paid or unpaid)? _____

_____ Part-time Full-time Retired N/A

14. At any point have you had to change your primary occupation due to complications from MS? Yes No N/A

15. What do you spend the majority of your time doing? _____

16. Who else lives with you? (Check all that apply) I live alone Spouse/Significant other

Child/Children Sibling(s) Friend Parent(s) Relative Other _____

17. Type of living community? Large Urban (city) Small Urban (city)

Suburban (living immediately outside a city) Rural (country)

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18. What is your age?

- Under 18 18-29 30-39 40-49 50-59 60-69 70 or over

19. Are you Male Female

20. I completed this survey independently.

I supplied the answers but had assistance with writing my answers in order to complete this survey.

A loved one supplied the answers for this survey

MULTIPLE SCLEROSIS

Appendix E: Global Quality of Life Scale

Global Quality of Life Scale

100	Perfect quality of life
95	Nearly perfect quality of life
90	
85	Very good quality of life
80	
75	
70	Good quality of life
65	
60	Moderately good quality of life
55	
50	
45	
40	Somewhat bad quality of life
35	
30	Bad quality of life
25	
20	
15	Very bad quality of life
10	
5	Extremely bad quality of life
0	No quality of life

Write any number between 0 and 100 that describes your quality of life: _____