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Fine Motor Skills and the Occupations of Young Adults with Multiple Sclerosis

by

Mary Squillace

Submitted in partial fulfillment of the requirements for the degree of
Doctor of Philosophy in Occupational Therapy
Occupational Therapy Department
Dr. Pallavi Patel College of Health Care Sciences
Nova Southeastern University
Fort Lauderdale, Florida 33328

April 2018

NOVA SOUTHEASTERN UNIVERSITY
HEALTH PROFESSIONS DIVISION
DR. PALLAVI PATEL COLLEGE OF HEALTH CARE SCIENCES
OCCUPATIONAL THERAPY DEPARTMENT
FORT LAUDERDALE, FLORIDA 33328

This dissertation, written by Mary Squillace, under direction of her Dissertation Committee, and approved by all of its members, has been presented and accepted in partial fulfillment of requirements for the degree of

DOCTOR OF PHILOSOPHY

DISSERTATION COMMITTEE

____ _______________
Max A. Ito, PhD., OTR/L Date
Chairperson of Dissertation Committee

____ _______________
Elise Bloch, Ed.D., OTR/L Date
Dissertation Committee Member

____ _______________
Leigh Charvet, PhD., Neuropsychologist Date
Dissertation Committee Member

NOVA SOUTHEASTERN UNIVERSITY
HEALTH PROFESSIONS DIVISION
DR. PALLAVI PATEL COLLEGE OF HEALTH CARE SCIENCES
FORT LAUDERDALE, FLORIDA 33328

Certification

We hereby certify that this dissertation report, submitted by Mary Squillace, conforms to acceptable standards and is fully adequate in scope and quality to fulfill the dissertation requirement for the Doctor of Philosophy degree.

Approved:

Rick D. Davenport, Ph.D., OTR/L — Date
Ph.D. in Occupational Therapy Program Director

Rebecca Estes, Ph.D., OTR/L — Date
Chair of Department of Occupational Therapy

Peter Taylor, PhD. — Date
Associate Dean of Academic Affairs

Stanley H. Wilson PT, Ed.D., CEAS — Date
Dean, Dr. Pallavi Patel College of Health Care Sciences

Abstract

Objective: Multiple sclerosis (MS) is one of the most common neurological diseases affecting adults of working age, and those of younger ages of onset have been increasingly recognized. Twenty-seven percent of people with MS (PwMS) are age 30 years old or younger. The burden of MS for young adults puts them at risk for poorer outcomes regarding their education, family planning, vocation, and social skills as they transition to adulthood. Fine motor (FM) skill impairment might impede performance within the daily occupations of young adults who are transitioning into adulthood. Few studies focus on the occupations and occupational performance of younger adults with MS. ***Method:*** Forty participants with MS between the ages of 18 to 30 were recruited to participate in a study. Two standardized measures were used to identify possible FM dexterity deficits and one standardized self-report was used to measure the perceived satisfaction and performance of occupations for this population. A semi-structured interview was conducted with a subgroup of 18 participants to understand the lived experiences of young adults with MS (YAwMS) and their FM performance during their occupations. ***Results:*** With quantitative and qualitative analysis, a relationship was suggested between FM scores and both perceived performance and satisfaction scores of an adapted performance measure. ***Conclusion:*** Young adults with MS perceive difficulties with occupations that are influenced by their FM status. It is recommended that occupational therapy professionals consider the motor skill needed to perform and complete occupations that specifically require FM skills.

Keywords: Multiple sclerosis, chronic diseases, young adults, occupations, occupational therapy, activities of daily living, cognition, fatigue, occupational participation

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Chapter 1: Introduction

Introduction to the Chapter

Multiple sclerosis (MS) is a degenerative disease of the central nervous system. Multiple sclerosis is typically diagnosed during the most productive time of an adult’s life with onset usually occurring between the ages of 18 and 50 years (Buchanan, Chakravorty, Tyry, Hatcher, & Vollmer, 2009).   At this time, the quality of life of people with MS (PwMS) was compromised through the disruption of vocation, social, and family life (Naci, Fleurence, Birt, & Duhig, 2010). Due to the disease’s effects on the neuromuscular functioning of PwMS, limitations are placed on the performance of activities in a variety of daily occupations. Symptoms of MS, such as fatigue, lower cognitive abilities, and physical deficits, compound the occupational limitations of PwMS. The most common limitations are mobility within the home and community, home management, activities of daily living (ADLs), vocational needs, and social interactions (Finlayson, Impy, Nicolle, & Edwards, 1998). Independence in any of these areas produces a healthier quality of life in personal, social, and familial roles, but within the lifespan of PwMS, limitations may create problems in functional areas not initially affected by the disease. Activities of daily living involving self-care, such as productivity in work or school or leisure tasks, may be compromised due to intermittent relapses of the disease. A relapse is a period when existing symptoms of MS worsen or new symptoms appear. There has been research to show that the combination of MS symptoms may be responsible for deficits in occupational performance (Mansson & Lexell, 2004).

Management of ADLs for PwMS will minimize the effect of the limitations in this area and create a more independent life at home and within the community for this population (Mansson & Lexell, 2004). Yeh, Hopkins, Grover, and Mod (2015) has suggested that physical activity for PwMS can improve overall functional health related outcomes, including social wellbeing. There is evidence that the general symptoms of MS influence occupational performance (Lexell, 2009); however, the effect of FM deficits and occupational task performance has not been examined.

Background and Overview

Occupation-Based Studies

Finlayson et al. (1998) found that instrumental activities of daily living (IADL) (i.e., cooking, cleaning) that were all required tasks for independent living were reported as the more difficult tasks for PwMS. Individuals with MS show more independence with their personal ADLs, such as grooming and feeding, than IADLs but indicated a high incidence in limitations within the areas of self-care and leisure tasks for all types of MS (Finlayson et al., 1998). It is also suggested that ADL performance is reduced with the progression of the disease (Finlayson et al., 1998). It has been shown that specific activity limitations are based on the type of MS and area of occupational performance (Lexell, 2009).

Dohle, Fisk, Ritvo, and Murray (1994) investigated IADLs (i.e., home management tasks), using a standardized measure for functional competence: the Assessment of Motor and Process Skills (AMPS). They found that 22 individuals with mild to moderate MS scored significantly less on the AMPS than their control group on the motor and processing skills for their IADLs (Dohle et al., 1994). The final composite score of all domains prevented the determination of which IADL was the most problematic. Mansson and Lexell (2004) used the Functional Independence Measure (FIM) and the AMPS to measure ADLs and IADLs in a group of individuals with moderate to severe MS. They found that 24 of the 44 participants were dependent in their personal ADLs as measured by the FIM measure and two thirds of the participants rated themselves independent to modified independent with personal ADLs on the FIM but scored as dependent on the AMPS. They found that those with moderate to severe MS present with limitations in performing both ADLs and IADLs (Mansson & Lexell, 2004). Adding to these results, Mosley, Lee, Hughes, and Chatto (2003) found that 78% of a total sample of 40 participants had difficulties in at least one daily occupation, being within the areas of mobility, work, IADs, or ADLs.

Daily occupations, such as ADLs and IADLs, are required for the coordination of upper extremity muscle strength, control, and dexterity. If the combination of these components of upper extremity function is compromised, simple tasks may become more difficult. Simple tasks within daily occupations, such as opening and closing objects, manipulation of writing tools or utensils, or dressing and grooming oneself, are required for the use of FM skills. If the FM skills of a younger adult are affected by the symptoms of MS, the result may be problems performing daily occupations.

FM and occupations. Neurological disorders can cause impairment of digit muscle strength and manipulative skills throughout the developmental process (Vollmer et al., 2010). Both gross motor and FM deficits are very common in PwMS with 80% to 90% reporting weaknesses, coordination issues, and spasticity as the most common complaints that contribute to functional limitations (Finalyson et al., 1998). Limitations due to reduced activity levels may lead to muscle weakness and atrophy in PwMS (Hojjatollah, Khosrow, Shirazi, Masudoi, & Monireh, 2012). Kierkegaard, Einarsson, Gottberg, von Koch, and Widen-Holmqvist (2012) reported that two functional skills needed for ADL performance, manual dexterity and walking, are important components of perceived problems in ADL performance for PwMS, especially those with independence in mobility skills. Sufficient digital muscle strength is required to initiate and maintain appropriate grasp pattern while pinching and grasping.

Motor development follows a pattern of gross motor development, creating the foundation of movements, to FM development involving smaller muscle groups. Gross motor muscle weaknesses typically indicate that FM weaknesses may be present with various central nervous disorders (CNS) disorders. Simple ADLs are required for coordinative and appropriate synchronization of fingertip pressure for the successful performance of these activities (Gorniak, Plow, McDaniel, & Alberts, 2014). The result of an inability to coordinate FM movements and forces may lead to dropping or slipping of objects, thus creating an inability to perform ADLs that require FM skills (Gorniak et al., 2014). Squillace, Ray, Milazzo, Charvet, and Krupp (2016) measured the pinch strength of adolescents with MS and found weakness in the right hand two-point pinch strength as compared with a healthy control group.

The pinch grasp will generate an opposing force against an object for the intention of grasping smaller or finer objects that require precision of a grasp (Deutsch & Newell, 2002). In assuming a pinch force grasp, there are the issues of coordination of the digits involved in the grasp, including the size of the hand and the strength (Moerchen, Lazarus, & Gurben, 2007). A thumb and finger oppositional position is used for finer grasping intentions and the coordination of the digits along with other factors, such as the shape and size of the object, which has an important role in FM manipulation that will require a certain level of strength (Li, Nataraj, Marquardt, & Li, 2013). Young adults with MS who experience FM issues may have an inability to oppose the thumb and extend the digits to assume an appropriate pincer grasping pattern.

The hand has both intrinsic and extrinsic muscles, and the combination of these structures creates complex and different gasp patterns (Rybski, 2012). The strength that is required during pinch grasping patterns is controlled by several factors, such as independent digital force, intrinsic coordination, and the force required by particular tasks. It is a combination of the biomechanics, anatomical structure, neuromuscular control, and task limitations that makeup the force required for FM skills (Li et al., 2013).

The coordination of sensation, proprioception, joints, and muscles of the hand are used to produce the requirements for accurate prehensile skills (Rybski, 2012). The neurological relationship between the intrinsic and extrinsic muscles of digits that are used in finer grasping patterns may explain why peripheral factors may be negated as an influence on the coordination of the grasp (Moerchen et al., 2007).

It is not uncommon for those with weaknesses to use compensation in an attempt to generate sufficient pinch strength in order to successfully perform the task, and the grip configuration will play a role in the level of strength needed (Sharp & Newell, 2000; Moerchen et al., 2007). Therefore, if there are more digits incorporated in a pinching task, the result will most likely yield more strength and better coordination.

In testing the gross and FM strength changes of adolescents with pediatric MS as compared with a matched control group, Squillace, Milazzo, and Ray (2015) found that gross grasp strength was not a contributing factor in the FM tasks for this population, but the right hand, two-point pinch strength was found to be weaker for this population with MS. In this study, pinch weaknesses for this population was used to support the concept of the relationship between intrinsic muscle strength and the coordination skills needed for participation in functional and daily activities.

Krishnan and Jaric (2008) found that dexterity is linked to gross grasp strength in adults with MS and that differences exist in the FM skills and grasp strength within the control group and related these differences to those with advanced types of MS, such as secondary progressive MS (SPMS), progressive relapsing MS (PRMS), and primary progressive MS (PPMS; see Appendix A; Litchfield, 2010). PwMS have been found to display atypical grip force control in basic manual tasks and a larger grip force with compensation for strength loss during the grasping of static objects (Gorniak et al., 2014). Hojjatollah et al. (2012) found that PwMS present with a 30% to 70% difference in muscle strength as compared with a healthy adult population. Gorniak et al. (2014) investigated the incurred kinesthetic deficits when performing tasks that require bilateral activities measured the overall time tasks of common ADL tasks between PwMS and healthy controls. They found (a) task times were longer for PwMS, (b) time was influenced by the type of task and kinetics used to complete the tasks, (c) grip forces of the MS group were significantly larger than the healthy group when completing their tasks, and (d) PwMS showed differences between grip and load forces exerted in handheld objects (Gorniak et al., 2014). These findings indicate that a person with MS may lose dexterous abilities required of bilateral or typical functioning for finer ADL tasks, such as fastening clothes or writing.

FM weaknesses have been found in previous studies that investigated FM control and manipulation weaknesses (Julian et al., 2013; Squillace et al., 2015). Tal-Saban et al. (2014) found a link between motor coordination and the influence of the symptoms on the level of function at one point in the disease. Squillace et al. (2015) found significant differences in dexterity between adolescents with MS and an age and gender control group as measured by Purdue Peg Board Test (PPBT) and Nine-Hole Peg Test (9HPT). In a study of adults with MS, it was found that difficulties in ADLs were linked to manual dexterity issues and general FM problems (Kierkegaard et al., 2012).

By recognizing FM limitations with functional activities and occupations, occupational therapists can direct their focus to the underlying reason for these limitations and look at the intrinsic functions of the hand, such as FM strength and coordination.

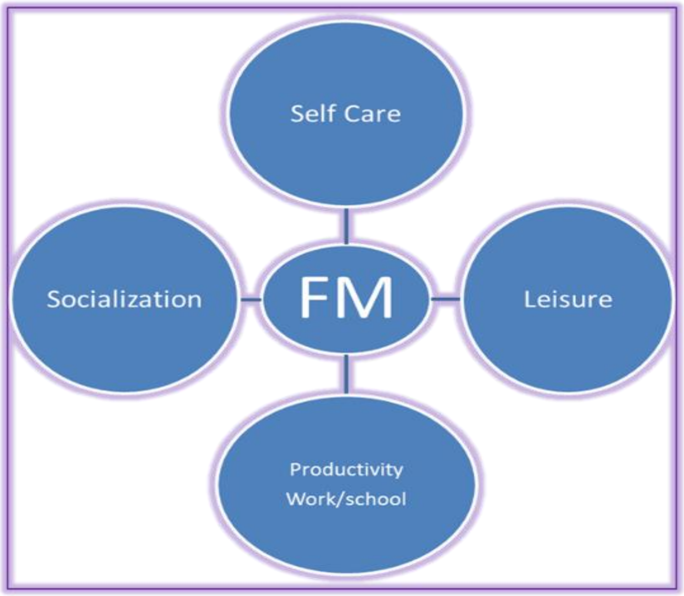

Figure 1. Fine motor (FM) deficits may have effects on the components of the COPM in terms of self-care, leisure and productivity along with social occupations of YAwMS.

Fatigue and occupations. Fatigue is reported to be the most common symptom of PwMS (MacAllister & Krupp, 2005). Fatigue has been found to play a significant role in the outcome of occupational performance limitations for PwMS (Stroud & Minihan, 2009). It is reported that PwMS who engage in physical exercise are less likely to experience fatigue as a primary factor in limitations of occupations (Stroud & Minihan, 2009). Yu and Mathiowetz (2014) determined with a systematic review that intervention programs benefit the functional performance of PwMS if they have individualized programs and goals. Finlayson et al. (1998) reported that 55% of 115 patients with MS described that fatigue was the main contributor to problems with ambulation or standing, followed by IADLs and ADLs. Lundmark and Bronholm (1996) measured the preferred occupations of PwMS and found that those with less fatigue were more independent with personal ADLs and satisfied with their IADLs and leisure tasks, but 15 of the 30 in the sample size were dissatisfied with their occupations.

Invisible symptoms, such as fatigue, mood changes, and cognitive slowing, are common and can also contribute to deficits in occupational functioning. Sandroni, Walker, and Starr (1992) found that fatigue in PwMS resulted in a slower reaction time during memory tasks. Krupp, LaRocca, & Schienberg (1988) found that PwMS demonstrated more disabling performances in ADLs than those without MS when fatigued.

Cognition and occupations. Approximately 65% of PwMS exhibit a cognitive impairment (Caramia, Tinelli, Fracia, & Pozzilli, 2010). Although cognitive impairments are common in MS, there is limited evidence that links cognitive impairments to the occupational or functional status of PwMS. It has been recognized that cognitive deficits affect the ability to perform everyday tasks for PwMS (Kierkegaard et al., 2012). Cognitive impairments related to MS can have damaging ramifications on the social, vocational, and daily life occupations in the lives of those with the disease (Caramia et al., 2010). Dohle et al. (1994) found that PwMS who demonstrate cognitive impairments are more likely to suffer vocational disparities, present with problems with ADLs/IADLs, and avoid social activities.

Nunan et al. (2015) reported that PwMS show cognitive deficits, such as memory, visual-motor integration, attention span, executive functioning, verbal fluency, attention, and working memory are the result of impaired processing speed. Using a meta-analysis of 57 studies, Nunan et al. (2015) found that a large component of cognitive deficits for PwMS lies in processing speed and focused attention, leading to deficits in word retrieval and other language skills. For YAwMS, cognitive deficits have been found in executive functioning and issues with problem solving, planning and sequencing, and selfregulation. These same deficits have been found to affect functioning abilities in all PwMS (Nunan et al., 2015).

Baruch et al. (2016) compared the cognitive status of adults with pediatric-onset MS (POMS) to adult-onset MS (AOMS) showed that those diagnosed with MS at a younger age resulted in more information processing speed delays than the AOMS group. These results indicate that there is a diminishing factor within the cognitive areas of those with long standing MS, and there are potential deficits within functional occupations due to cognitive abilities as the disease progresses.

Kalmar, Guardino, Moore, Halper, and DeLuca (2008) recruited 74 clinically diagnosed participants with MS who were compared to 35 healthy individuals using the Executive Function Performance Test (EFPT). The EFPT is a standardized measure of functional capacity that involves participants engaging in everyday tasks within their familiar environmental context. Scoring was based on observation of assistance needed by the participants to complete five essential simple tasks for independent living. Kalmar et al. found a relationship between cognition and the functional status of PwMS, especially during more complex tasks. Participants with MS with cognitive impairments required more assistance to complete the test than the healthy controls (Kalmar et al., 2008). The strongest relationship between cognition and functional status were in executive functions, new learning tasks, and processing speed, thus determining the level of independence in occupational performance within ADLs (Kalmar et al., 2008). Similarly, Kierkegaard et al. (2012) found a relationship between cognitively challenging tasks of ADLs and cognitive processing speed for PwMS. They also found that independence with IADLs was related to faster ambulation and manual dexterity speed.

Tadic and Dajic (2012) used the MS Quality of Life-54 (MSQOL) questionnaire with 50 participants (22 males, 28 female) and found that the cognitive function domain had the least influence on the quality of life (QOL) but lower scores for the effect of physical problems on health perception, QOL, and role limitations contributed to poorer quality of life for participants.

Relationships between cognitive processing speed and depression have been found in cognitive tasks that require varying levels of effort. Psychological factors were a significant determinant on thought processing and the quality of life, including functional daily activities for those with MS (Diamond, Kaufman, Johnson, & Graves, 2008).

Depression and occupations. Major depressive disorder is believed to occur in 27% to 54% of PwMS. Major depressive disorder was found in 26% in PwMS aged 18 to 45 as compared with 8% of the general population in a population-based study (Patten, Beck, Willams, Barbui, & Metz, 2003). Invisible symptoms of MS, such as depression, often play a significant role in affecting the occupations and the overall participation and performance of occupations. Depression is one of the more common symptoms of MS that begins upon the initial diagnosis and remains a constant factor of the disease process (Rumrill, 2009a). Depression, along with other variable symptoms, contributes to the occupational limitations and prevents engagement in ADLs needed for autonomous living (Rumrill, 2009a).

Depression is often masked by the visible symptoms of MS and often remains untreated. Frequently, other symptoms of MS, such as fatigue and cognitive issues, appear similar to depressive symptoms. Contrary to expectation, PwMS manifest symptoms of depression through higher irritability and anxiety but demonstrate less social withdrawal and indifference (Nunan et al., 2015).

Depression is a common symptom within all age groups. Both younger and older adults with MS express similar levels of depressive symptoms (Buchanan et al., 2009). Physical and mental health symptoms were found in young adults less than 31 years of age. Buchanan and Huang (2011) found less physical disability in younger adults with MS based on the Health-Related Quality of Life survey as compared with older adults. No significant differences were found within the area of mental health.

Young Adults with MS

Approximately 250,000 American young adults are diagnosed with MS (Rolak, 2002). Progressive technology and increased knowledge of the disease has allowed for early diagnosis of MS in young people (Uccelli, 2013). The proportion of MS is higher in young adult females than males. African-American females between 18 to 25 years of age are found to be diagnosed younger than the Caucasian population. African-American woman comprise a larger population of young female adults with MS, and it is double the size of those among the older adult population with MS (Buchanan et al., 2009). The ratio of 2.3 to 3.5:1 has increased within the last few decades (Harbo, Gold, & Tintore, 2013). With the increase in age of onset, the incidence of diagnosis leans towards the male gender (Buchanan et al., 2009). Furthermore, women experience an earlier onset of the disease with a lower prevalence of more advanced types of MS and less progression of disability then men (Harbo et al., 2013).

Buchanan et al. (2009) found differences in the reported symptoms and disabilities of young adults (<30 years) and older adults (>30 years) with MS. Buchanan et al. (2009) found that although there were reported “fewer and less severe disabilities” with the younger adult population, many of the studied young adults reported high level of impairments in more than one domain (p. 277). Buchanan et al. (2009) found that younger adults reported less physical disability but no differences in total depression symptoms as compared with older adults with MS. Higher levels of mild to moderate fatigue were reported in four out of 10 subjects of young adults with 22% suffering with severe disability as it is related to fatigue (Buchanan et al., 2009). Younger adults demonstrated less frequent disability in regard to gait, cognition, and bowel and bladder control, but a large proportion experienced moderate to severe disability in these areas (Buchanan et al., 2009).

Significant milestones evolve during young adulthood, such as development of more mature relationships, emotional independence, vocational decisions, significant and appropriate social roles, and the development of age appropriate activities, which are symbolic of their needs as a young adult (Llorens, 1970). Through a young adult’s developmental process, responsibilities, relationships, and significant life choices occur. For young adults, depending on their personal life and culture, living with MS becomes a relevant part of their life decisions (Uccelli, 2013). Young adults experience many milestones; therefore, living with MS is required for successful mastering of self-care, productivity, and self-management. Older teens will experience concerns regarding school performance, transitions to higher education, and vocational choices. At age 20 to 30, young adults seek to find balance between their career, family, and management of the disease (Uccelli, 2013). YAwMS experiencing life transitions may require additional supports from their environmental and social contexts in order to obtain success in their occupations throughout the remainder of their lives.

In the United States, the cultural expectations of healthy young adults to leave home, engage in healthy relationships, and to find a career are a common developmental stage that are also expected for young adults with a chronic illness (Verhoof, Stam, Heymans, Evers, & Grootenhuis, 2014). The difference lies in the challenges the young adults with chronic illness face regarding their disease. Stam, Hartman, Deurloo, Groothoff, and Grootenhuis (2006) found that adolescents and young adults with chronic illnesses have achieved fewer social developmental milestones. Stam et al. (2006) discussed the importance of transitioning into adulthood and maintaining social contacts and social development. A diagnosis of a chronic illness for young adults may influence or change relationships with peers due to self-image issues and foster feelings of rejection or separation from their peers. Stam et al. (2006) suggested a diagnosis of chronic illness for a young adult complicates their transitions to adulthood in terms of living independently, attending higher education, or finding a career. Other challenges of this population are relationships with parents, self-image problems, and difficulty in informing life partners or significant others of their diagnosis (Uccelli, 2013). Verhoof et al. (2014) found that regardless of the type of chronic illness, younger persons demonstrate limited occupational performance and participation in everyday life tasks as opposed to their peers.

The quality of life of YAwMS can be affected by the occurrence or reoccurrence of a significant neurological event. An exacerbation or attack may require hospitalization and disrupt vocational, social, and family life. The physical disabilities along with cognitive and psychosocial deficits acquired from frequent attacks may temporarily or permanently affect the functional skills required for age appropriate occupational performance. It was found that inactivity related to MS symptoms can lead to deconditioning and further be the cause of secondary medical issues, such as depression or cardiac issues (Kayes et al., 2011). Naci et al. (2010) stated that MS can damage a person’s confidence and place limitations on his/her professional and personal life tasks. The common symptoms of MS that include weakness, fatigue, and cognitive impairments can lead to depression and isolation and increase the likelihood of economic stressors due to the inability to work (Naci et al., 2010).

Problem Statement

Among those living with MS, one in four people have been diagnosed at age 30 years or younger, yet limited literature is available in which the focus is on the occupations and occupational performance of younger adults with MS (Buchanan et al., 2009). While most PwMS are diagnosed between 20 to 50 years of age, MS can present in younger children or much older adults. The management of the disease differs from that of a young adult from very young children or an older person with MS (Buchanan et al., 2009). FM skill impairment may impede performance within the daily occupations of young adults who are transitioning into adulthood.

Purpose of the Study

The purpose of this dissertation study was to explore the FM motor status of YAwMS and determine the role FM skills play in their functional and social occupations.

This research project has four specific research objectives: (a) to assess FM skills using the Purdue Peg Board Test (Lafayette Instrument, 2002b) and Grooved Peg Board

Test (Lafayette Instrument, 2002a) in approximately 40 young adults between the ages of 18 to 30 diagnosed with MS; (b) to measure the perceived level of satisfaction and performance as related to the self-care, productivity, and leisure occupations of YAwMS using the adapted Canadian Occupational Performance Measure (COPM; Law et al., 1998); (c) to determine the difference and relationship between FM deficits (independent variable) and occupations (dependent variable) of YAwMS through a mixed method research approach; and (d) to determine the factors of the disease that affect occupational performance as defined by the participant through a semi-structured interview.

Research Questions and Hypotheses

The overarching research question guiding this study is "How does the FM status of YAwMS relate to their perceived occupation was used to address the physical, emotional, and psychosocial complexities that affect the occupations and occupational performance of YAwMS in terms of self-care, productivity, and leisure. This mixed method research strategy had characterized symptoms experienced by YAwMS and the disease's effect on their occupations as a young adult. The combined design was used for a richer understanding than an individual application of either method (Plano-Clark, Huddleston-Casas, Churchill, O'Neill, & Garrett, 2008).

Quantitative Questions

The following research questions were investigated using quantitative methods:

1. What is the FM status of YAwMS between the ages 18 and 30 years as measured by the Grooved Peg Board Test and Purdue Peg Board Test?

2. What is the level of perceived satisfaction and performance of occupational tasks that are prevalent in YAwMS as measured by an adapted Canadian Occupational Performance Measure?
3. Is there a difference between the perceived performance and satisfaction of occupations as measured by the adapted COPM and the FM skills as measured by the PPBT and GPBT of YAwMS?
4. Is there a relationship between the perceived performance and satisfaction of occupations as measured by the adapted COPM and the FM skills as measured by the PPBT and GPBT of YAwMS?

It is hypothesized that young adults will not be satisfied with their occupational performance in their problem areas as related to their FM status.

Qualitative Question

What are the lived experiences of the occupations and occupational performance associated with the FM skills of MS for young adults?

Overarching Question

How does the FM status of YAwMS relate to their perceived occupational performance and satisfaction and lived experiences?

Definitions of Variables

Occupation and Occupational Performance

Conceptual definition. The American Occupational Therapy Association (AOTA) defines occupation as the following:

1. Occupations refers to the daily life activities in which people engage.

> 2. Occupations occur in context and are influenced by the interplay among client factors, performance skills, and performance patterns. Occupations occur over time; have purpose, meaning, and perceived utility to the client; and can be observed by others (e.g., preparing a meal) or be known only to the person involved (e.g., learning through reading a textbook). Occupations can involve the execution of multiple activities for completion and can result in various outcomes. (AOTA, 2014, p s5)

Townsend (2002) described occupation as any task that people do to occupy themselves. These tasks include self-care, leisure, and productivity tasks. Occupations are individualized and relative to each person in which they are organized and given meanings within an individual’s context, including culture. Overall health, wellbeing, and quality of life is an attainable goal when addressing all components that make up a person, including their occupations.

Self-care includes tasks that are needed for personal care, functional mobility, and community management. Productivity includes tasks involved in work duties, household responsibilities, and school activities if appropriate. Leisure activities include two levels of recreation, such as quiet or active recreation, and socialization skills (Law et al. 2014).

Occupational performance is the outcome of the interaction and the relationship of the occupation, the person, and the environment. Kielhofner (2008) described occupational performance as how a performance interacts with itself and other performed occupations within the context (social, physical, and cultural) to which it was performed. The result of this interaction is an observation of people doing something (Kielhofner, 2008)

Operational definition. Occupations for the dissertation study were measured using the Canadian Occupational Performance Measure (Law et al., 2014). The COPM is a semi-structured, interview, self-report-based rating scale that measures changes in the client’s self-perception of occupational performance over time. The COPM is an outcome measure that will identify problem areas in the participant’s occupational performance, determine the level of importance of each area of occupational performance, and evaluate the participant’s performance and satisfaction relative to possible problem areas (Law et al., 2014).

The scores on the COPM were calculated using mean scores of satisfaction and performance of the self-reported problematic areas of self-care, productivity, and leisure skills. For the purposes of the dissertation study, the scores were not related to an outcome due to an intervention but on learning the perceived performance, satisfaction, and problem areas for young adults diagnosed with MS.

FM Skills

Conceptual definition. Fine motor skills and coordination include the small muscle groups of the hand. These skills are needed for essential daily activities, such tying or buttoning for dressing, tool manipulation for feeding, writing, and cutting, and for work activities that require assembling (Cantell, Ahonen, & Smyth, 1994; Losse et al., 1991; Stoeger, Ziegler, & Martzog, 2008).

Operational definition. The fine motor skills and status for this study was measured using the Grooved Peg Board Test and Purdue Peg Board Test (See detailed description on page 67).

The scores for the PPBT include a total number of pegs placed with the right and left hands (individually and together) in 30 seconds, the assembly component of washers, collars, and pegs in 60 seconds, and a combined score of the left and right-hand performance. The primary score is derived from the time it takes to complete the GPBT. The mean scores of each hand were calculated and compared with the standardized normative data provided by the GPBT manual and transformed to *z* scores. These scores were defined as above or below mean performance (See Quantitative Data Analysis on page 81).

Multiple Sclerosis

Conceptual definition. Multiple sclerosis is a chronic, progressive autoimmune disease that results in permanent neurological deficits, such as muscle weakness, compromised motor skills, sensory issues, visual and cognitive deficits, and speech and language deficits (Buchanan et al., 2009).

Operational definition. The level of impairment for this dissertation study was defined by the Kurtzke Expanded Disability Status Scale (EDSS; Tarver, 2015). The aim of this tool is to offer an objective measure of the level of neurologic functioning for PwMS (Tarver, 2015). The dissertation study included those with scores from 0 to 6.0, with any subtype of MS. The scoring 6.0 had a requirement of ambulation assistive devices to walk approximately 100 meters with or without a rest and were not expected to have upper extremity abilities and endurance to perform occupational tasks.

Rationale

Currently, there is a paucity of research on the relationship between the FM skills and the occupations of YAwMS. The FM status utilizing the PPBT and GPBT and the satisfaction and performance of occupations using the COPM were measured in the dissertation study. These quantitative results were used to provide a baseline for the qualitative semi-structured interview to explore the effects of FM skills with or without deficits on the occupational experiences of YAwMS.

The combined FM motor assessment, the PPBT and GPBT, were the tests for the physical component of the study. Each assessment was used to find a FM status of the participants. These assessments also were used to address cognitive skills, such as memory, visual perception, and an ability to follow directions. The PPBT included both individual and bilateral FM skills that required a coordination of cognition and motor skills during timed testing. Fernandes et al. (2015) found significant relationships between motor coordination and cognitive functioning in which visual motor coordination and visual selective attention can affect functional occupations that require cognitive functioning. Loras, Stensdotter, Ohberg, and Sigmundsson (2013) found differences in motor timing and cognitive performance. They reported that the PPBT is dependent on thought processing and not related to differences in manual dexterity. The GPBT has an ability to assess higher dexterity functioning along with other neurobehavioral functions, such as cognition and visual perceptual skills. Motor experts feel that these neurobehavioral functions may confound the manual dexterity results of the GPBT (Wang et al., 2011). Although the specific use of these assessments is to determine the individual FM status of participants, observation of the testing with note taking helped to develop qualitative lines of inquiry relating FM and cognitive abilities that may interfere with occupational functioning. The final quantitative assessment, the

COPM, was used to determine the perceived level of performance and satisfaction of the occupations of YAwMS.

Symptoms of MS vary for all age groups and are not influenced by age, thus a young adult who is 18 years old may present with similar symptoms as a 24 year old (Buchanan et al., 2009). In observation of the quantitative measures combined with a semi structured interview, the dissertation study showed new characteristics of YAwMS and the effect of FM deficits on the occupations.

The occupational therapy profession indicates that occupation in any form of human activity has effects on the health of the person engaged in the activity (Wilcock, 1998). According to the International Classification of Functioning, Disability and Health (ICF; WHO, 2008), the interactions between diseases or disorders and contextual makeup affect the functional performance and participation of those with a chronic illness, such as YAwMS (see Figure 2). The ICF uses a standard language in describing disability and health. The ICF is organized into two categories: functioning and disability (divided into body structures and activity and participation) and contextual factors (divided into environmental and personal factors; Lexell, 2009; WHO, 2008).

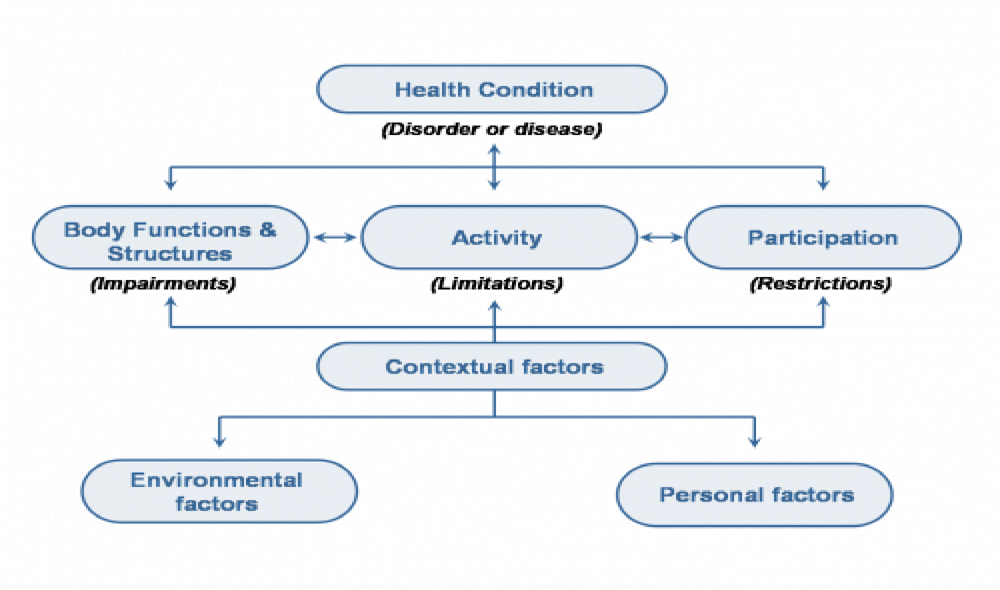

Figure 2. ICF model. This mapping of the ICF model for use with MS in an occupational based concept illustrates the possible impairments in terms of body functions, the occupations in terms of activities and participation, the contextual factors in terms of possible environmental factors and adaptations needed, and personal factors that may be compromised due to the effects of MS. Adapted from “The International Classification of Functioning, Disability and Health,” by Rehab-Scales.org, 2007, (http://www.rehab-scales.org/international-classification-of-functioning-disability-and-health.html). Copyright 2007 by Rehab-Scales.org.

Occupational therapists clinical use of the ICF framework may incorporate the concept of occupations as it is related to health, wellbeing, and human development. The principle concept of occupation is the familiar tasks that people do daily that are meaningful and provide satisfaction (Wilcock, 1998). Occupation is defined as the things people do to occupy their time, but this definition expands past this simplistic meaning. Active participation in tasks is a requirement of occupations. To gain a fulfilling experience from an occupation, the greater picture must be considered, including participation in tasks and where these tasks occur to produce successful occupations and occupational performance.

Occupation is a term that is missing from the ICF framework; therefore, because an individual's health is influenced by all ICF factors, occupational therapists must juxtapose their concepts of occupation with the ICF language (Lexell, 2009; see Figure 3). The concept of occupation can be included within the ICF model. As seen in Figure 3, a young adult with MS will show muscle weakness, fatigue, cognitive deficits, and motor disabilities within the body functions (BF) of the ICF. Limitations of BF will include decreased FM skills, ataxia, and decreased mobility. The activities and participations (AP) component of the ICF is viewed as decreased self-care, productivity and leisure occupations. In the contextual factors of the ICF, the environmental factors (EF) are seen to be home and work adaptations and ergonomics, and personal factors (PF) include decreased socialization and self-care.

Law (2002) stated that many OTs exchange the terms occupation and activity in order to create a better understanding of the term occupation, but participation is also integrated within the idea of occupation. Participation is the primary term used within the ICF, drawing on similar concepts of the term occupation. Due to this similarity of terms, the ICF has been subjected to criticism for not including the meaning of the occupational experience (Lexell, 2009).

For the purposes of this dissertation study, Figure 3 displays a conceptual framework using the ICF model as it applies to multiple sclerosis and occupations.

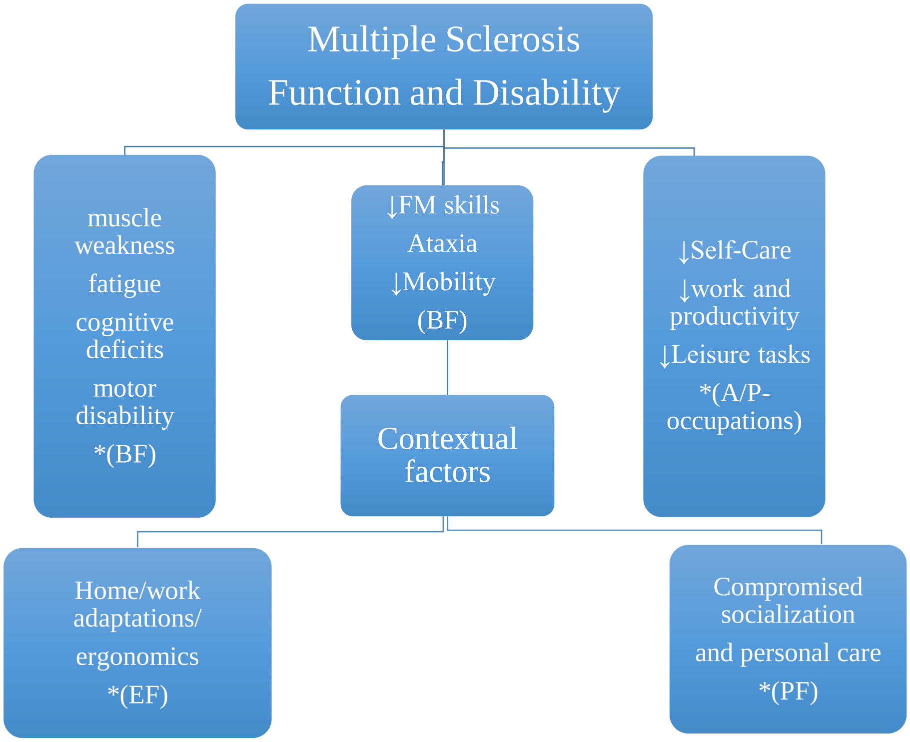

Figure 3. ICF model applied to MS and occupations. **Note*. BF = body functions. AP = activities and participation. EF = environmental factors. PF = personal factors as listed by the ICF. Adapted from "The International Classification of Functioning, Disability and Health," by Rehab-Scales.org, 2007, (http://www.rehab-scales.org/international-classification-of-functioning-disability-and-health.html). Copyright 2007 by Rehab-Scales.org.

At the International Consensus Conference, studies were selected for the ICF core categories for the Comprehensive ICF Core Set for MS. Four perspectives were used to determine this core set: (a) a systematic literature review of the main categories of the ICF that included PwMS, (b) a patient perspective using a qualitative focus with 27 participants, (c) expert perspective using a survey of 173 health care professionals from 46 countries with 5 years of experience, and (d) a clinical perspective from Europe utilizing the ICF with 205 individuals with MS (Coenen et al., 2011). Following these four studies, it was found that the perception of PwMS experience problems in activities and participation when completing the COPM (Karhula, Kanelisot, Ruutiainen, Hamalainen, & Salminen, 2013). Overall, the most important occupational performance problems were found in recreation and leisure, a category not listed within the brief ICF core set for MS, and self-care, mobility, household management, and community participation were also listed as problems for this population (Karhula et al., 2013).

The Occupational Therapy Practice Framework (OTPF; AOTA, 2014) and ICF have a similar general focus on health and wellbeing. The OTPF states that participation will happen naturally with individuals engaging in occupations that have meaning and a purpose. The OTPF (AOTA, 2014) is a framework for OT practice, founded on evidence of occupations and health as related to people as occupational beings (AOTA, 2014). Within the OTPF, health and wellbeing are gained and maintained through engagement in occupations (AOTA, 2014). The core principal of the OTPF is how successful engagement in tasks is based on participation supported by the context at which it occurs. Occupational therapy practitioners understand the multifarious interactions between a person, the environment, and the activities needed to fulfill daily occupations and lives.

Environmental factors have a significant role in successful occupational outcomes for YAwMS. Often, accommodations are needed as a result of consequences of the disease. These accommodations have resulted in other emotional and psychosocial issues, resulting in a further effect of the quality of life, wellbeing and overall occupations. Therefore, in choosing the appropriate OT model to address the needs of young adults, a therapist must have insight into the developmental milestones of this age group. The occupations of a young adult in their pre-vocational life and into adulthood requires higher levels of motor, cognitive, and social performance within their perspective contextual environments. Delays of these skills will result in the need for accommodations for productivity and management of their age appropriate skills (Case-Smith & Exner, 2015).

People environment occupation performance (PEOP) model (see Figure 4) (Christiansen, Baum, & Bass-Haugen, 2005) is a useful guide for therapists treating PwMS. This model presents a guide in developing a strategy against issues that may limit occupational performance and impede the wellbeing and health of PwMS. The PEOP is a combination of the integrated factors and interactions with the client to provide clarity as to the client's needs for successful occupations. This client-centered perspective benefits a therapist in the development of an intervention that utilizes occupations that support successful and meaningful occupational performances, thus resulting in achieving overall health and wellbeing and quality of life. When using the PEOP model for any age group, it is necessary to recognize age appropriate milestones and the context in which these milestones occur.

Figure 4 presents the intertwining components (person, environment, occupation, performance) of the PEOP model. The PEOP demonstrates a complexity of factors that contribute to a well formulated, client-centered strategy with an ideal occupational performance outcome for that client. Within this model, well-being is the result of well-adjusted psychosocial, emotional, spiritual, thought processes, and neurobehavioral and physiological factors. The model's physical and social environments, cultural norms, and values factors if well established and healthy will help in creating quality of life for an individual (Christiansen et al., 2005). On the contrary, it appears that these same factors may cause limitations within a young adult's occupational performance if not healthy.

For example, if the symptoms of MS influence the person, occupation, environment, and performance areas of a young adult with MS, then it can potentially affect the person's perception of his/her overall wellbeing.

Figure 4. Person-environment-occupation-performance model. Adapted from *Occupational Therapy: Performance, Participation, and Well-Being* (p. 246), by C. Christiansen, C. Baum, & J. Bass-Haugen, 2005, Thorofare, NJ: Slack Inc. Copyright 2005 by Slack Inc.

Throughout the human lifespan, people, their occupations, and environments change as do their method of engagement for participation. Whether or not changes occur from MS, the PEOP is an appropriate model that occupational therapists can use to understand those ongoing changes experienced by YAwMS, which is done through performing occupations within their contexts. The PEOP uses the top-down approach. This approach occurs when attention is given to a person's participation within his/her daily lives, occupations, and the significance of the environment in which a person performs occupations and daily tasks. This approach helps to understand skills and abilities in physically, emotionally, and socially challenged areas as determined by the client. Therapists may follow the medical model and treat a diagnosis of MS for the purposes of immediate remediation of symptoms but will often fail to address important factors that contribute to the overall performance of that person.

The PEOP is appropriate in addressing the symptoms that effect the person, the environment, occupations, and occupational performance. Symptoms affecting FM skills can produce impairments in the occupations and occupational performance of YAwMS, including performance in their environmental context. The dissertation study contributed to evidence needed in finding a link between FM deficits and occupational performance.

Assumptions and Limitation of Study

This study had several limitations. The convenience sample was limited to YAwMS recruited from local clinics and support groups. Internal validity may have been threatened due to the limited sample size, unpredictable relapses of the population, and the need for subjects to be at least one month out of a relapse.

Limitations with the measures could influence the results of this study. Multiple sclerosis is a disease with relapses and remissions (Buchanan et al., 2009); therefore, the test was completed when participants were at least one month after an exacerbation. Other factors of the disease, such as fatigue, cognitive impairments, depression, and disease modifying, and depression medications could have influenced both the FM performance skills and occupational performance of the participants.

With the COPM, direct observation was not allowed during tasks and relied on self-report, thus possibly biasing the scoring. The scoring was based on the participants' interpretation of how they experience problems within specific occupational categories. The responses were based on how they felt at the time of the assessment. The participants may have based their responses on their experiences at the time of an exacerbation of symptoms and not in a recovery state, which could have influenced their perceptions how they were performing at the time. Participants were not able to accurately describe their experiences, which could have resulted in inaccurate descriptions of the lived experiences of the participant (Law et al., 1990).

The aim of the COPM was to obtain the occupational perspective of the participant, but a participant may have a different meaning of occupation within his/her life in regard to well-being and health (Hemmingsson & Jonsson, 2005). Assisting a participant in completing the COPM may have influenced the responses to how much participant wanted the investigator to know. The COPM is an outcome measure used primarily as a test-retest method, but, Law et al. (1990) stated that the COPM can be used for other purposes, such as for “useful clinical information” for both the participant and clinician (p. 86).

Other confounding factors, such as visuospatial or cognitive deficits, may have interfered with the FM performance on the GPBT and PPBT. Permanent symptoms at the time of the assessment, such as tremors, muscle weakness, visual disturbances, and confusion (Burgess, 2010) may interfere with the participant’s performance. Such permanent symptoms may result in a higher EDSS score for the participant, thereby causing possible elimination from the study and potentially reducing the sample size.

Summary

During the lifespan of a typical young adult, occupations change. A young adult with MS may experience these same changes but are faced potential interruptions during these milestone years. When unexpected new symptoms or an exacerbation occurs, there is a disruption within the life pattern, such as physical impairment impeding on work, less socialization due to fatigue, or problems with typical day tasks. A chronic disease, such as MS, can alter those milestones forcing many levels of adaptations and changes in occupational status and performance. The fluctuation of symptoms and the disruption of life plans can affect how a young adult perceives their performance of their daily occupational tasks. Assessing the level of independence for a young adult with MS can be difficult due to the lack of consistency within the performance of their daily tasks.

An understanding of the experiences with the disease as related to daily occupations within the environments would be beneficial in the development of effective goals and treatment plan. Using the PEOP model, a therapist can incorporate his/her client's contextual make up into the overall assessment of the occupations. The conceptual foundation of the PEOP model's interaction between the person, environment, and occupation has consideration for the new life experiences for a young adult with MS. Adaptation is required for the unpredictability of the symptoms to their lives so that occupational performance can be successful for a young adult with MS. Learning about the link between the FM skills and occupations of YAwMS contributed to the growing literature on the functional skills of this population. The development of appropriate treatment plans that incorporate the physical, social, and emotional status with environmental considerations will lead to successful occupational outcomes.

Chapter 2: Review of Literature

Introduction to the Chapter

Multiple sclerosis is considered the most common neurological disease among young adults (Karussis, 2014). Multiple sclerosis is an autoimmune disease in which the immune system attacks the myelin sheath (a protective type of insulation for the neurons of the brain), marked by acute periods of neuroinflammation affecting the central nervous system. Multiple sclerosis means "many scars" which refers to the inflammation of areas when scarring is present on the brain or spinal cord (Litchfield, 2010, p. 33). The symptoms of MS are dependent on the location of the scarring. Multiple sclerosis is a neurological degenerative disease that typically affects adults, specifically more women than men between the ages of 25.3 and 31.8 with an average age of onset at 29.2 years of age (WHO, 2008). Other data have shown that the estimated average age for MS diagnosis is between 37.0 to 37.1 years of age. Twenty eight percent of this data has shown a diagnosis at age 30 years or younger (Buchanan et al., 2009). Approximately 350,000 to 400,000 American young adults are diagnosed with MS (Buchanan et al., 2009). The World Health Organization (WHO, 2008) reported that the estimated prevalence for PwMS is approximately 30 per 100,000 globally and approximately 1.3 million diagnosed with MS.

Historical Overview

The etiology of MS is unknown; however, it has been found that a variety of neurological deficits are the result of this autoimmune disease. Multiple sclerosis is known to present with demyelination of the myelin sheath for certain neurons, which then generates lesions within the white matter of the brain and spinal cord (McKenzie &

Green, 2009). This selective process of demyelination creates an unpredictable clinical course of MS. Most individuals with MS will experience neurological recurrent exacerbations causing chronic or progressive impairment that leads to motor and cognitive disabilities with time (Karussis, 2014). The presentation and management of the disease differs between that of a young adult and older person with MS.

There are four classifications of MS that present with various levels of involvement as well as progression. It is important to understand each subtype of MS to gain a perspective on the level of disability that is presented.

Classifications of MS

The course of the disease is uncertain, but four clinical subtypes that define the expectations and level of severity have been identified: relapsing remitting MS (RRMS), secondary progressive MS, progressive relapsing MS, and primary progressive MS (see Appendix A; Litchfield, 2010). Relapsing remitting MS is the most common subgroup of MS. Eighty five percent of all those diagnosed with MS are classified with RRMS. If symptoms within this subgroup do not progress after 10 to 20 years, it is considered benign MS, resulting in minimal disability (Litchfield, 2010). Benign MS refers to a milder disease course at least initially. Relapses are unpredictable and severe relapses may occur later in life. A relapse or remission from RRMS may last from several days to months (Litchfield, 2010). The severity of relapses varies from person to person. Remissions will end when a new symptom appears and worsens in at least 30 days after the initial symptom. If a symptom lasts for at least 24 hours, it is then considered a relapse (Litchfield, 2010).

Secondary progressive MS is usually diagnosed after symptoms present with an increase of disability in the absence of relapses (Litchfield, 2010). Fifteen years after an initial diagnosis of RRMS, 65% of those diagnosed with RRMS will develop a progressive form of MS. To confirm the diagnosis of SPMS, neurologists will observe the presence of progression for 6 months without a relapse (Koch, Uyttenboogaart, van Harten, & De Keyser, 2008).

Primary progressive MS is a subgroup that presents with little to no remission with a gradual worsening of symptoms. Ten percent to 15% of those diagnosed with MS are between the ages of 50 to 60 years. Primary progressive MS will present with demyelination and inflammation of the white matter of the central nervous system and will show lesions on the spinal cord. These lesions will result in deficits within the lower limb movements, bladder and bowel control, and sexual functioning (Litchfield, 2010). Deficits will range from mild to severe disability. Mild disability, may have a complete recovery or severe with partial recovery (Litchfield, 2010).

Progressive relapsing MS is similar to PPMS as it presents an aggressive progression of MS. This subgroup presents with a steady progression of symptoms combined with acute relapses, which will periodically occur (O'Connor, 2002). This rare subgroup is seen in approximately 5% of MS patients.

Within each classification of MS, the relapse frequency varies from person to person. Some individuals may present with one attack and no relapses for many years, but others may present with relapses every few months (Scalfari et al., 2010). Pseudo-relapses usually occur if there is high stress or infections. This relapse is not seen as an actual relapse because the symptoms fluctuate and last for a few hours. A true relapse includes the development of new symptoms that will worsen for a few days into weeks (Stark, n.d.).

Ben-Zacharia (2011) divides symptoms of MS into three categories: primary, secondary, and tertiary. Primary symptoms are visual, sensory, and muscle weakness, all due to demyelination and axonal degeneration. Secondary symptoms of urinary tract infections are due to the primary symptoms. Tertiary symptoms are social are psychologically related issues.

Diagnosis of MS

Diagnosis of MS usually occurs after some individual presents with a single clinically isolated attack of a symptom of MS. A clinical symptom along with a magnetic resonance image (MRI) can confirm a diagnosis, known as clinically isolated syndrome (CIS). Approximately half of individuals with MS have experienced optic neuritis (ON), a common symptom of MS that is often noted as a factor when determining a MS diagnosis (Jasse et al., 2013). This disorder involves a pain with movement of both or one eye, sudden loss of vision, and possible loss of color vision. Optic neuritis occurs with the immune system attacking the myelin sheath of the optic nerve, causing inflammation and damage to the nerve (Pau, Zubidid, Yalamanchili, Plant, & Lee, 2011). A diagnosis of MS can be made when neurological symptoms occur after a previous relapse, two exacerbations occur at least 30 days apart, or if new lesions appear after 6 months of initial lesions (Lublin et al., 2014).

A common diagnostic tool for MS is the McDonald criteria (Karussis 2014). This measure was developed to show the existence of demyelinating lesions through the lesion images on an MRI or by neurological symptoms as presented through time and space as characteristics for MS. Two clinical attacks that vary in time and space will establish a definitive diagnosis, according to the McDonald criteria. The focus of the McDonald criteria is on combination of clinical laboratory results and MRI data to establish a diagnosis (Karussis, 2014). An MRI will show plaques to be predominant within the white matter, periventricular regions of the brain, and spinal cord. These images may at times show atrophy of the brain.

The most prevalent clinical feature of a diagnosis of MS is the location of the plaques and number of relapses. Diagnosis of MS is considered reliable when relapses occur within the typical anatomical locations. Relapses are useful in determining a sure diagnosis and are indicative of loss of function whether permanent or temporary, but over time, progressive disability is the reason for certain medical, social, and economic effects on a person with MS (Scalfari et al., 2010).

Common Symptoms of MS

Multiple sclerosis symptoms are neurological in appearance and age related. The levels of involvement of symptoms are measured by the Expanded Disability Status Scale (EDSS) as it is related to the age of the individual (Tavar, 2015). The EDSS scale ranges from 0, showing a normal neurological exam, to 10, death due to the MS (see Appendix B).

Damage to the central nervous system can result in a range of symptoms. Symptoms of MS include fatigue, muscle weakness, changes in motor skills, spasticity, sensory deficits, including numbness and tingling, speech deficits, visual deficits, bladder and bowel issues, depression, sexual dysfunction, poor coordination, cognitive difficulties, and pain in the extremities (Ness et al., 2007; Buchanan et al., 2009). The clinical course of MS has been found to follow a pattern over time with the severity of symptoms along with the level of disability and functional decline varying over time as the disease progresses. Multiple sclerosis presents as periodic acute phases, described as attacks or exacerbations, with a slow worsening of neurological symptoms. These symptoms will result in permanent neurological deficits with an outcome of increased disability, decreased function, and overall health and physical decline over 30 to 40 years (Buchanan et al., 2009). It is important to note that not all symptoms and affected functional abilities associated with the disease will worsen with time, as seen in larger populations of PwMS (Buchanan et al., 2009).

Depression and fatigue are the two common symptoms that appear early in the disease and remain significant symptoms throughout the course of the disease. Rumrill (2009a), reported that fatigue is recognized early in the process of the disease. Fatigue typically presents as a sudden onset and lasts from hours to days. Fatigue has been found in 40% of the MS population with exhaustion being described separately from physical fatigue or depression (Krupp, 2003; Lexell, 2009).

In larger populations of PwMS, other symptoms, such as physical and motor disabilities, cognitive decline, and bowel and bladder dysfunction, will also increase in severity over time and with age (Buchanan et al., 2009). A common physical disorder, ataxia, presents as uncoordinated muscle control and movements and is recognized as one of the initial physical symptoms of MS. This loss of motor control affects both gross and FM strength and skills needed for functional movement. The prevalence of ataxia is greater in female than male gender (Ruggieri, Iannetti, Polizzi, Pavone, & Grimaldi, 2004). Ghezzi et al. (2010) stated that more involved physical disability will develop in the first, third, and fourth decades of life with more impairment of the vocational achievement of young adults with early onset MS.

Physical impairments due to MS are commonly known because they are easily identified, but cognitive deficits in memory, processing speed, learning, visuospatial processing, and executive functioning are not as apparent. These undetected symptoms are seen in 43% to 70% of those diagnosed with MS (Goverover et al., 2015). Baruch et al. (2016) and Rumrill (2009b) stated that impairments in cognition for PwMS include sustained attention and concentration, short- and long-term memory, FM skills, executive processing skills, including, the rate of learning new skills, short- and long-term memory, and abstract reasoning. These cognitive deficits affect the ability of a person with MS to perform the necessary activities that support independent, community and social life skills (Goverover et al., 2015).

As these symptoms emerge and progress, a cumulative effect on the psychological, physical, and emotional stability will affect a person's ability to engage in basic activities of daily living that are required for an independent lifestyle (Rumrill, 2009a).

Validity of Theory and Research Measures

Canadian Occupational Performance Measure

The literature review for this dissertation study demonstrated the need for more understanding of YAwMS. There is limited knowledge regarding the effect of MS on the occupations of young adults, although diminished occupational performance has been shown on standardized assessments of varying age groups with MS (Lexell, 2009). Self-reports indicated that there is a need for some form of assistance with their daily tasks, but further investigation is warranted due to the lack of depth in the participant's responses (Lexell, 2009). Lexell, Iwarsson, and Lexell (2006) reported that although the COPM has only touched the surface as to participants' perception of their performance and satisfaction, the reasons for these responses were not further investigated.

There is a particular value to client centered outcomes and care. Client-centered care has the client in the center of decision making regarding his/her health care, thus leading to individualized care. Client-centered outcomes respect the clients' opinions, culture, and lifestyles throughout their health care intervention and practices. An interview-based rating scale, such as the COPM, is used for the investigator in discovering the clients' personal circumstances in regard to their occupations.

The COPM is a commonly used standardized, semi-structured, interview-based rating scale used within occupational therapy practice. This tool is an outcome assessment used to measure changes in the client's self-perception of occupational performance over time (Law et al., 1998). The target population for this measure is individuals within all ages and developmental stages who have a variety of disabilities (Law et al., 2014). Although the semi-structured interview of the COPM is a valuable measurement tool, it lacks in supplying the details needed to truly understand the participants' perception of their occupational performance (Lexell et al., 2006).

In a study of 28 females and 19 males (total 47 participants) with MS, the most commonly reported occupational problems were recorded as IADLs in terms of household management, and half of these occupations were regarding ADLs and mobility (Lexell et al., 2006). The results showed high rates for listed occupations in the domain of importance, but performance and satisfaction ratings appeared to be low and the reported performance of their occupations was unsatisfactory (Lexell et al., 2006).

Lexell (2009) found similar results and reported that a total of 44 participants with MS. It was reported that 366 occupations were perceived as difficult to perform as a result of their symptoms with MS with the highest area within self-care performance followed by productivity and then leisure (Lexell, 2009). Lexell found average ratings of performance to be low, the lowest being in active recreation and highest in paid/unpaid work. Satisfaction had average ratings in active recreation, whereas socialization was the lowest (Lexell, 2009).

Karhula et al. (2013) used the COPM as it is linked to the concepts of the ICF to obtain the self-perception of 113 participant's problems in everyday activities and participation. The COPM was used as an exploratory measure and not an outcome measure for the purposes of this cross-sectional study. Four trained occupational therapists interviewed the participants within their home. In this study, 113 Finnish community-dwelling persons with MS were assessed using the COPM to obtain participants' self-perceived problems in everyday activities and participation. Problems were linked to the ICF categories under activity and participation components of the ICF. They found that 527 most important occupational performance problems existed within the categories of recreation and leisure (27.5% of the population), categories not listed within the Brief ICF core set for MS (Karhula et al., 2013). Participants also listed problems in mobility (25.4%), self-care (15.9%), domestic life (18.6%), and community life (27.7; Karhula et al., 2013).

Dedding, Cardol, Eyssen, Dekker, and Beelen (2004) compared the convergent (relationship between different approaches to measuring the same construct) and divergent validity (distinguishing the focus of the study from other constructs) of the COPM to the Sickness Impact Profile (SIP68), a measure of illness on daily functioning and behavior, and the Disability and Impact Profile (DIP), a self-report questionnaire regarding disability and the level of importance of the impact for the client and an open ended question interview, with a population of 113 participants. It was found that the ability of the COPM to identify occupational performance problems exceeded the items reported in the SIP68, the DIP, and the open-ended question interview. Low correlation between the SIP68 scores and COPM demonstrates divergent validity with 74% of the listed occupational performance problems reported on the COPM had consistent items on the DIP, and 49% were consistent with the SIP68 (Dedding et al., 2004). Dedding et al. showed convergent validity with 63% of related problems listed on the DIP were said to disrupt quality of life and 74% of the problems on the SIP68 were identified as a disability (Dedding et al., 2004).

FM Skills

Purdue Peg Board test and Grooved Peg Board test. FM skills are necessary for accurate performance on daily occupations. Assessing the FM status combined with assessment of the perception of satisfaction and performance of occupations for YAwMS will help in determine the link between potential FM deficits and occupational disturbances.

Measures of the FM status of the MS population have included the Grooved Peg Board Test (GPBT), 9HPT, and the Purdue Peg Board Test. In a neurocognitive study, Nunan et al. (2015) investigated the differences between the subtypes of MS and found that the GPBT showed decreased performance in quick coordination of motor and FM skills in adults with MS. These findings have shown the need of measurement of the effects of FM deficits on daily occupations. Julian et al. (2013) evaluated adolescents with MS and found that 23% of a population of 231 participants demonstrated severe impairment on the GPBT of their dominant hand, and 20% with moderate impairment of their non-dominant hand (Julian et al., 2013).

The GPBT has shown differences within FM dexterity performance in those with neurological disorders. Matthews, Cleeland, and Hopper (1970) established that those with a diagnosis of MS were seen to be considerably slower than patients with other neurological deficits. Matthews et al., (1970) were first to report that MS patients (*n* = 30) had significantly slower performance than controls with a mean time of 323.40 seconds (*SD* = 176.98) while the control group had a mean of 171.77 seconds (*SD* = 48.20; Trites, 2007, p. 5).

In a previous quasi-experimental quantitative study, Squillace et al. (2015) utilized the PPBT as a predictive measure in discovering the FM deficits of adolescents with pediatric multiple sclerosis. They found significant differences in various areas of FM manipulative skills but lacks in addressing how the progression of the disease influence the participation and occupational performance of this population in regard to their FM deficits (Squillace et al., 2015).

In an effect size analysis for the neurocognitive profiles of MS subgroups, motor speed, and dexterity was reviewed as a component of this meta-analysis. Zakzanis (2000) found the largest effect sizes in tests of manual dexterity and motor speed were within the GPBT and PPBT. It was found that manual dexterity and bilateral performance overall, had larger effect sizes on the PPBT results than the GPBT results, especially those with chronic progressive MS (Zakzanis, 2000).

Relevant Concepts of Literature

Research in MS includes the remediation of symptoms, review of subgroups of MS, and experiences of living with MS as it relates to quality of life (Lexell, 2009). Less attention is given to the effects of MS on the engagement and participation of occupations for those living with the disease, specifically young adults. The lack of ability to engage in familiar or typical occupations can lead to occupational deprivation (Wilcock, 1998). Occupational deprivation may have a significant effect on a young adult with MS and how they view their own wellbeing.

As MS progresses, the young adult is confronted with issues that affect life's milestones. Occupational performance and engagement in occupations change, thus requiring adaptations to occupations throughout the remainder of their lives. Kielhofner (2008) described occupational adaptation as how individuals view themselves as related to their level of competence in performing meaningful occupations in a relevant environment. Occupational adaptation is a continuous process with those with a chronic illness like MS. When life changes, milestones continue to transpire, thus necessitating adaptations within the course of a young adult's life.

The unpredictability of MS presents challenges for younger patients during their transition to adulthood. Milestones can become greater hurdles to bear when considering the potential of interfering symptoms. Finlayson et al. (1998) discussed how these challenges often obstruct or prevent occupational engagement or performance. Wellbeing and balance are compromised with forced adaptations and changes within their occupational engagement of tasks. YAwMS adjusting to the new challenges will require practice of prior occupational skills and adaptations in order to face future challenges associated with the disease (Schkade & Schultz, 1992; Lexell, Iwarsson, & Lund, 2011).

In a qualitative study, Lexell et al. (2011) evaluated occupational adaptations for PwMS, and the participants described their experiences with the ongoing process of MS and their life adaptations. The participants of the study group described their occupational adaptation experiences as a dynamic and constant process. The results also demonstrated a gravitation towards attaining a desire of self and family life, but occupational adaptations were geared towards family needs and not the self (Lexell et al., 2011).

As young adults transition into adulthood, occupational adaptations must occur daily for successful engagement in future occupations throughout the course of their life. Occupational therapy practice follows theoretical approaches in occupations to break down the barriers that hinder engagement and participation in occupations for those with an injury or illness, such as MS. Interventions are aimed at creating strategies towards enhancing occupational performance while adapting to the changes experienced by the symptoms of MS.

A primary concern for YAwMS is to complete their education and establish a career. Rumrill (2009b) discussed how the relationship between age and MS is a factor in unemployment for PwMS. As the disease and symptoms progress, difficulty in meeting the physical demands of the job also intensifies (Rumrill, 2009b). Physiological symptoms, such as fatigue, are strong factors in job loss or leaving a job for adults with

MS. Other factors, such as cognitive deficits with visual and memory impairments, physical deficits, such as ataxia and low mobility skills, are high predictors of job loss associated with MS (Rumrill, 2009b).

LaRocca, Kalb, Scheinberg and Kendall (1985) reported that there is a link between age and unemployment of PwMS in which middle-aged individuals with MS maintain their employment at higher rates than the younger or older populations, which may be due to the adaptation period of the disease for younger adults or the progression of the disease in the older adults.

Relevant Contexts

Theory in occupational therapy presents how occupation influences the health and wellbeing of people and how it is employed therapeutically to encourage engagement in occupations that are valuable to their lives (Crepeau, Schell, & Cohn, 2009). Reed, Hocking, and Smythe (2013) stated that occupational therapy uses occupation as its focus of concern and creates a relationship between the use of occupation, health, and wellbeing. The use of occupations to enhance wellbeing is based on the premise that health and wellbeing can be achieved if the clients perform their occupations within their individual social, physical, and cultured context with their own belief systems. A range of occupations are used to support physical, psychological, social, and overall wellbeing (Hocking, 2009). When well-being is disrupted due to injury or illness, it is expected that occupations will also be disrupted.

In YAwMS, a population that assumes many changes and life roles at poignant times in their lives, there is an urgency to maintain occupational skills. With biological and physiological disruption, it is common for PwMS to place meaning on the disability and the changes that occur due to the ramifications of the disease (Hammell, 2004). In situations of those with a chronic illness, overall meanings of activities are redefined from positive meanings of abilities in activities to negative meanings of inabilities (Hammell, 2004). Goverover et al. (2015) discussed how PwMS may experience a lesser quality of life due to their impairments and poor functioning in significant life activities.

Meaningful occupations are implied to represent occupations that have been satisfying and purposeful, but if an occupation that was once meaningful is perceived as not personally satisfying due to an interruption in function, it may then lose its meaning and purpose. Nelson (1998) stated that the term meaningfulness relates to the perception and cognitive abilities associated with a task in order to deem it significant. The relationship between a person's body and time can be disrupted by the need to regain or reestablish normal occupational behaviors after there is an interruption in function (Seymour, 2002).

Introspectively, throughout the lifespan, people, their occupations, and environments change as do their method of engagement for participation. It has been shown how a chronic illness, such as MS, may cause an interruption in age-related occupations, such as academia, socialization, vocation, and the challenges of early adulthood (Hammell, 2004). The unpredictability of the disease is a major concern for this population, especially during major milestones within their lives. An exacerbation of the disease can cause an interruption in the performance skills, meaningful roles, and socialization of a young adult. Plans of meeting a life partner, starting a family, and settling into a seemingly typical lifestyle can be grossly disrupted with a diagnosis of MS. Over time, YAwMS may find it difficult to participate in employment, maintain household or self-care tasks, and engage in social activities (Finalyson, Dahl, Preissner, 2008). Goverover et al. (2015) discussed how PwMS may experience a lesser quality of life due to their impairments and poor functioning in significant life activities. Therefore, survival alone may be the influential factor for the quality and meaning of life and not necessarily engagement in personally meaningful occupations (Hammell, 2004).

Socialization, vocational, and academic performance play a pivotal role in peer competence in performance and self-confidence for a young adult. A young adult with MS will often spend time contemplating how to adapt and cope with the effects of the disease on their daily occupations as a partner, family member, friend, and employee (MacAllister et al., 2007). According to the ICF (WHO, 2008), the interactions between diseases or disorders and contextual makeup affect the functional performance and participation of those with a chronic illness, such as a young adult with MS.

It is important to remember that client-centered and occupational-based models are not diagnosis based. Therefore, these models indicate that an individual with a chronic illness, like MS, is viewed as someone who is limited in his/her occupations, or in other words, in doing the best one can or want to do. Occupational therapy practice for YAwMS is used to address the problems associated with deficits in occupational performance but many times neglect to address the underlying causes of the person's occupational difficulty. As therapists, we may understand the pathogenesis and physiological ramifications of a diagnosis but gaining further understanding of the underlying factors that affect the FM skills and occupations of YAwMS, such as fatigue and depression, will help support the planning within client-centered practice. Although, the physical functional component of a problem is a necessary part of the intervention, it is also necessary to determine why an occupation has become difficult. For example, fatigue or FM issues may prevent optimal occupational performance, or there may be a cognitive or psychosocial link to the lack of occupational performance. Occupational therapy is used in addressing YAwMS in introducing new methods of engagement in occupations; helps in fostering success, confidence, and a new sense of self through rebuilding competence in adapted occupational skills; and uses a client-centered approach, thereby allowing the young adult to gain control of their occupational future (Hammell, 2004).

Occupations can be explored by examining how occupations meet intrinsic needs, such as spirituality, as demonstrated within the PEOP model (Christiansen et al., 2005; Hammell, 2004; Law et al., 1996). Occupations can be better understood through the meaning of the occupation and not the activity of the occupation; therefore, when meaning is associated with the occupation, quality of life and wellbeing are improved (Hammell, 2004).

Summary of Literature

Multiple sclerosis is a chronic neurodegenerative disease that affects the central nervous system and is one of the more common neurological disorders of the young adult population (Karussis, 2014). The residual scarring along the central nervous system and associated loss of brain volume can result in a variety of symptoms for young adults. Along with physical symptoms of ataxia, muscular weakness, spasticity, and incoordination, symptoms can include cognitive and language impairments, bladder and bowel dysfunction, fatigue, and depression. These symptoms can interfere with the physical, cognitive, and social participation of young adults within their occupations.

Problems with cognition and fatigue are two initial symptoms of MS that newly diagnosed report. Both symptoms have been linked to complaints of depression and anxiety, but maybe regarded as just fatigue by the person with MS (Nunan, 2015). These symptoms, combined with the more obvious physical symptoms like FM deficits, add to the occupational limitations that affect ADL and IADL performance needed for independent living (Rumrill, 2009a).

Fine motor concerns are among the early symptoms for adults with MS (Buchanan et al., 2009). In addition, muscle weakness, loss of strength, and incoordination are reported by adults as early symptoms (Hojjotollah et al., 2012). Young adults with MS may experience gross or FM issues that prevent them from engaging in occupations for self-care, productivity, and leisure tasks. Bladder and bowel difficulties can interfere with socialization and affect employment due to the need for frequent bathroom visits and accidents. A misinterpretation of poor performance at work or home may result in decreased competence and affect self-confidence, especially for the younger population (MacAllister et al., 2007).

Occupations, such as self-care, productivity, and leisure, have been affected by the symptoms of MS. However, the lived experiences of symptoms and their link to occupations is not well understood (Lexell et al., 2011). Buchanan et al (2009) indicated that for PwMS, there are less disabilities for young adults than for older adult in terms of physical disability. Fatigue and depressive mood disorders, such as depression, can be related to any physical disability. The mental health consequences of living with this disability will likely affect the cognitive, self-image, and role functioning needed for a productive and satisfying life (MacAllister et al., 2007).

Finlayson et al. (1998) found that although ADL performance diminishes as the disease progresses, PwMS report more difficulty with IADL performance. Lexell (2009) found that occupational performance limitations are related to the type of activity and the skills needed to perform the activity.

Buchanan et al. (2009) discussed the many symptoms of MS that influence the functional abilities of PwMS, but currently, no research exists regarding the effect of FM status of YAwMS on their age appropriate occupations, such as vocational skills, home management, self-care, and leisure tasks.   Occupational therapists must consider the occupational experiences of YAwMS in relation their FM skills in order to develop an effective treatment plan related to these issues discussed.

Chapter 3: Methodology

Introduction to the Chapter

This study is built on previous work by the investigator, which examined the prevalence of FM deficits for adolescents with pediatric MS (Squillace et al., 2015). Squillace et al. (2015) identified a statistically significant difference by using validated assessments and comparative norms. To date, no studies have assessed FM skills of YAwMS using the PPBT. For this dissertation study, the aim was to not only assess FM deficits but also to investigate the consequences of these FM deficits on the occupations and satisfaction of YAwMS. In an effort to capture the lived experiences, a subgroup of the study sample was interviewed using a semi-structured interview guide. The combination of the quantitative approach and qualitative approach was used to allow the investigator to develop multiple perspectives and complete understanding of the research question. This method was used to identify potential intervention methods for OT practitioners.

Research Design

A mixed methods research design was used to address the research questions. The combination of quantitative and qualitative data was used for identifying the FM status (quantitative) and emotional and psychosocial complexities (qualitative) that affect the occupations of YAwMS. The specific mixed method design used for this dissertation study was an explanatory sequential design. This design consists of two phases in which one method (quantitative) is followed by the (qualitative) method as described by Creswell and Plano-Clark (2011) notation system as Quant + Qual. This notation infers that there is equality between the methods and neither method is dominant. The strands of an explanatory sequential design involve the following sequence: (a) collection of the quantitative data, (b) analyzation of quantitative data, (c) selected subpopulation for qualitative data collection based on quantitative result, (d) collection of qualitative data, (e) analyzation of qualitative data, and (f) interpretation and merging of both data sets (see Figure 5). The mixed method design is used for the results of the quantitative phase to inform the qualitative phase (Creswell & Plano-Clark, 2011). This method has allowed triangulation of the data by combining the qualitative and quantitative data collection analysis.

Methodology Rationale

The mixed methods involved the quantitative and qualitative data collection approaches. The quantitative design was to use the validated assessments of the PPBT and GPBT to objectively measure the FM status. The COPM was selected to measure the self-reported perception of occupational performance and satisfaction with performance. Individuals who demonstrated below average scores on the peg board assessments were invited to participate in an audio-taped, semi-structured interviews. The aim of the qualitative method was to gain an understanding of underlying motivations, preferences, and attributions. The interest was to gain and find the way YAwMS think and feel about their occupations. Merging quantitative and qualitative data in analysis had rich information about the disease and its consequences on the lives it affects (Fetters, Curry, & Creswell, 2013; see Appendix K).

The advantage of mixed method research in occupational therapy practice is the potential to generate rigorous, rich, empirical evidence (Mortenson & Oliffe, 2009). A main advantage to the mix method dissertation study was to examine processes and experiences along with the quantitative outcomes (Plano-Clark, 2010). The disadvantages of mixed method research include the time required to record the qualitative data and the level of experience the researcher must have in both quantitative and qualitative methods (Mortenson & Oliffe, 2009).

Although quantitative research has the strengths of internal and external validity, reliability, and objectivity (Tovin, 2015), they rely on objective measures and disregard meanings of occupations, human interaction, and behavior from the study. Quantitative methods, therefore, lack the capacity to discover the lived experiences of the population being studied (Portney & Watkins, 2009). The aim of this dissertation study was to capture the meanings and perspectives of the participants living with MS. Through various methods of data collection and triangulation, an occupational therapist can explore and offer an in-depth view of the occupations of young adults with multiple sclerosis along with how their current level of functional occupations meet their fundamental needs (Hammell, 2004).

An explanatory sequential design is used to provide a thorough understanding of the FM status on the occupations of YAwMS. This evaluation was done through comparing quantitative and qualitative results, substantiating the results, and using evidence of one method to expand on the results of another method (Plano-Clark et al., 2008).

Phase	Procedure	Product
Recruitment: A convenience sample 40 patients, referred from neurological clinics in Manhattan and Long Island, were identified using flyers, letters and word of mouth. A subgroup (18) was selected upon completion of the quantitative measures. The SDMT was administered to screen for cognitive impairment. IRB approval secured.		
Quantitative data collection (Phase I) ↓	• Standardized assessments (*n*=40). ~15 minutes	• SDMT, PPBT, GPBT, & COPM (numerical data).
Quantitative data analysis ↓	• Independent *t* test, Spearman correlation and *z* score conversion • SPSS software	• Descriptive statistics, independent *t* test and correlation
Sample selection (18) for interview ↓	• Selection based on common responses & observations from Quant data collection.	• Individual cases (18) identified by quantitative scores.
Qualitative data collection Phase II ↓	• Individual in-depth interviews of the subgroup.	• Semi-structured audio-taped and transcribed interviews.
Qualitative data analysis ↓	• Thematic analysis and open coding.	• Coding and thematic categories. • Cross thematic matrix
Integration of quant/qual results Phase III	• Interpretation and explanation of merged quant/qual results.	• Discussion • Implications • Future Research

Figure 5. Mixed method design: Explanatory sequential design. *Note*: *Designing and Conducting Mixed Methods Research* (2^{nd} ed., p. 305), by J. W. Creswell & V. L. Plano-Clark, 2011, Los Angeles, CA: Sage. Copyright 2011 by Sage.

Threats of Design

Threats to internal validity include selection bias instrumentation. There were several threats to this design. Internal validity was threatened in several ways. Clinics referred potential participants to the investigator. Even though they may have met the inclusion criteria at the time of the screening, disease exacerbations prohibited inclusion in the study. Participants lacked clarity in the definition of an attack or exacerbation. This dissertation study's inclusion criteria were that participants must be one to two months out of an exacerbation in order to participate within this study. The rate of relapses of MS are reported to be one time a year during with newly diagnosed cases and can last for 24 hours or longer (Ontaneda & Rae-Grant, 2009). There is no objective measure for the length of an exacerbation; therefore, relying on the participant's self-report is the threat to validity. The investigator relied on the clinical judgment of the referring practitioner to verify state of remission. The state of remission was verified and documented at the time of data collection.

Threats to external validity are situation and contextual factors. Testing was conducted within a private setting within participants' homes or identified public spaces, such as a quiet room in a library or the neurology office.

In addition to threats to external validity, the consequences of testing in multiple locations may have contributed to variability in the assessments. These consequences may contribute to measurement error based on time and place of data collection. For example, participants tend to be more comfortable within their home environment as opposed to before or after a clinical appointment.

Avoiding measurement error was of concern regarding both the quantitative and qualitative components of this dissertation study. During the interview, if participants appeared apprehensive in responding to sensitive questions regarding their abilities and symptoms, the question was reworded to adapt to the participant's emotional sensitivities at the time. Such questions may lead to a fear of being judged or a desire to see themselves as a person without a disability, resulting in biased data (Boeije & Mulders, 2002). Leading questions within the semi-structured interview were avoided to ensure an increased chance of quality and honesty in the questions.

Establishing methodological rigor and low ability to reproduce a study are also disadvantages with the use of qualitative research for this population (Portney & Watkins, 2009).

Strengths of Design

There is a lack of mixed methodological in which the effects of FM status on the occupations of YAwMS have been investigated. Although previous researchers have used the COPM to examine the occupations of the general population, more research is needed to understand the effects of FM status on occupations for YAwMS.

This dissertation study contributed to existing knowledge about MS but targeted young adults age 18 to 30. This dissertation research will generate future strategies to intervene with YAwMS.

Weaknesses of Design

There was limited control over the data collection environments. Although considerations were made within all data collection environments, such as use of a quiet space, other factors were involved. There was a pause required for minor distractions from medical staff or family members during either the quantitative or qualitative data collection that may or may not have affected data accuracy or quality. The quantitative component of the study had a lack of resources for a large-scale research due to the population criteria, therefore, reducing the qualitative subgroup population. The adapted COPM was developed by adding specific items that focused on FM skills from the original assessment, possibly placing the assessment's validity at risk. Appointments were scheduled at the convenience of the investigator and study participant.

Study Setting

Clinics offered a quiet room or office that had one table with two or more chairs. The participant was situated at the table directly across or adjacent from the investigator to avoid influence or intimidation during the standardized testing and semi-structured interview. Participants evaluated outside of the clinic setting were evaluated in a mutually agreed upon setting, such as their home or Stony Brook University (SBU)-affiliated sites located in Manhattan. The SBU-affiliated site was within a library quiet room and had one table and chairs. The participants sat in a similar arrangement as the clinic setting, directly across or adjacent from the investigator to avoid influence or intimidation during the standardized testing and semi-structured interview. Data collection in the participant's home took place in a private area at a table with chairs. Semi-structured interviews followed the PPBT and GPBT. Participants who scored in the low average range of the PPBT and GPBT were selected and invited to participate in the interview.

Time

Each participant meeting included travel time and testing. Data collection for the quantitative part of the study took between 30 to 45 minutes. The qualitative interviews took between 1to 1.5 hours.

Facilities

The facilities for this study included the following sites: Neurology Associates of Stony Brook Medical Center, South Shore Neurological Associates outpatient clinics, and a SBU-affiliated educational site. All sites were in Manhattan and Long Island. Private clinics within the New York metropolitan and Long Island regions gave permission to use their sites if needed. All study sites required institutional review board (IRB) approval from Stony Brook University and Nova Southeastern University. The South Shore Neurological Associates were not affiliated with either institution but required proof of IRB approval prior to agreeing to have access to its clients and study site. Each facility provided a quiet testing area for the investigator and participant.

Subjects

Sample Size

The target sample size was 40 young adults between 18 to 30 years of age of mixed gender with a diagnosis of MS. A subgroup of 18, derived from the 40, who scored within the low average range, were invited to participate in the semi-structured interview. The participants were recruited from the Neurology Associates of Stony Brook Medical Center, South Shore Neurological Associates, and private outpatient neurological and support groups within the New York metropolitan and Long Island regions. This sample was a convenience sample due to the specific criteria of the population, diagnosis, and symptoms. This age group is typically in the early stages of multiple sclerosis or were diagnosed as an adolescent; therefore, permanent neurological symptoms may have not yet manifested. Buchanan et al. (2009) stated that MS-related symptoms may become more permanent after the age of 30.

A basic mixed method sampling technique, purposive sampling was used to select the sample size for the qualitative component of this study. Purposive sampling is used to analyze a small sample of participants from a larger target population (Teddlie & Tashakkori, 2009). It is the method of purposefully recruiting participants who have experienced the same phenomenon (Creswell & Plano-Clark, 2011). Homogenous purposive sampling refers to the selection of participants with similar characteristic and life experiences, including age range and occupations. This method was used for the investigator to focus on the similarities of the participants and their association with the dissertation study. For example, a large percentage of the participants scored within the low average range with their FM testing and nearly all of the subgroup expressed difficulty with age-related occupations, which is a specific topic within a homogenous sample.

The qualitative data were from audio-recorded interviews that followed the quantitative testing with the selected participants. All 18 subgroup participants who scored within or less than the low average range or slower on the pegboard tests were chosen for the qualitative component. Selection was made following quantitative data collection. According to Teddlie and Tashakkori (2009), a typical sample size used within phenomenological research is 6 to 10. A smaller number of participants will provide an in-depth perspective regarding their experience with MS (Creswell & Plano-Clark, 2011).

Participants were offered an honorarium of a $25 gift card for completing the quantitative component of the study and if selected were asked to volunteer for the qualitative component. If the participants chose to volunteer for the interview component, they were offered an extra $10, totaling $35 for their participation in this study. The participants were advised that receiving this compensation was not predicated upon completing the interview.

Power

Raosoft (2004) reported that previous researchers who used the COPM and FM assessment used similar samples sizes. In a sample power analysis, the mean samples of previous studies were calculated to identify the appropriate sample size for this dissertation study. Sample sizes from seven studies of researchers investigating PwMS and occupations were added to obtain a raw score of 282 participants. The raw score was then divided by 7 to obtain a mean of 40.3. A common power analysis calculator (Raosoft, 2004) was used. By calculating a 5% margin of error; a 95% confidence level, which included a 50% chance of rejecting the null hypothesis (Type I error) and 20% chance of failing to reject the null hypothesis (Type II error) with a standard deviation of 1.00, the power analysis calculation resulted in a sample size of 37.

Inclusion criteria.

- Participants between 18 to 30 years (due to their range of symptoms typical for this age).
- No prior history of neurological or physical impairment that may influence the testing results.
- EDSS score of 6.0 or less.

- Demonstrating retention of some self-care abilities (see Appendix B).
- In a recovery state of at least 1 to 2 months following their last exacerbation.
- Express an average level of independence through the initial screening or indicate a level of functioning requiring minimal assistance with ADLs.
- Age-based normative *z* score on the oral condition of the SDMT, of -3.0 or higher, indicating sufficient cognitive functioning (Sheridan et al., 2006).
- Diagnosed functional with mild depressive disorders by neurologist.

Exclusion criteria. Participants were excluded from this dissertation study if

- Their age was below 18 or over 30.
- Presentation of prior physical or neurological impairments that may affect the study results; a score of 6.5 or greater on the EDSS (Tarver, 2015) demonstrating greater than a maximum assistance with self-care and mobility tasks.
- Recently discharged from inpatient care.
- Active exacerbation of symptoms.
- Age-based normative *z* score below -3.0 on the oral condition of the SDMT, indicating severe cognitive impairment (Parmenter, Weinstock-Guttman, Garg, Munschauer, & Benedict, 2007).
- Received treatment for major depressive disorders.
- Expression or documentation of frequent exacerbations.

Recruitment procedures. The investigator met with liaisons from MS clinics within the Long Island and New York City metropolitan regions to discuss possible recruitment options from their clinics. A meeting with nurse practitioners and neurologists occurred to discuss the aims of the dissertation study and recruitment of participants from their clinics Neurology Associates of Stony Brook Medical Center and South Shore Neurological Associates. The Neurology Associates of Stony Brook Medical Center is an affiliate of SBU; therefore, the investigator's credentials were allowed for access to this clinic. The South Shore Neurological Associates outpatient clinic in Huntington, New York, stated that approval from the SBU and Nova Southeastern University IRB was necessary to access the clinic participants. Communication was ongoing with other potential recruitment sources, such as support groups and the National Multiple Sclerosis Society (NMSS, n.d.) within the Long Island and New York City regions and the International Multiple Sclerosis Management Practice.

Following the approval of the IRB from SBU and Nova Southeastern University, the investigator distributed a flyer to the clinics, support groups, and outside organizations, such as the NMSS, including information about the dissertation study and contact information of the investigator (see Appendix C).

The clinic's staff referred potential participants based on the inclusion and exclusion criteria. A letter of agreement that was approved by the IRB was sent to the clinic's lead nurse practitioners and neurologists for permission for access of all clinics for recruitment and data collection. The letter of agreement stated that the investigator would be granted access to a list of potential participants (see Appendices L and M). Each clinic was given a list of participant criteria to ensure that all inclusion criteria were met for participation in this dissertation study. Supervising nurse practitioners of the selected clinics referred appropriate candidates for the dissertation study. A nurse practitioner reviewed the criteria, created list of participants, and distributed a letter and flyer for recruitment to the potential participants.

Each participant received a letter explaining the dissertation study, procedures, and requesting their voluntary participation. An informed consent was included with the letter. If the participant was already present in the clinic at the time of the recruitment, an explanation of the dissertation study was provided by the nurse practitioner. If the participant agreed to volunteer for the study, an appointment was made to meet with the investigator to provide an explanation of the informed consent. The consent was also read to the participant, which gave an opportunity for the participant to ask any concerning questions regarding the study. The participant was encouraged to ask the investigator for further verbal explanation before beginning the data collection.

The data extraction form was used for the investigator to maintain consistent demographic and inclusion criteria for successful selection of the subgroup of participants for the qualitative interviews. For example, participants who had the same type of MS, did not have a diagnosis of depression, or were in long-term remission were asked to participate within the qualitative part of this study. The participants were asked to participate on a voluntary basis following the quantitative data collection.

Instruments and Measures

Diagnostic Measure

The Kurtzke Expanded Disability Status Scale (EDSS) is a screening tool used to quantify the disability status of PwMS of all ages and monitor changes of the level of disability over time (Tarver, 2015). It is the most common assessment of neurological disability for PwMS used today (Tarver, 2015). The EDSS was initially called the

Kurtzke Disability Status Scale (DSS), which was developed in 1950 and revised in the 1980s (NMSS, n.d.). It initially featured a 10-step disability scale. It was eventually expanded and renamed the EDSS when the sub-scores were created (Christensen, 2014). Prior to the expanded version of the EDSS, the DSS was used to investigate PwMS. It was found that 51% of PwMS had an EDSS score of 5 or lower, and 88% had a score of 7 or lower (Tarver, 2015). Severity scores range from 0 to 10 in increments of 0.5. High level of ambulation skills is seen at a score of 1.0 to 4.5 in which scores at levels 5.0 to 9.5 indicate a loss of ambulatory ability (Tarver, 2015). The low-level scores between 0 to 4 are determined using the Functional System (FS) scores. Scores from 1.0 to 4.0 indicate that PwMS are ambulatory without an assistive device. Therefore, those with a score higher than 4.0 have a form of gait impairment. Scores higher than 4.0 are determined by both EDSS and FS scores. These low scores are measured based on the FS eight sub scores of neurological dysfunctions (Christensen, 2014). The FS scores are seven sub-scores that measure eight neurological systems: the pyramidal (weakness of the limbs), cerebellar (coordination), brainstem (visual, speech, and swallowing), sensory (sensations), bladder/bowel, cerebral (cognitive functioning), and visual functions. Thus, the EDSS is a combination of the gait and FS scores (Tarver, 2015).

Test-retest and inter-rater reliability have shown a variance in values of the EDSS over the years (NMSS, n.d.). The majority of researchers showed that the lower end range of the EDSS distribution results were due to variances in the neurological exams, the middle was due to gait disturbances, and the higher distribution points indicated dependence with ADLs (NMSS, n.d.). A significant problem with the EDSS is void of sensitivity to the variations and unpredictability of MS-related impairments (NMSS, n.d.).

There are several advantages to the EDSS. It is the most common clinical assessment used for aid in MS diagnoses and follow-up care. No equipment is required, and it is easy to use (Christensen, 2014). The disadvantages include its dependence on mobility, lack of sensitivity to the variations of the disease over time, no assessment of cognitive or observable ADL skills, and little time spent utilizing the tool allowing for biases and potential error (Christensen, 2014). For the purposes of this dissertation study, the EDSS score was designated by the attending neurologist and verified by the nurse practitioner if the attending neurologist used this method of assessment. If the EDSS score was not available or utilized by the attending neurologist, the remaining inclusion criteria along with observation of ambulation skills were used to determine appropriateness for participation in this dissertation study.

Cognitive Screening

Learning, memory, visual spatial, processing speed, and executive functioning are common impairments observed within 50% of individuals diagnosed with MS (Kalmar et al. 2008). Due to potential cognitive deficits that may affect a participant’s ability to follow directions, processing speed, and ability to understand and provide consent for the study, a cognitive screening was performed following the consent signing. Although risk to the participants, it was important for the participants to understand the study and the confidentiality of the data.

A brief standardized cognitive screening using the Symbol Digit Modalities Test (SDMT; Smith, 1991; see Appendix E) was conducted with the participants to rule out any potential cognitive impairments that would conflict with the study measures. The SDMT was conducted as the first measure at the start of the testing before the GPBT, PPBT, and the COPM.

The SDMT is a standardized cognitive screening tool that measures neurocognitive functions, such as attention, visual scanning, and motor speed (Sheridan et al., 2006). The SDMT has a written and oral component of the assessment that can be used together or independently of each other. The participants performed the oral cognitive screening of the SDMT. With the SDMT, the participants were required to pair nine symbols to their corresponding numbers. When looking at the blank assessment form, the participants were asked to state the correct number that matches the symbol. The participants were given 90 seconds to complete each part of the test. The investigator's written scores were totaled for the correct number of answers that were matched. The scores range from 0 to 110 with higher scores sloping towards a better performance (Pereira, Costa, & Cerqueira, 2015).

Normative data across genders for those under 30 had a mean score of 69.4. These normative data have been found to identify those with neuropsychological issues involving processing speed and memory (Parmenter et al., 2007; Sheridan et al., 2006). The mean scores were used as a cutoff score for the purposes of this dissertation study to include those with relatively intact cognitive functioning in order to complete the study measures. All participants were found cognitively competent to participate within in this dissertation study based on their SDMT scores.

The test-retest reliability correlation of the verbal SDMT is high at 0.76 (Smith, 1991) and the coefficient was higher, 0.97 with a sample of 34 PwMS within a two-week time span (Benedict et al., 2012). One study of PwMS used alternate SDMT forms of the written component of the test and found reliability at 0.70 on both forms, demonstrating moderate reliability for those diagnosed with MS (Pereira et al., 2015). Benedict et al. (2012) also used two alternate forms for healthy subjects and found a high reliability rate of 0.86 (Pereira et al., 2015). Schependom et al. (2014) found a high sensitivity of 0.91 with a specificity of .60 for PwMS.

Construct validity correlation between the verbal and written test is 0.78, suggesting that the two forms are not interchangeable. Gongora, Querol, and Escartin, (2015) tested cognitive impairments for PwMS and compared the SDMT to the Paced Auditory Serial Addition Test (PASAT) and found sensitivity of 0.80 upon the first testing and 0.824 on the one-year follow-up testing of the SDMT. Scores on the verbal format of the SDMT have been found to be higher than other tasks of reaction times, such as with the PASAT, when testing for cognitive impairments in those with traumatic brain injury (Smith, 1991).

FM Measures

The Purdue Peg Board Test and Grooved Peg Board Test were chosen to measure the manipulative dexterity, a component of FM skills necessary for proficiency in occupational performance. The GPBT and PPBT were used in this study to maintain consistency with previous multiple sclerosis testing batteries and studies that included these measures.

Squillace et al. (2015) has utilized these measures to assess FM performance in adolescents with MS. The PBGT and GBPT measured differences in FM movements of the hands and digits as well as digital dexterity and FM bilateral coordination (Zakzanis, 2000). Potential confounding factors, such as existing MS symptoms (i.e., fatigue, weakness, emotional interference) were monitored through observation to minimize interferences during the data collection. To avoid the influence of confounding factors, the inclusion criteria included a post 1 to 2 months exacerbation remission. Review of the initial data extraction form helped to determine if these factors were existing at the time of the testing and aided in determining if the participant was appropriate for the study.

Purdue peg board test. The PPBT is an assessment measure that was initially utilized in testing employees for industrial vocations (Lafayette Instrument, 2002b; Model #32020). The PPBT (Lafayette, 2002b) has been described as a principle test of hand dexterity with a high reliability rate of 0.82 to 0.92 (Lindstrom & Veenstra, 2015).

The PPBT consists of 50 pegs, 40 collars, and 40 washers, each located within the top cups of the test for easy access. The pegs were situated at the far right, and left cups for hand dominance and collars and washers were situated per hand dominance as well. If a person was right-side dominant, the washers were used closest to the right-side cup and same for the left side dominant participant.

The PPBT consists of four parts of measure: preferred and non-preferred hands, both hands, and assembly. The participant was seated at a table within a quiet area of his/her home or clinic. The participant was seated directly in front of the PPBT with pegboard situated with the top row of four cups furthest from the participant. The top four cups contained the pegs, washers, and collars. The top far right and left cups contained 25 pegs each for a total of 50 pegs. Washers and collars were located in the center cups; therefore, if the preferred had was the right hand, the participant would grab washers from the cup nearest to the far-right cup, and if it were the left hand, the washers were closer to the far left peg cup (Lafayette Instrument, 2002b; Figure 6).

Reliability has been found for single trial scores within the first edition of the PPBT. Test retest reliability ranged from .60 to .76 for a single trial and .82 to .91 for three trials (Lafayette Instrument, 2002b; Tiffin, 1948). In 1965, test-retest correlation was performed on the revised PPBT, establishing a range of .68 to .67 with one trial and .86 to .85 for three trials (Lafayette Instrument, 2002b). In a systematic review for upper limb assessments, Lamers, Kelchtermans, Baert, and Feys (2014) found a high interrater, intrarater, and test-retest reliability with the PPBT as compared to other commonly used upper limb assessments.

Gallus and Mathiowetz (2002) used the PPBT in PwMS and found that with a one-trial administration of the PPBT, the test-retest reliability coefficients ranged from .85 to .90 and higher from .92 to .96 for three trials, which suggests that one trial of the PPBT is sufficient in use with PwMS. In contrast, Yancosek and Howell (2009) found a high validity and reliability for a typical population and individuals with disabilities, such as MS, but emphasized that a three-trial administration was more reliable than one trial of the PPBT. Gallus and Mathiowetz (2002) also reported that when using the PPBT with PwMS, the test-retest reliability was higher than persons considered healthy.

Inter-correlation scores were obtained from a large group showing low scores ranging from .41 to .50, which may indicate that each test of the PPBT may be used as a predictor for finger dexterity or for manipulation speed (Lafayette Instrument, 2002b). These low scores may be due to the population being tested and may not be indicative of specific conditions (Lafayette Instrument, 2002b). In 1963, validity was determined in previous tests with those diagnosed with a variety of chronic neurological disorders with a range of .56 to .64 across all subtests (Lafayette Instrument, 2002b). There was a high correlation of validity between the PPBT and the box and block test (Lamers et al., 2014). Wang et al. (2011) reported a correlation with the 9HPT to the PPBT at -0.74 to -0.75 and to the Bruininks-Oseretsky Test of Motor Proficiency (BOT-2) at -0.73 to -0.78. High concurrent validity was found between the PPBT and GPBT (Wang et al., 2011).

Grooved peg board test. The GPBT is also a test of manipulative dexterity in which the pegs must be maneuvered and manipulated for appropriate fitting into their lock and key shaped designated spaces (Lafayette, 2002a; Model # 32025). The test includes a board with 25 randomly designed slots and pegs with a matching design for the slots (Trites, 2007). This is a measure of cognitive and visual motor skills as well.

The GPBT test was also a timed test that is recorded in seconds. Each hand was scored on three areas of performance, the total time, total number of drops, and the total number of pegs correctly placed in the board to for a complete score (Lafayette Instruments, 2002a; Figure 7).

The GPBT has limitations. Trites (2007) suggested that the scoring can be confusing and warned that that the test was designed for corporate use. A major strength of the GPBT is that visual motor coordination is required that is more complex than other peg board tests due to the random positioned slots that require the key like peg to be rotated for an exact fit (Trite, 2007).

Reliability of the GPBT has been found as a dependable measure for testing manual dexterity. Retest reliability for the dominant hand is $p < .01$ and $r = .74$ and non-dominant hand, $r = .72$ (Yancosek & Howell, 2009). Validity has been shown to be excellent with established criterion, construct, discriminate, face, and content validity (Trites, 2007). Wang et al. (2011) found that in a comparison study of tests for manual dexterity, the coefficients for test retest reliability for the GPBT were high (0.85-0.91) for the right and left hands. Concurrent validity showed a higher correlation with the PPBT than other tests of manual dexterity (Wang et al., 2011).

In other measures of manual performance, it was found that finger tapping and grooved pegboard tasks are closely related when testing for validity for PwMS (Lafayette Instrument, 2002a). A strong correlation was found between visual acuity and pegboard time with the dominant hand and higher relationships with visual perceptual and attention measures (Lafayette Instrument, 2002a). A weak relationship was found between GPBT and ADLs with PwMS (Kessler, Cohen, Lauer, & Kausch, 1992; Lafayette Instrument, 2002a). A modest association has been found between the GPBT scores and ADLs in those with MS (Kessler et al.,1992).

Canadian occupational performance measure. The COPM is a semi-structured, interview-based rating scale that measures changes in the client's self-perception of occupational performance over time (Law et al., 1998). The COPM is an outcome measure that was used as a tool to identify problem areas in the participant's occupational performance, determine the level of importance of each area of occupational performance, and to evaluate the participant's performance and satisfaction relative to possible problem areas (Law et al., 1998; Lexell et al., 2014).

With the COPM, the participants are required to describe their performance within three subcategories of self-care, productivity, and leisure through a semi-structured interview. They identify their perceived satisfaction and problems with their performance within each area. Minor adaptations within the domains of the COPM helped with consistency across the testing results. For example, each domain of the COPM, self-care, productivity, and leisure, contained subcategories with examples of occupational performance tasks. Permission was given by the authors of the COPM to adapt the measure for the purposes of this study (see Appendix H). The original three categories of the COPM had examples of subcategory activities for the participant to rate, and for the purposes of this dissertation study, items that were requiring dexterous or FM skills were provided. By convention, the COPM uses a clinical outcome measure for interventions. In this dissertation study, the COPM was used to discover performance patterns in FM skills, satisfaction, and problem areas for YAwMS.

During the COPM interview, the participants rated their level of importance for activities within the provided subcategories on a scale of 1 to 10 with 1 representing *not important at all* and 10 *extremely important* (Law et al., 2014). Based on the scores of the rating scale, the participants were asked to choose five of the most significant problems that they rated as most importance (Law et al., 2014). Once the most important activities had been identified, the participants were asked to complete a self-evaluation with their current performance and their satisfaction in that area (Law et al, 2014). These scores were an indication of the clients' perception and satisfaction of their performance (Law et al., 2014).

The psychometric properties of the COPM have shown a test-retest reliability to be acceptable at one- to two-week intervals, ranging from 0.63 to 0.89 for performance and 0.76 to 0.88 for satisfaction (Law et al., 2014). Content, criterion, and construct validity have also been evaluated for the COPM. Content validity is supported through national and international recognition of the use of the tool within occupational therapy practice through addressing self-care, productivity, leisure, being client centered, and the influence of the environment on performance. The COPM has shown criterion validity through the successful identification of problems of an individual's occupational performance across the ages. Evidence of construct validity was found through the occupational therapy's foundational beliefs that occupational performance is intrinsically satisfying, is an important part of independent living, and is related to life satisfaction (Law et al., 2014). Validity has shown responsiveness to self-perception over time and the COPM has been shown to be a valid measure of occupational performance after several investigations (Law et al., 2014). Lexell (2009) utilized the COPM as a component of the two-part study in which they investigated the engagement of occupations for PwMS. They found that more than 350 items of occupations were perceived as difficult to perform by PwMS (Lexell, 2009).

Semi-structured interview. The qualitative component of this dissertation study was a phenomenological approach that consisted of a semi-structured interview with 18 of the 40 study participants. All 18 subgroup participants, who scored within or less than the low average range or slower on the pegboard tests, were chosen for the qualitative component following the quantitative part of the dissertation study. Open-ended questions were used for exploration of responses regarding their occupations and performance as they relate to their perceptions of their FM skills.

A semi-structure interview questionnaire was created by the investigator of this dissertation study (see Appendix I). These questions were derived from information gained from previous research and literature reviews as well as from observations from the COPM testing. This interview had a focus on the experiences of occupations for those with MS. The sole interviewer was the primary investigator. There was consistency across the questions on the interview and the transcriptions. The semi-structured interview guide was reviewed for face validity by a member of the SBU faculty who was unfamiliar with the study. This review resulted in revisions of the questions to ensure consistency and fluency.

The items were directed toward the participants' FM performance during their daily activities at home, work, or school. The aim of the interview was to understand participants' perceptions of their occupational tasks or occupations as related to their FM skills and their perception of change due to their MS symptoms.

Equipment

The following is a list of the equipment used in this dissertation study.

- Purdue Pegboard (Lafayette Instrument, 2015).
- Grooved Pegboard (Lafayette Instrument, 2002a).
- Stop watch (IPhone 7.0).
- Canadian Occupational Performance Measure (adapted format).
- Audio recording device Apple IPhone 7.0.
- IBM SPSS Statistics 24 (IBM Corp, 2017) data software.

Ethical Considerations and Review

The Stony Brook University committee on research involving human subjects and Nova Southeastern University IRB approved this dissertation study on August 3, 2017. Following IRB approval, participant recruitment began with distribution of a formal letter by nurse practitioners of the participating clinics. The letter used non-expert and comprehensible language at an elementary-school-grade level to ensure clarity for the reader or participant. An informed consent form was provided to all potential participants informing them of the study. IRB approved flyers were disseminated to local MS support groups. The consent form assured participants that their participation was confidential, they could withdrawal from the study at any time without consequences, and their participation was voluntary. The participants were informed that all data, written or auditory, were confidential and held in a safe and locked area until the study was over at which time the data was destroyed.

The participants were informed within the informed consent form that (a) their name would not be used and would be coded to maintain confidentiality; (b) the coded, transcribed recordings would be kept in a locked environment until it was no longer needed; (c) in the event the dissertation study is presented in the future, the participant's name would not be used; and (d) all transcriptions and audio recordings would be destroyed when no longer needed.

Resources and Funding

The study was privately funded by the investigated. This dissertation study required the purchase of two sets of each measure: the PPBT, GPBT, and the COPM. Study costs included local travel expenses for the investigator and $25 compensation for participants ($35 for participants who were interviewed). Additional expenses included the purchase of SPSS statistics software program (IBM, 2017) for analysis of the quantitative data, and payment for interview transcription services.

Data Collection Procedures

Participants were informed about the study from nurse practitioners at the participating clinics. Clinic clients indicating interest in participating were given the investigator's contact information or permission for the investigator to contact the participant. An appointment was made, giving the participants the option of meeting at the visiting clinic, SBU affiliated library, or their private home. At the start of the testing, the inform consent form was reviewed. Data collection began with the quantitative measures, the PPBT, GPBT, and COPM. The PPBT took approximately 10 minutes, GPBT 5 to 8 minutes, and the COPM 25 minutes for a total time of approximately 45 minutes for the quantitative components of the study. The qualitative audio-recorded, semi-structured interview followed the standardized testing for those selected. The total time for the qualitative interviews was approximately 30 to 45 minutes. The total test time for all measures was estimated at approximately 1 to 1.5 hours for both quantitative and qualitative data collection.

FM Procedures

Instructions were given to the participants explaining the test parts and the purpose of the test. The participants were instructed to use their preferred hand first to manipulate the pegs into the holes in a systematic method of completing the tests. The participant was positioned as indicated by the measure's procedures. The first component of the data collection consisted of measuring the FM dexterity and speed using the PPBT and GPBT.

Purdue pegboard test. Due to time limitations, the participant completed one demonstration of the test followed by one trial of the actual test. The following directions are for single subject testing.

The PPBT is a timed test requiring 30 seconds for the first independent hand function using single parts and then 60 seconds for the assembly of the pegs, washers, and collars. Data were collected on the PPBT score sheet provided within the measure's kit (see Appendix J). The results per participant were compared with the standardized norms to determine the level of performance on each part of the test. Approximate total time of completion for the PPBT was 10 minutes.

Figure 6. Purdue Peg Board test (PPBT). Adapted from "Purdue Pegboard Dexterity Test," by Pro Healthcare Products.com, 2018, (http://www.prohealthcareproducts.com/purdue-pegboard-dexterity-test-lafayette-instrument/). Copyright 2018 by Pro Healthcare Products.com.

Grooved Pegboard test. For the purposes of this test, the total time to complete the test was the data used within the analysis to maintain consistency with PPBT times. Total time to complete the GPBT was between 5 to 8 minutes per participant.

As in the directions of the PPBT manual (Lafayette Instrument, 2015), the participant was seated with the pegboard placed at the edge of the table with the tray of pegs above the pegboard aligned in mid-line to the subject. Instructions were given to the participant, explaining the test parts and the purpose of the test. The participants were instructed to use their dominant hand first to manipulate the pegs into the holes in a systematic method of completing each row at a time from end to end of the peg board. To ensure that one hand was used, the non-used hand was held on the participant's lap. If necessary, cues were given as to the placement of the first peg per row. Each hand was scored on three areas of performance, the total time (in seconds), total number of drops, and the total number of pegs correctly placed in the board to for a complete score. A data collection form was created by the investigator for this measure (see Appendix K).

Figure 7. Grooved Peg Board test. Adapted from “Grooved Pegboard Dexterity Test,” by Pro Healthcare Products.com, 2018, (http://www.prohealthcareproducts.com/grooved-pegboard-dexterity-test/). Copyright 2018 by Pro Healthcare Products.com.

Canadian occupational performance measure. The final component of this quantitative investigation was a measure of the perceived performance and satisfaction of the participant’s occupational performance using the COPM. The investigator adapted the COPM by choosing common occupations listed within the measure for each domain to allow for consistency within the study (see Appendix G). This adaptation has been approved by the authors of the COPM contingent upon the questions being adapted without the intent to distribute this alternate version of the COPM (see Appendix H).

At the start of the testing, the participant was given a description of occupational therapy and occupational performance. Law et al. (2014) described occupational performance as an “integrated and balanced approach” of three essential performance areas, self-care, productivity, and leisure (p. 3). The occupations included in self-care were geared towards daily tasks required for preparing oneself for a day (i.e., grooming, bathing, and feeding); occupations considered for productivity were work, play, or school activities; and occupations for leisure included recreational and socialization activities (Law et al., 2014). Performance within any of these areas were considered occupational performance. The 40 participants were asked to rank the 34 COPM items according to most perceived occupation problem affected by FM issues. This process had clarity for the participant and ensure timeliness of the assessment by avoiding confusion regarding the topics. The first portion of the COPM began with the participant choosing common problem areas within three main categories: self-care, productivity, and leisure. Once the problem areas were identified, the participant rated the level of importance and degree to which the task was problematic. The top five problem areas were identified. Lastly, participants rated the level of perceived performance and satisfaction of the five problem areas on a scale of 1 to 10 (Law et al., 2014). A total average score for performance and satisfaction was calculated to determine the participants' level of perceived satisfaction and performance of their identified problematic areas. Total time to complete the COPM was between 20 minutes to 30 minutes.

Semi-structured interview. The investigator was the sole interviewer of this project. The participants and investigator engaged in an interview from prepared questions and, if needed, probes regarding the effects and experiences the symptoms of MS had on their FM skills and occupations were used. When appropriate, the interviewer included open-ended questions following unrelated responses that could potentially add to in-depth information within the conversation. This method of interviewing was used to steer towards relevant topics that provided additional understanding of the phenomenon (Cohen & Crabtree, 2006). The semi-structured interview guide was used to inquire about the age of diagnosis, symptoms, family support and reactions, attribution theories, equipment needs, interventions and medicinal care, socialization, reaction to diagnosis, work and school performance, emotional responses, FM and upper extremity symptoms, and ADLs. During the interviews the investigator observed non-verbal behaviors.

Each participant was assigned a de-identified code. A master list identifying the code and name of each participant was held in a separate secured and locked file. The electronic master list was secured with an encrypted password and only available to the investigator.

Data Analysis

With the mixed method approach, there was independent analysis of the quantitative and qualitative data and synthesis of the findings to answer research questions. The following steps were used for the analysis of this mixed method study.

Quantitative Questions

Analysis was used to answer the following questions.

- What is the FM status of YAwMS between the ages 18 and 30 years as measured by the Grooved Peg Board Test and Purdue Peg Board Test?
- What is the percentage of perceived satisfaction and performance of occupational tasks that are prevalent in YAwMS as measured by an adapted Canadian Occupational Performance Measure?
- What is the difference between the perceived performance and satisfaction of occupations (dependent variable [DV]) as measured by the adapted COPM and the FM skills (independent variable [IV]) as measured by the PPBT and GPBT of YAwMS?

- What is the relationship between the perceived performance and satisfaction of occupations as measured by the adapted COPM and the FM skills as measured by the PPBT and GPBT of YAwMS?

Qualitative Question

What are the lived experiences of YAwMS in terms of the occupations and occupational performance associated with FM status?

Overarching Mixed Question

How does the FM status of YAwMS relate to their perceived occupational performance and satisfaction and lived experiences?

Quantitative Data Analysis

To answer the first question, raw scores of the PPBT on the GPBT were compared to establish norms and then categorized into a level of performance. The GPBT norms were based on age and hand dominance. The GPBT results were grouped into slow speed group and fast speed group, according to the GBPT norms (Lafayette Instrument, 2002a). The PPBT norms were derived from the mean performance of healthy male and female young adults using a one trial per subtest mean (Lafayette Instrument, 2015). The normative data of the PPBT subtests, preferred and non-preferred hand manipulation (dominant and non-dominant), both hands and assembly, and the total time to complete the GPBT, were compared with the collected data.

The adapted COPM was conducted to identify the participant’s level of perceived satisfaction and performance of occupational tasks. The COPM is a client-specific measure with scales that are difficult to calibrate because it is based on the client’s perception and cannot reflect a level of validity.

The COPM's perceived performance rating scale of 1 to 10, was used to describe perceived performance as 1 being *not able to perform the tasks* and 10 *to perform the task extremely well*. The COPM's perceived satisfaction rating scale was also 1 to 10 with 1, *not satisfied* and 10 being *extremely satisfied*. A three-group rating scale was developed to categorize the scores for each participant. This scale was solely reflective of the percentage of participants who scored themselves low (1-4.9), average (5-7.9), or high (8-10 range; see Figure 9). This scale included enough points within each group to differentiate the ranges from one another and defined the ranges as closely as possible within the concept of the scale.

To identify differences between the perceived performance and satisfaction of occupations and FM skills status, an independent two sample *t* test was conducted. All analyses were performed using IBM SPSS Statistics Grad Pack Base 24 (IBM Corp, 2017) data software.

Next, to determine if there were a relationship between the PPBT, GPBT subtests, and the COPM satisfaction and performance findings, a correlation analysis was conducted. A Spearman correlation was performed because of the monotonic nature of the continuous data, the ability to compare two variables, and the variables were on an interval measurement scale. The aim of the correlation was to determine the direction of the relationship between FM status and perceived performance and satisfaction of participant occupations, which was done by transforming raw performance scores to age-based normative of both pegboards.

Qualitative Data Analysis

The guiding research question for the qualitative component of this mixed method dissertation study was “What are the lived experiences of the occupations and occupational performance associated with the FM skills of MS for young adults?”

There were two sources of qualitative data within this dissertation study: interview transcripts and notes taken during data collection. The interviews took place within the privacy of the participant’s home, a quiet area within the clinic setting, or SBU affiliated library. Each interview took between 20 to 30 minutes and followed the quantitative data collection.

Sixteen of the audio recordings were transcribed by a transcription company and two were transcribed by the investigator and IRB-approved student assistants. Each transcript was read, then re-read for initial coding, and then thematic analysis with open coding was completed. Observations of behaviors and field notes taken during quantitative data collection was noted on the score sheet. These data were reviewed and interjected into interview transcripts. Quantitative test results were synthesized.

To increase the validity of the results, member checking was performed by sending a lay version of the findings to the 18 interviewed participants. A letter with detailed instructions to ask them to read the findings and consider the extent to which they agreed with the summary. Member checking findings provided in-depth verbatim quotes from the participants, observation, and data collection forms. Creswell & Plano-Clark (2011) stated that approaches to establishing validity can be through member checking and triangulation of results. With methodological triangulation, there is utilization of multiple qualitative and quantitative approaches to reduce the effects of researcher bias (Guion, 2002).

Trustworthiness was achieved through credibility, confirmability, transferability, and dependability. Credibility was obtained by ensuring that the interview was measuring the construct that was intended to be measured (Shenton, 2004). Credibility was established through the participants' reflection on similar situations they have encountered during the use of FM skills and everyday tasks (Shenton, 2004). Examples of situations presented were "How do you perform a self-care task?" "Tell me about your hands when you perform a task?" Member checking of findings confirmed the investigator's interpretations. Member checking was done by sending the participants a summary of the findings followed by coordination of an email response or in-person discussion in which the participants provided input regarding accuracy of the themes and concepts that emerged from the interviews. Confirmability is ensuring that the results of the study are from the participant's experiences rather than the investigator's biases (Shenton, 2004). Confirmability was achieved by providing in-depth methodological descriptions, including an insightful explanation on the investigator's decision making for the methods chosen for this dissertation study. Transferability was demonstrated by providing a thick description of the research, enabling other investigators to make comparisons to the settings and contexts to which they are working (Creswell & Plano-Clark, 2011). Dependability was demonstrated by using an audit trail of raw data, quantitative data reduction and analysis, notes during COPM process, and notes taken from semi-structured interviews. Dependability also included review of the investigator's methods of collecting and interpreting data and report of the results.

Mixed Method Data Analysis

Data analysis for this explanatory sequential design occurred within three phases. First, the analysis of the quantitative data, then the analysis of the qualitative data, and finally an analysis of the mixed methods question addressing how the qualitative data helped to explain the quantitative results (Creswell & Plano-Clark, 2011).

A matrix was developed to integrate, merge, and clarify the findings from both the quantitative and qualitative components of this dissertation study. The merging of the data crossed on the matrix in demonstrating which areas were merging with the method results (see Table 3; Onwuegbuzi & Teddlie, 2003). The results of the FM and COPM data are displayed at the top of the matrix with the participants' narrative and responses from the interviews and COPM responses between the quantitative results (see Chapter 4 results and Table 3 for more details.)

The qualitative component of the matrix displays the participant's responses in terms of their lived experiences in their occupations and occupational performance of self-care, productivity, and leisure skills as they are related to their FM skills, thus answering the qualitative question, What are the lived experiences of the occupations and occupational performance associated with the FM skills of MS for young adults?

Onwuegbuzi and Teddlie's (2003) model for mixed method analysis was utilized to guide the analysis. First, quantitative data was reduced through a statistical analysis and qualitative data through summary of findings, which was done by providing a statistical analysis of the quantitative data and reading and coding the qualitative transcripts. Second, further reduction of the data to tables and rubrics into organized tables that included all data demonstrated a qualitizing of the quantitative data through interpreting the numerical data of the COPM and conveying the participant's responses as related to the data while they completed the self-report on the quantitative measure of the COPM. This analysis continued by finding relationships between the quantitative and qualitative data, comparing data, and integrating data using a comparison chart through which is shown as a description of the merging of the data sets. This analysis demonstrated the statistics of the quantitative data and the merging of the quantitative results with the qualitative theme results.

Results Presentation

The quantitative results are displayed in a table illustrating the correlation scores of the FM tests and the COPM, satisfaction and performance scores, the normative data of each component of the FM tests as compared with the collected data, and the high and low scores obtained from the adapted COPM in areas of satisfaction and performance (see Table 3). This matrix displays the common themes extracted from the qualitative data that may inform the quantitative results. Following the matrix, a summary of the results was provided. The qualitative results include a definition and label of the themes derived from the participant's experience.

Summary

Multiple sclerosis is the most common neurological disorder of the young adult population, yet most research has focused on the older adult with MS. Between the ages of 18 to 30 years, significant life changes occur. Career choices, relationship changes and decisions, and transition to independence from home are a few of these life changing experiences for this age group. For YAwMS, a diagnosis of MS complicates their lives by disrupting their current and future plans. Older adults are in a more stable developmental stage and may be better able to focus on the symptoms of MS.

The multitude of symptoms from MS can have deleterious effects on the occupational performances of persons with the disease. Young adults who are planning their future are now faced with impairments that may disable their abilities to perform the typical tasks needed as a stepping stone towards a fulfilling lifestyle. Symptoms that affect motor performance, such as ataxia and tremors during hand functioning, interfere with typical ADL and IADL tasks. It has been found that physical symptoms are more apparent than the silent symptoms of memory loss, depression, or fatigue; therefore, they are often remediated with medicinal solutions (Buchanan et al., 2009). The more silent symptoms are harder to recognize and may be initially overlooked in the context of motor symptoms. Once these symptoms are identified, the diagnostic experience is complete.

There has been a focus on the validity of objective, empirical diagnostic instruments for MS in the literature (Karussis, 2014; Rolak; 2002). The treatment approach has been largely derived from the medical model of disease. Occupational therapy intervention models emphasize client-centered practice with a focus on the individuals within their context, including the experiences of their personal occupations. In review of the PEOP model, the disabling factors for a YAwMS are addressed through their occupational performance skills within their personal and environmental context.

This mixed method dissertation study was used to understand the effects of MS symptoms on the FM performance and occupations of YAwMS. The utilization of the both methods was used for a better understanding of the effect of FM skills with or without impairment on the daily occupations of YAwMS. Focused effort was made to cross verify multiple data sources to respond to the research questions with reliability, validity, and credibility.

Chapter 4: Results

Introduction to Chapter

Forty individuals, 11 male and 29 females, aged 18 to 30 years, participated in this dissertation study. This distribution is consistent with the 3:1 female to male gender ratio of PwMS (Finlayson, Chitnis, & Harman, 2013). Data on hand dominance were collected for both the PPBT and GPBT with five left-hand dominant participants. The aim of this dissertation study was to address the following research questions: (a)

1. What is the FM status of YAwMS between the ages 18 and 30 years as measured by the GPBT and PPBT?
2. What is the level of perceived satisfaction and performance of occupational tasks for YAwMS as measured by an adapted COPM?
3. What is the difference between the perceived performance and satisfaction of occupations (DV) as measured by the adapted COPM and the FM skills (IV) as measured by the PPBT and GPBT of YAwMS?
4. What is the relationship between the perceived performance and satisfaction of occupations as measured by the adapted COPM and the FM skills as measured by the PPBT and GPBT of YAwMS?

It is hypothesized that young adults diagnosed with MS will not be satisfied with their occupational performance in their self-identified problem areas as related to their FM status. This aim of the hypothesis was used to discover if YAwMS were dissatisfied with how they perform their daily tasks that require FM skills.

Data Analysis Results

Quantitative Results

Question 1. What is the FM status of YAwMS between the ages 18 and 30 years as measured by the GPBT and PPBT?

Purdue pegboard test mean scores of the groups (age, gender, and hand preference) were compared to the mean performance score of young adults according to age, gender, and preferred hand within the PPBT manual (Lafayette, 2015, pp.12). These norms are based on a one trial per subtest for those without MS, according to the PPBT manual. Tables 4.1a and 4.1b show the number of participants in each age group and category per gender. These results are an average mean score for each age group and category and the overall mean score per category and gender.

Table 1

Purdue Pegboard Distribution of Results for Females

Females		Age (*n* = 8)		Age (*n* = 21)
Category	(*n*)	20-25	(*n*)	26-30
Preferred R	6	12.25 (*M* =16.64)	18	11.66 (*M* =17.25)
Preferred L	2	14.00 (*M* =16.64)	3	13.33 (*M* =17.25)
Non-preferred R	2	14.00 (*M* =15.89)	3	13.33 (*M* =16.13)
Non-preferred L	6	12.25 (*M* =15.89)	18	11.66 (*M* =16.13)
Both hands	8	15.88 (*M* =13.75)	21	18.36 (*M* =13.31)
Assembly	8	28.12 (*M* =42.47)	21	23.76 (*M* =40.44)

Note: *N* = 29. *n* = number of participants for that group. Mean raw scores for age group (m = PPBT norms). Preferred hands considered dominant hand.

Table 2

Purdue Pegboard Distribution of Results for Males

Males		Age (*n* = 1)	Age (*n* = 2)	Age (*n* = 8)
Category	(*n*)	18-20	21-25	26-30
Preferred R	11	10.00 (*M* = 15.56)	13.00 (*M* = 15.44)	12.00 (*M* = 16.22)
Preferred L	11	0 (0)	0 (0)	0 (0)
Non-preferred R	11	0 (0)	0 (0)	0 (0)
Non-preferred L	11	11.00 (*M* = 15.09)	11.25 (*M* = 15.08)	11.00 (*M* = 15.41)
Both hands	11	14.00 (*M* = 13.75)	20.50 (*M* = 12.97)	17.75 (*M* = 12.94)
Assembly	11	17.00 (*M* = 40.25)	29.00 (*M* = 38.39)	26.12 (*M* = 39.13)

Note: *N = 11. N* = number of participants for that group. Mean raw scores for age group (*M* = PPBT norms). Preferred hands considered dominant hand.

The majority of the participants were right handed (females = 24 and males = 11). Only five of the female participants were left handed. Individual raw data results showed 88% of participants scored below the mean performance norms in the preferred, non-preferred, and assembly, according to the PPBT subtest means. In contrast, for both-hands testing, 83% of the participants scored above the mean performance norms for young adults, according to the PPBT manual. The PPBT both-hands scores were calculated by adding the right- and left-side scores to achieve a both hand total score, therefore, possibly resulting in a higher score range.

Table 3 presents the GPBT participant scores as compared with the GPBT's matched cohort of age, hand dominance, and time in seconds to complete the board (Lafayette Instrument, 2002a, p. 8).

Table 3

Grooved Pegboard Participant Results

	< $\bar{x}$		DOM			ND		
Age	RHD	LHD	< $\bar{x}$	$\bar{x}$ sp	≥$\bar{x}$	< $\bar{x}$	$\bar{x}$ sp	≥$\bar{x}$
15-19	1	0	1	66.05	0	1	70.50	0
20-29	23	4	13	63.40	14	15	69.10	12
30-39	11	1	11	62.95	1	11	67.15	1
N = 40	35	5	25 (63%) < $\bar{x}$ sp			27 (68%) < $\bar{x}$ sp		

Note. RHD = right-hand dominance. LHD = left-hand dominance. Dom = dominant hand. ND = non-dominant hand. $\bar{x}$ = mean. sp = speed. < indicates less than mean norm scores. > indicates greater than mean norm scores. ≥ indicates greater than or equal to mean norm speed.

Faster groups scored higher than the GPBT norms, according to age and hand dominance, and slower groups scored lower than the GPBT norms, according to the age and hand dominance. In consideration of the hand dominance with the GPBT, out of 40 participants, 25 (63%) scored below the GPBT norms and 15 (37%) scored within normal ranges of the GPBT. Non-dominant scores were similar with 27 (68%) participants scoring below the GPBT means (slower) and 13 (32%) scored within normal ranges of the GPBT.

Table 4

Grooved Pegboard Participant Z Score Results

	Age		
	15-19 (*n* = 1)	20-29 (*n* = 27)	30-39 (*n* = 12)
	$\bar{x}$ z score (sd)	$\bar{x}$ z score (sd)	$\bar{x}$ z score (sd)
Dom	-1.67 (10.40)	-3.30 (7.90)	-3.90 (8.40)
NonDom	-0.20 (11.10)	-1.21 (18.70)	-11.32 (12.20)

Note: SD = standard deviation. $\bar{x}$ = mean. Dom = hand dominance. NonDom = hand non-dominance. *SD* per age group and hand dominance is derived from Grooved Pegboard Test User Instructions (Lafayette Instrument, 2002a).

Z scores were computed for raw scores in the GPBT data set. For the mean raw score for the dominant and non-dominant hand of the of the 15 to 19 age group, *z* = -1.67 (Dom), -.20 (NonDom). For the 20 to 29 year age group, *z* = -3.30 (Dom), -1.21 (NonDom). For the 30 to 39 age group, *z* = -3.90 (Dom), -11.32 (NonDom). All *z* scores within the three age groups are below the mean standard deviation. Table 4 shows that scores are lower within both dominant and non-dominant categories as the age increases. The younger group scores are closest to the mean scores with a *z* score of -.20 for the non-dominant hand.

The PPBT and GPBT findings showed that more than half of YAwMS perform worse in the areas of independent right and left-hand manipulation and speed. The assembly component of the PPBT showed delayed coordination skills for the majority of the study participants.

Question 2. What is the level of perceived satisfaction and performance of occupational tasks that are prevalent in YAwMS as measured by an adapted COPM?

An adapted COPM, a measure created to reflect tasks that require FM skills, consisted of three main categories: self-care, productivity, and leisure. Subcategories for self-care are personal care and community management. Subcategories of productivity are paid and unpaid work, household management, and school. Last, the category of leisure subcategories includes quiet recreation, active recreation, and socialization.

The 40 participants were asked to rank the 34 COPM items according to their perceived most problematic occupations that FM issues affect. A difference was found in the distribution of occupations among subcategory items. Among the 34 COPM items, eight were rated as the most important occupations that are problematic. Figure 8 presents the most frequently identified problematic occupations reported by participants. Occupations that involve the manipulation of objects or writing tools comprised 63% of the most frequently identified problems relating FM skills and occupations.

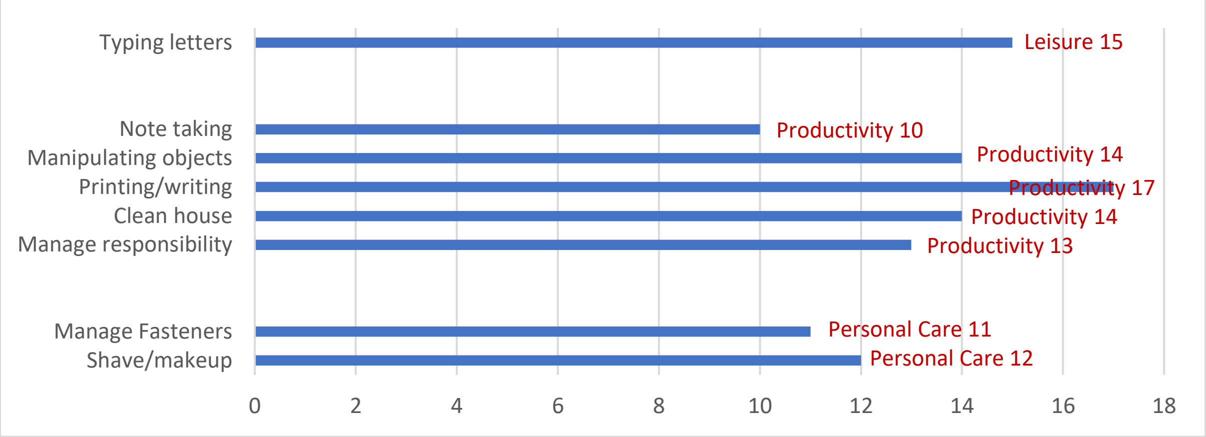

Figure 8. Most frequent perceived problem occupations in relation to FM skills of YAwMS.

The COPM is a client-specific, self-report measure. It was developed for measuring change, which increases the value of a score based on change. This study did not measure change. For the purposes of this study, a description of only the initial scores were used. The COPM's perceived performance rating scale of 1 to 10 was used to describe perceived performance as 1 being *not able to perform the tasks* and 10 to *perform the task extremely well*. Participants rated importance as 1 (least) to 10 (most), performance as 1 (able to perform) to 10 (unable to perform), and satisfaction as 1 (not satisfied) to 10 (very satisfied). A three-group rating scale was developed for this dissertation study to categorize the scores for each participant. This scale was used to define the percentage of participants that scored themselves low (1-4.9), average (5-7.9), or high (8-10 range; see Figure 9). This scale includes enough points within each group to differentiate the ranges from one another.

Table 5

Average Ratings of Problematic Occupations

	Number of occupations (34)		
	n (%)	Performance	Satisfaction
Self-care			
Personal care	31 (69)	6.4 (average)	5.3 (average)
Community management	14(31)	7.6 (average)	6.8 (average)
Total times items chosen	45		
Productivity			
Paid/unpaid work	24 (21)	7.0 (average)	6.1 (average)
Household management	37 (32)	6.5 (average)	5.4 (average)
School	54 (47)	6.7 (average)	4.9 (low)
Total times items chosen	115		
Leisure			
Quite recreation	14 (30)	7.9 (average)	5.9 (average)
Active recreation	13 (28)	6.1 (average)	4.2 (low)
Socialization	20 (42)	6.8 (average)	5.4 (average)
Total times items chosen	47		
Average		6.9 (average)	4.4 (low)

Note: *n* = number of items. % = participants who scored in that category.

Table 5 shows the total perceived performance and perceived satisfaction ratings. The mean ratings of performance were all average. For satisfaction, the ratings were all lower than the performance ratings, but lowest in the areas of school and active recreation tasks. Overall perceived performance scores were higher than perceived satisfaction scores within the average and high ranges (see Figure 9). Twenty five percent of the 40 participants rated themselves within the low range for perceived performance.

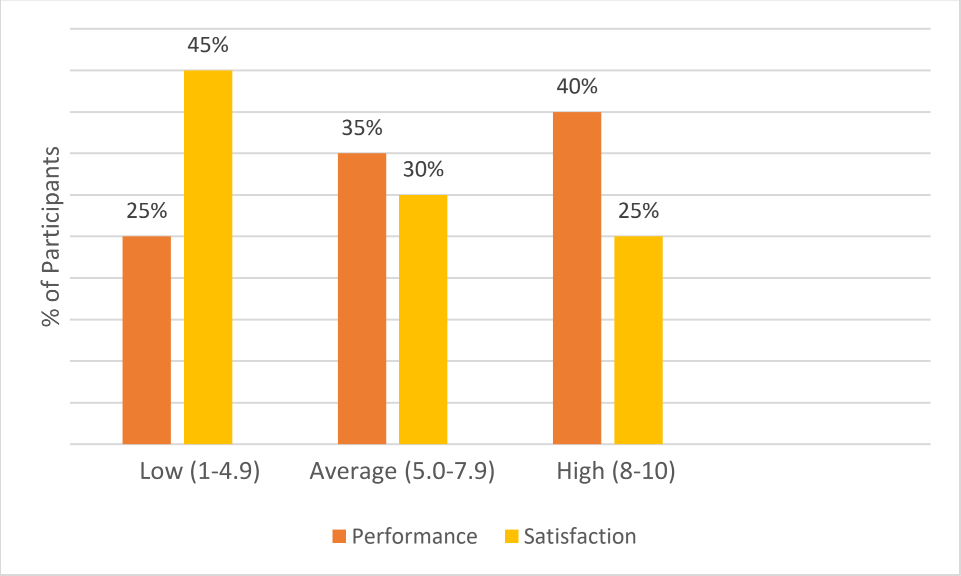

Figure 9. Perceived performance and satisfaction ratings.

Three subcategories accounted for almost 50% of all occupations identified by the participants as difficult to perform. They were in personal care (self-care), school (productivity), and socialization (leisure).

Self-care. Over two thirds of participants rated personal care as most problematic. The most frequently reported single problematic occupations were shaving and applying makeup. These occupations were reported to be difficult tasks due to visual deficits related to MS symptoms. Managing fasteners for dressing, such as buttons, laces, and zippers, and general dressing tasks, such as donning sweaters, pants, and shoes without fasteners, differed in the responses because of the motor skill needed for each task. General dressing tasks, such as donning shirts or pants, were frequently reported as a problem when the task required balance to stand. Tasks with dressing that involve more gross motor movement from proximal structures were reported to be less of a problem. Finer movements of the distal structures of the hands are required fasteners for dressing.

Opening containers and maintaining nails also requires Finer movement are also required, however, participants often received assistance with both tasks.

Productivity. The next highest problematic occupations were in the productivity subcategory of school (47%). School includes tasks that require FM skills, such as writing/printing, object manipulation, notetaking, doing homework, and draw/cut/paste. Some participants indicated accommodations for writing and notetaking at school or work. Household tasks, such as cleaning the house and doing laundry, include gross motor movements that were reported to cause fatigue, resulting in an inability to complete the tasks. Tasks that include FM movements, such as doing dishes, table care (e.g., setting the table), preparing foods, and minor household repairs (e.g., change bulbs), were reported to be difficult when the participant's hands were unsteady or weak. Participants indicated concerns about child care noting that they have trouble attending to their child's needs in a timely manner. Examples included attending to a crying baby, preparing a bottle, or bathing the child. Last, unpaid and paid work problems included learning new tasks and managing responsibilities including job duties or changes in lifestyle, such as moving or living alone, and preparing a resume.

Leisure. The third highest percentage of problematic occupations is in the leisure subcategory socialization. Writing letters in terms of typing emails or typing letters rated the second most identified item on the adapted COPM list. Telephone manipulation, such as texting or dialing, and hosting parties were rated as two of the less identified problematic tasks. Quiet recreation items, such as knitting/sewing, creative arts, playing cards or board games, medial tool manipulation and hobbies/collections that included exercise, were on the lower range of chosen problematic items. Active recreation, such as caring for a pet; dining out, specifically with utensil manipulation; and driving, including car knob manipulation, rated relatively low on the adapted COPM item list.

One of the more frequently reported impairments was functional ambulation in relation to work abilities and personal care tasks, such as shopping and house cleaning. The most cited issue was low standing tolerance during work or home-related tasks that required extended standing time. These issues combined with fatigue were the cause of decreased ability to complete these occupations. The fatigue would later result in a lack of ability to complete other tasks that require FM skills, such as manipulating objects; holding onto objects; socialization; and various self-care tasks, specifically dressing.

Analysis of follow-up interviews with 18 participants indicated several themes that confirm the FM testing results and the influence of FM deficits on the occupations of young adults, such as writing or printing tasks, manipulation of objects, and cleaning the house. Table 6 presents the problematic occupations cited by participants.

Table 6

Reported Problematic Occupations from the Adapted COPM

Occupation	Activity	Task
Self-care	Personal care	Managing nails (*n* = 1) Opening containers (*n* = 3) General dressing tasks (*n* = 4) Managing fasteners (*n* = 11) Shaving/applying makeup (*n* = 12)
	Community management (14)	Paying bills (*n* = 4) Handling money (*n* = 7) Shopping (*n* = 3)
Productivity	Paid/Unpaid work (*n* =24)	Learning new tasks (*n* = 7) Managing responsibilities (*n* = 13) Preparing resume (*n* =4)
	Household management (*n* =37)	Prep food (*n* = 7) Cleaning house (*n* = 14)[a] Doing dishes (*n* = 5) Doing Laundry (*n* =4) Minor house repairs (*n* = 5) Child care (*n* = 2)
	School (*n* = 54)	Manipulating objects (*n* = 14) Draw/cut/paste (*n* = 5) Print/writing (*n* = 17) Note taking (*n* = 10) Doing homework (*n* = 8)
Leisure	Quiet recreation (*n* = 14)	Knitting/sewing (*n* =1) Hobbies/collections[b] (*n* =6) Creative arts (*n* =1) Play cards/board games (*n* =3) Media tool manipulation (*n* = 3)
	Active recreation (*n* = 13)	Caring for pet (*n* = 3) Dining out (utensil use; *n* = 5) Driving car (door and knob manipulation (*n* = 5)
	Socialization (*n* = 20)	Telephone manipulation (*n* = 2) Hosting parties (*n* = 2) Writing (typing) letters (n = 16)[c]

Note: *N* = number of participants. [a]Occupations included in house cleaning are dusting, kitchen cleaning and dusting. [b]Occupations included in hobbies are exercise. [c]Writing letters includes typing emails or letters using a keyboard.

Question 3. What is the difference between the perceived performance and satisfaction of occupations (DV) as measured by the adapted COPM and the FM skills (IV) as measured by the PPBT and GPBT of YAwMS?

With the GPBT, there was a required measurement on hand dominance and age, and with the PPBT, there was a required measurement according to gender, age, and preferred and non-preferred hand dominance. All of the participants scored below the total mean performance range within for right, left, preferred and non-preferred hand usage, and assembly components of the PPBT with both genders. Most (83%) of the participants scored above the mean performance for both hands on the PPBT, but in contrast, 100% scored below the total mean performance norms in each category of the preferred and non-preferred hands and assembly components, according to the PPBT. One-way ANOVA was performed for all PPBT subtests. Due to the limited variation in individual raw scores, no statistical significance was found between the occupations and FM status of YAwMS using solely the PPBT. A Spearman correlation was performed to determine if there were a relationship between these variables as well as the GPBT.

An independent two sample *t* test of the fast and slow scores of the GPBT dominant and non-dominant and the COPM performance and satisfaction mean scores was performed.

Findings of Grooved Pegboard test dominant and non-dominant hands.

The GPBT dominant hand and COPM satisfaction. There were no significant differences between the satisfaction scores for the GPBT dominant hand fast group ($\bar{x}$ = 7.67, *SD* = 2.04) and slow group ($\bar{x}$ = 6.34, *SD* = 2.41), (*t* = 1.75, *p* = .088). The lack of statistical significance may be the result of a small sample size; however, a large effect size of .60 shows a large difference in distribution of scores between the groups. A larger sample size will result in a more accurate estimate of effect than a study with a smaller sample size (Portney & Waltkins, 2009).

The GPBT dominant hand and COPM performance. There was a marginal significant difference between the performance scores for the GPBT dominant hand fast group ($\bar{x}$ = 6.40, *SD* = 2.85) and slow group ($\bar{x}$ = 4.66, *SD* = 2.46), (*t* = 2.01, *p* = .051). The effect size shows a large practical difference in the distribution of scores between the variables at .65.

The GPBT non-dominant hand and COPM satisfaction. There were no significant differences between the satisfaction scores for the GPBT non-dominant hand fast group ($\bar{x}$ = 6.33, *SD* = 2.84) and slow group ($\bar{x}$ =5.28, *SD* = 2.85), (*t* = 1.09, *p* = .279). The effect size shows a medium practical difference in the distribution of scores between the variables at .37.

The GPBT non-dominant hand and COPM performance. There were no significant differences between the performance scores for the GPBT non-dominant-hand fast group ($\bar{x}$ = 7.13, *SD* = 2.30) and slow group ($\bar{x}$ = 6.87, *SD* = 2.33), (*t* = .337, *p* = .738). The effect size of .112 shows a small difference in the distribution of scores between the variables.

Table 7 illustrates the significant differences between the variables GPBT dominant and non-dominant hands and COPM satisfaction and performance. The effect size was measured for each result to determine the size of the difference between the fast and slow groups within the GPBT.

Table 7

Independent Samples t Test of GPBT and COPM Variables

	COPM Sat *M* (*SD*)	Sig. (*p*)/*t*	COPM Per *M* (*SD*)	Sig. (*p*)/*t*
GPBT Dom				
Group 1 (*n* = 14)	7.7 (2.04)	.088 /1.75	6.4 (2.9)	.051/ 2.01
Group 2 (*n* = 26)	6.3 (2.41)		4.7 (2.5)	
Effect size	.63		.65	
GPBT Non-dom				
Group 1 (*n* = 13)	6.3 (2.8)	.279 /1.09	7.1 (2.3)	.738/.337
Group 2 (*n* = 27)	5.3 (2.9)		6.9 (2.3)	
Effect size	.37		.112	

Note: SD = Standard deviation. GPBT Dom = Grooved Peg Board test dominant hand. GPBT Non-dom = Grooved Peg Board test non-dominant hand. COPM Sat = Canadian occupational performance measure satisfaction. COPM per = Canadian occupational performance measure performance. Group 1 = fast group. Group 2 = slow group with number of participants in parentheses. Sig. = significance. $p < .05$.

Question 4. What is the relationship between the perceived performance and satisfaction of occupations as measured by the adapted COPM and the FM skills as measured by the PPBT and GPBT of YAwMS?

A Spearman correlation was performed between the COPM and the PPBT subtests and the GPBT subtests to determine if there were a relationship between the PPBT and GPBT subtests and the COPM satisfaction and performance.

A Spearman correlation was chosen because of the monotonic nature of the continuous data, the ability to compare two variables, and the measures are on an interval level of measurement (Plichta & Kelvin, 2013). A statistically significant relationship was found between the COPM satisfaction and PPBA (Purdue pegboard assembly; $r = .424$, $p < .01$). COPM satisfaction and preferred hand (right or left) PPBT ($r = .470$, $p < .01$) and non-preferred hand PPBT ($r = .468$, $p < .01$).

Correlations were found between the COPM satisfaction and preferred ($r = .470$, $p < .01$) and non-preferred hands ($r = .468$, $p < .01$). A correlation was also found with the COPM performance and non-preferred hand ($r = .359$, $p < .05$). Correlations between the PPBA and COPM satisfaction (*r* = .424, *p* < .01) and performance (*r* = .350, *p* < .05). There was a significant correlation between COPM satisfaction and dominant hand GPBT (*r* = .377, *p* < .05). There are no significant correlations with COPM satisfaction and performance for the PPBT both hands and GPBT non-dominant hand (see Table 8).

Table 8
Correlations between the PPBT subtests, GPBT, and COPM Satisfaction and Performance

Pegboards	Satisfaction (r)	Performance (r)
PPBT Preferred	.470**	.236
PPBT Non-preferred	.468**	.359*
PPBT (both hands)	.204	.168
PPBT Assembly	.424**	.350*
GPBT Dominant	.377*	.291
GPBT Non-dominant	.226	.212

Note. **p* < .05. ***p* > .01. *r* = correlation coefficient.

Qualitative Results

A subgroup of 18 participants were interviewed in order to answer the qualitative question "What are the lived experiences of the occupations and occupational performance associated with the FM skills of young adults?"

Emergent themes were relationship changes, disease attributions, FM deficits that affect daily performance, avoidance of assistive equipment, and a lack of knowledge of OT interventions.

Relationship changes. Participants said that their social relationships changed following their diagnosis of MS. Twelve of the 18 reported a loss of friends or aspects of their social network. Some had close friends who remained in contact with the participant, but other friends evolved into acquaintances or relationships ended all together. Most of the participants felt that friendships slowly deteriorated, describing this as a “slow trickle of friends.”

> It was hard on it [social life], it was definitely hard on it because I was angry, definitely, especially with people who I thought would be there and weren’t there or going to be bothered with it because there were all having fun and doing everything that I was supposed to be doing (Heather, 21, diagnosed 4 years).

Relationships were described as generally unsupportive with participants citing a lack of understanding of symptoms of the disease. Statements, such as “friends disappeared after my diagnosis,” or “you learn who your friends are,” demonstrated the perceived change in loyalty and support from friends. Some said that when old friends were lost, new friends and social networks were formed through MS support groups. Participants began friendships with those who understood the participant’s experiences with MS. Participants said their inability to maintain the relationships was primarily due to their difficulty keeping up with the social activities. Symptoms of MS limited their mobility and energy levels. One participant stated, “I’ve been told I’m lame because I don’t party much” after saying that her medications slowed her down, causing fatigue. This fatigue resulted in an inability to physically keep up with her friends. Many said that friends started to infrequently visit or call and would stop calling. Some dealt with this physical limitation by turning to family for support and socialization. They developed new social networks through MS support groups and new friends who understood their potential limitations due to MS.

Many participants said discussing MS with others could be difficult for them. Beginning new friendships or intimate relationships was stressful because they were unsure about how to raise the topic. One participant said she would only discuss her MS if her symptoms were visible. “There needs to be a visual for others before I can tell.” Another participant expressed fear of developing a serious romantic relationship because she has MS. “In terms of dating, it brings out a lot of “how would I tell someone, or should I tell them, that thing.” Maintaining relationships or forming new relationships is hard for participants because of others’ lack of understanding regarding the participant’s disease. “They really cannot understand what it is I’m going through because they are not going through it themselves.”

Attribution theories. Many participants believed that stress was one of the main reasons for acquiring MS. Three participants experienced break ups prior to being diagnosed, and they attributed the disease to the level of their stress from the breakup. Others said they believed environmental factors, such as electronics and diet and food preservatives contributed to acquiring MS. Others mentioned pregnancy and post-natal exacerbations caused MS. Another suggested autoimmune disease triggering it, such as Lyme disease. This person said his/her disorganized motor planning, such as clumsiness, occurred “like before” the diagnosis, and suggested that the symptoms are related solely to MS. One participant described her hands as “underdeveloped” and the cause of her difficulties opening objects.

> My hands were like not fully developed, so I always have trouble with opening things. I don’t know how accurate that is. But there, I mean, even to this day regardless if that’s sure or not, I still sometimes have trouble. I guess weakness, more so, when like when I first wake up and

> before, like, going to sleep, I'll have like it's more difficult for me to open things (Joann, 29, diagnosed 6 years).

Fine motor deficits or symptoms that affect daily performance. Many of the participants described common symptoms, such as shakiness of their hands, pain in the arms and fingers, hand fatigue, hand weakness, spasms, numbness and tingling of the hands having an effect on their activities of daily living skills. One participant stated, "Just because I get it done doesn't mean it was easy to do." Others said, "My hands and arms are a problem," "My right hand is going to drop a lot," and "My left hand is bad. I have trouble with it." One participant described how it may appear to others when she was frequently dropping objects or had slow mobility skills. She said, "You would think I was drunk."

Fatigue is a symptom of MS that participants said affected their dressing skills. Many reported feeling "exhausted" after a morning routine. Dressing seemed to be a common problem when manipulating buttons and fasteners or even requiring stabilization to dress their lower extremities. "On a day like today, if I had to button up or something, it may take a bit long for me to get to that button." Some participants reported that they "compensated" in order to perform their ADLs independently or faster. A common complaint from participants was the need to focus when grasping objects during work or ADLs, such as using writing tools or eating utensils. One said

> If I concentrate hard enough like with that, I could do it very well. But if I'm just trying to do it because it's something that you normally do like hold the fork or spoon, I tend to drop it. I tend to, like, because I also can't feel my fingertips very well, so when I go to pick something up sometimes

> I'm like, oh there it is, but it's really like not there or something wrong shape or something like that. So, I tend to have a harder time doing stuff like that (Pamela, 27, diagnosed 2 years).

"I can't sign checks," said one participant when making attempting to pay bills. A few participants said, cutting and prepping food is a problem due to hand fatigue and weakness. "Like cooking, definitely if—I need to be more careful, it's again concentrating more when I'm cutting veggies and stuff and prepping meals, making sure that—yeah, making sure I don't cut myself."

Independent activities of daily living skills, such as driving and house cleaning, were reported by participants to be affected by fatigue, hand spasms, numbness and tingling, and weakness. "If I'm using a screwdriver for too long, I get tired very fast, things like that." Participants said that manipulation of knobs both inside and out of a car require more focus to operate. Feelings of low spatial awareness affects their ability to manipulate knobs.

> Often still I'll go to reach for something and I'll hit my hand on it because my distance doesn't seem to be working that well in my brain. I'll hit my hand on the counter or on the faucet even though I'm trying to go under it (Heather, 21, diagnosed 4 years).

Some participants, like service people, such as cashiers, would need to leave their jobs due to low manipulation skills of the tools of their trade. "I braid hair sometimes, but I had to stop doing that because my fingers get like locked, so I had to stop doing that." One participant said if she performs her job with shaky hands, it would be unethical.

> I tell the nurse that supervisors . . . look I can't do the drawing of blood today so I'll ask one of the others "can you do me a favor and draw my patients today because I don't think I can." One day my hands were too shaky, and I wasn't comfortable (Maria, 24, diagnosed 1 year).

Standing for long periods of time were particularly problematic due to fatigue. One participant stated that MS symptoms had a significant effect on handwriting. Symptoms of pain, spasms, and constant feelings tingling of the hands and arms made writing tasks difficult. These symptoms caused slower writing, slow moving hands, and less spatial awareness when performing typing tasks. Slower writing, printing or typing skills frequently resulted in the need to change jobs or create accommodations for school work. "My handwriting looks absolutely delirious."

Most participants said frequent dropping of objects is a serious problem. "My hands do not do what my brain tells me to do." Some said that their cigarettes slipped out between their digits.

> I do drop things more. I do smoke, so I've noticed my first thing was when I noticed when I'm holding my cigarette. Sometimes I was dropping more often like I wasn't conscious of how tight I was holding it and I was just dropping it more often (Robyn, 27, diagnosed 8 years).

"Things fly out of my hands," said one participant describing dropping her phone. "If it's something, if it had some weight to it, it will bounce out of my shaking hands, but if it doesn't have weight to it, I might fumble and things like that." Handling of smaller objects, such as makeup wands or shaving tools also present a problem. Participants said manipulation of small objects during work is a problem. "Like even right here, paper clip, I'll find I'm having trouble getting a grip of it and smaller items like that I have trouble."

Many of the participants said they've had to change the type of leisure tasks they engage in. Passive tasks, such as playing video games, staying home with family, watching TV or going for relaxing drives have replaced long trips that can cause fatigue and demand frequent breaks.

> It definitely diminished my social life because I can't do things that I used to do. So I can't be going to the beach all the time. Even like little things just because I have to avoid certain temperatures and certain places, I stopped doing things (Johnny, 27, diagnosed 6 years).

Some described dining out as embarrassing because of weak utensil use. One said, "I would drop my fork." Some said that exercise would become too difficult due to fatigue. If they planned to go out for a long time, the day must be carefully planned to bring the correct mobility device they might need. "Like I don't travel too far without being with my mom or somebody, because I lose my balance too much and don't like when I get flare ups."

Avoidance of assistive equipment. Most participants said that they use a cane, walker, and grab bars. Many of the participants associated their need for equipment, such as a wheel chair, to their expectation of MS symptoms in their future. "I feel like the more I rely on something [equipment] that the more I'm going to deteriorate." "I hear from people who are, you know, in a wheel chair, and I'm like, that freaks me out. So, I push it aside."

Some participants said they refute their need for equipment when offered by medical providers. They said they feel it would contribute to feeling of depressed. “Everybody has been talking to me about a cane and I’m like, no I don’t, because it’s going to put me into depression. I know that.” Another said, “I really don’t want to walk with no cane, and I don’t want to do that. That will probably make me depressed.”

Independent mobility and self-care was a frequent theme when participants discussed potential equipment needs. Many participants said they would refuse the use of equipment in order to maintain their independence. “I just don’t want to rely on the people like as far as my kids go. My mom is in the house, but I would rather do it on my own, even if it’s a year from now to start doing it completely on my own again because I had one daughter before it even happened.” One participant stated that leaning on walls gives her balance; however, she does not want to use a cane for assistance. “Yeah, I use the walls a lot, or when I walk out of my yard into the door, I stumble, and I keep going. Well, I did actually fall one time though.” Another participant described using of walls to help with balance, rather than using a cane. “If anything, I’ll use the walls to move around.” This same participant required ankle foot orthoses for stabilization during ambulation. She said, “What happened was I felt like it makes me walk even worse than how I would walk so I never used that, like, I’ve been-I stopped using it.”

Lack of knowledge of occupational therapy services. All participants were treated by neurologists, but few were directed towards allied health professionals. Sixteen of the 18 interviewees had not received OT interventions since being their diagnosed with MS. Only two participants said they had received OT services. One felt that the service was not helpful, and the other received the service as a child for a condition unrelated to his/her MS diagnosis. Several of the participants who have not received OT expressed an interest in receiving the service after given a definition of OT. The few who were aware of OT and interested in receiving OT have never been referred for the service or it was never discussed or suggested by their health care provider. "Just for my rate of manipulation and for my self-care skills." One participant said that his/her PT suggested to go to an OT for self-care strategies and to improve hand skills. One of the participants confused the OT and physical therapy (PT) roles and services and was unsure as to which type of therapy occurred at home. When asked if OT came to the home, he stated, "I don't know what occupation is . . . they just worked on my feet." One participant who reported to have received both OT and PT said, "I did both; it didn't help." They continued, "The MS gave me a bulging disc on my spine . . . so that's why they referred me to the physical therapy." This participant said that due to depression regarding her diagnosis, she lacked in motivation towards therapeutic interventions. A participant who expressed difficulty with manipulation of writing tools, buttons, small objects and difficulty typing, reported that she had received physical therapy for her balance, but not OT to improve her hand skills. "I've done it before with my balance. They want to help me with my balance because is really bad, but they say that my hands, that they don't see anything wrong with them." Eight of the interviewees received PT and 10 have not received PT services. One participant explained why they did not want to continue PT services.

> I did PT for a while for the balance, but I feel like it's not going to be improved so I don't want to do it. The doctors told me it's going to be like

> this forever so there’s no—I’d rather use my time do something better (Janie, 25, diagnosed 3 years).

Other participants felt that PT would improve, their balance, saying, “PT will make it better.”

Participants said that alternative treatment methods, such as acupuncture, had been suggested, but they refused all services. One suggested replacing PT with equestrian therapy to work on her balance. She said, “They said that horseback riding releases all of that tension and it keeps your back straight, move and everything, so I’ve always loved horses. I want to kind of like move out and maybe do my own kind of physical therapy for myself.”

These emergent themes describe how the symptoms of MS affect the maintenance of interpersonal relationships, causing changes in the participants’ support and social activities. Emotional reactions to the diagnosis may lead to the deterioration of relationships. Attribution theories emerged through other outlier factors, such as stress, pregnancy, and environmental factors as reasons for their development of MS. Fine motor deficits that affect daily performance, such as with self-care, work or school productivity, and house care, have been described as the most problematic when describing their relationship between occupations and FM skills. Avoidance of assistive equipment by participants was expressed through the refusal of assistive equipment to preserve their idea of independence. Self-care or mobility devices may contribute to the participants’ recognition of an uncomfortable reality of their future with MS; therefore, it may be easier to live in denial. Lastly, there was a lack of knowledge of OT services and interventions. Most participants said they did not know or understand the concept of OT and how it could help them. This finding is consistent with Lexell et al. (2014) who stated there is a lack of knowledge about rehabilitation services and the contribution it makes in improving functional skills and ADLS for people living with MS.

Physical therapy was the more common interventions received by some of the participants. Although all of the participants were seen by neurologists, they were not being directed to receive OT. These participants felt that the loss of balance and ambulation skills were often seen as the first symptom to be addressed through therapeutic interventions, but interventions for independence in occupations related to self-care, work/school, or leisure tasks were not recognized as critical need.

Quantitative and Qualitative Merging

Eight of the 40 participants demonstrated below the mean performance on the FM testing and scored themselves high on perceived performance, but low on satisfaction ratings. One participant who rated himself/herself high in performance, but low in satisfaction, performed within the mean performance on the FM testing. Four participants performed low on the FM testing, but rated themselves high in both performance and satisfaction. Four rated themselves high or near equal on performance and high in satisfaction but performed below the mean performance on the FM tests. One participants scored himself/herself low on both performance and satisfaction and performed below the mean performance on the FM tests.

No significant differences could be found between the PPBT and GPBT subtests and COPM performance and satisfaction, but correlations were found between components of the PPBT, GPBT and COPM satisfaction and performance. These findings indicate that there is a degree of disability that is affecting the self-care (dressing), work, school, and household tasks (including childcare) and socialization occupations of YAwMS.

Table 9 shows the subgroup of 18 interviewed participants combined FM status, perceived performance and satisfaction averages, and interview themes. Each participant was categorized according to the criteria of his/her performance. The following five questions of performance between the FM status, interviews, and self-report of the COPM emerged: (a) Who rated themselves higher in performance and lower in satisfaction, but performed below the mean performance (↓m) on the FM tests? (*n* = 8); (b) Who rated themselves higher in performance and lower in satisfaction, but performed within the mean or better (↑m) on their FM tests? (*n* = 1); (c) Who rated themselves high in both performance and satisfaction, but performed below the mean performance on components of the FM tests? (*n* = 4); (d) Who rated themselves relatively high or near equal on their performance and satisfaction, but performed below the mean performance on the FM tests? (*n* = 4), and; (e) Who rated themselves low on both satisfaction and performance, but scored below the mean performance on the FM tests? (*n* = 1).

Table 9 shows the participants’ domain, PPBT and GPBT performance results, qualitative themes drawn from the interviews and COPM discussions, self-reported perceived FM effect scale, and participants’ perceived performance and satisfaction ratings. The FM effect scale is a scale created by the investigator to allow the participants to rate themselves about how they perceived their FM skills effected their occupations (1 = *no effect*, 10 = *very effected*).

Table 9

Cross-case Comparison using Subgroup Qualitative Finding and Mixed Method Integration of Qualitative and Quantitative Data

P#	Domain	FM	Qualitative results (themes)	FM Rating	Performance Rating	Satisfaction Rating
Who rates themselves higher in performance and lower satisfaction, but performed below the mean performance on the FM tests? (*n* = 8)						
1	↑Performance ↓Satisfaction Low FM Results	P:↓m, NP: ↓m B: w/i m Assem:↓m DH: 45 sec slower NDH: 59 sec slower	Numbness in hands; can't grasp objects (e.g., screwdriver/tools; writing and typing difficult but effected daily. "My left hand is weaker."	8	3.6	1
2		P:↓m; NP: ↓m B:w/i m Assemb: ↓m DH:54 sec slower NDH:.8 sec slower	Problems grasping (e.g., Phone, cigarettes); objects slip out of hands; drop things when carrying; lost job due to low performance; problems dining out b/c low utensil grasp and tremors	8	3.8	3.2
3		P:↓m; NP: ↓m B: w/i m; Assem: ↓m DH: 4 sec faster NDH: met norm	Dropping things; low hand spatial awareness hand fatigue; dresses slowly	7	4.4	4
4		P:↓m; NP: ↓m B:w/i m; Assem: ↓m sec slower DH: 1.7 NDH: 7.4 sec slower	Numbness, tingling, fatigue in hands; constant tingling or pain after activity or when first wake up; must concentrate to maintain grasp; drops utensils; frequent typing errors; fatigue	7	4.4	3

(continued)

P#	Domain	FM	Qualitative results (themes)	FM Rating	Performance Rating	Satisfaction Rating
5		P:↓m; NP: ↓m B:↓ m Assem: ↓m DH: 96 sec slower NHD: 139 sec slower	Pushes through writing tasks b/c hard to write; sloppy writing; types with one finger; drops objects often; writing and typing most affected; affects work and manipulation of small objects at work	10	4.8	1.8
6		P:↓m; NP: ↓m B: w/i m; Assem: ↓m DH: 37 sec slower NDH: 35 sec slower	Fatigue affecting FM skills; low FM skills with job tasks; food prep or cutting; tremors with applying makeup	5	6.0 (8 w/ attack)	3.8
7		P:↓m; NP: ↓m; B:w/i m; Assem: ↓m DH: 2.15 sec slower NDH: 15 sec slower	Numbness in right hand and thumb; frequently dropping objects; affects work; stopped work because of hand symptoms; low skills with fasteners	10	6.2	1.2
8		P:↓m; NP: ↓m B: w/i m Assem: ↓m DH: 18 sec slower NDH: 19 sec slower	Sloppy handwriting; difficulty opening things; daily weaknesses in hands; hand spasms	3	8.4	5.4

(continue)

P#	Domain	FM	Qualitative results (themes)	FM Rating	Performance Rating	Satisfaction Rating
Who rates themselves higher in performance and lower satisfaction, but performed within mean performance on FM tests? (*n* = 1)						
9	↑Performance ↓Satisfaction Good FM results	P: w/i m; NP: w/i m B: w/i m Assem: w/i m DH: 7.5 sec faster NDH: 18 sec slower	Inability to sign checks; difficulty with fasteners; compensates with typing or with typing or manipulating papers	7	10	4.7
Who rates themselves high in both performance and satisfaction, but performed below or at the mean performance on FM test? (*n* = 4)						
10	↑Performance ↑Satisfaction Low to Average FM results	P:↓m; NP: ↓m B: w/i m Assem: ↓m DH: 5 sec slower NDH: 9 sec slower	Bilateral UE ataxia R > L; tremors with attacks	1	9	6
11		P:↓m; NP: ↓m B: w/i m; Assem: w/i m DH: 5 sec faster NDH: 7 sec faster	Non-verbal indication with waving hands in air prior to testing	2	10	10
12		P: w/i m NP: ↓m B: w/i m Assem: w/i m DH: 7 sec faster NDH: 2 sec faster	Left hand delays. “left hand not so much.” Performs ADLs with one eye. Primary issues are visual deficits; little c/o FM issues and does not expect FM issues	1	10	10

(continued)

P#	Domain	FM	Qualitative results (themes)	FM Rating	Performance Rating	Satisfaction Rating
13		P:↓m; NP: ↓m B: w/i m Assem: ↓m DH: 2 sec slower NDH: 2 sec faster	Symptoms “tremendously” effect writing skills; drops objects; hand fatigue with writing; low hand spatial awareness; major concern is low FM skills after attack; c/o FM issues with and without attacks.	6	5.4	5
Who rates themselves relatively high or near equal on performance and satisfaction, but performed below the mean on the FM tests? (*n* = 4)						
14	≥Performance ≥Satisfaction Low FM Results	P: ↓m; NP: ↓m B: w/i m; Assem: ↓m DH: 150 sec slower NDH: 91 sec slower	Low typing skills needed for work; slow time with fasteners; tremors affecting writing skills; low manipulation skills; must concentrate to maintain grasp; ataxic UE R > L; compensation to stabilize UEs during tasks.	6	5.4	5
15		P: ↓m; NP: ↓m B: ↓m; Assem: ↓m DH: 54 sec slower NDH: 53 sec slower	Hand writing fatigue; requires rest periods; hand shaking with dressing son and manipulation of smaller objects; tremors with writing and fasteners; c/o of symptoms daily and unexpected appearance of symptoms.	8	7.8	6

(continued)

P#	Domain	FM	Qualitative results (themes)	FM Rating	Performance Rating	Satisfaction Rating
16		P: ↓m; NP: ↓m B: w/i m Assem: ↓m DH: 121 sec slower NDH: 213 sec slower	Numbness in hands, severe with attacks and sometimes so severe it incapacitates hand usage; trouble gripping objects; misses keys with typing; low manipulation of small objects; symptoms worse with stress; affected daily. “My left hand is bad and I have trouble with it.”	10	7.8	6
17		P: ↓m; NP: ↓m B: w/i m Assem: ↓m DH: 16 sec slower NDH: 34 sec slower	Constant numbness, tingling; pain limits hand writing, note taking, ADLs; tingling affects concentration; must focus to maintain grasp; shaky hands at work; concerns of FM affecting work.	2	8.8	9.4

(continued)

P#	Domain	FM	Qualitative results (themes)	FM Rating	Performance Rating	Satisfaction Rating
		Who rates themselves lower on performance and satisfaction and performed poor on the FM tests? (*n* = 1)				
18	↓Performance ↓Satisfaction Low FM results	P: ↓m; NP: ↓m B: w/i m Assem ↓m DH: 97 sec slower NDH: 60 sec slower	Feeds self fast to avoid spillage; must focus on hand skills and when carrying objects; slow manipulation of objects	3.2	8	3.2

Note: P# = participant number. FM rating = self-report rating on effect of FM skills on occupations. *m* = mean. P = preferred hand. NP = non-preferred hand. B = both hands. Assem = assembly. DH = dominant hand. NDH = non-dominant hand (GPBT). w/i m = within mean

The qualitative responses contributed to the quantitative findings and show some contradiction between the interview responses and the quantitative results. This table also demonstrates those contradictions in the areas of low FM scores, but higher perception on the participants perceived performance or satisfaction.

Below is one case study per category taken from the Table 9. These case studies are used to explain some of the additional factors that may also affect FM skills and the occupations of these YAwMS. One participant performed within the mean of his/her FM skills and high on performance, but very low on the satisfaction rating, indicating that there was an awareness of FM deficits that may influence the occupational outcome.

Case Studies

Susan (↑Performance, ↓Satisfaction, ↓mean of FM skills). Susan is 28 years old and lives with her two children, mother, siblings, and grandmother. Susan was diagnosed with MS at 26 years old. Susan has regular interaction with her immediate and extended family. She reported that her family is very supportive of needs. Susan reported most of her friends are aware of her diagnosis, but she has not told all of her friends. Susan reported that her close friends have remained supportive of her since her diagnosis and are understanding of her diagnosis. Susan’s social life is calm. She prefers to stay at home and have visitors, but she reported this pattern has always been her typical social life prior to her diagnosis. Susan said that she will only leave the house if she has the support of a family member due to her low standing balance issues. Susan stated that during her pregnancies, her legs would tingle, and her feet would go numb. Her MRI results showed indications of MS. Susan later experienced symptoms of numbness in her hand, memory loss, and general fatigue. Susan’s results indicated below mean performance for her FM skills. Her average rated perceived performance score fell within an average range (6.6), but her average perceived satisfaction score was low (1.2). Susan reported her frequent symptoms of hand numbness, particularly in one hand, but more importantly related these symptoms to her low FM skills during her occupations of dressing, work skills, and general daily tasks. Susan expressed concern for her children having a mother with a disability; therefore, she makes good attempts to remain as independent as possible. Susan is also fearful of losing her eyesight because she discovered visual deficits as a potential symptom during a recent investigation of MS symptoms. Susan will not investigate MS symptoms often for fear it will make her more depressed. She will not use assistive devices for ambulation because she reported that using the wall for support is all she has needed within the home, although she does use grab bars in her shower. Susan's higher performance rating indicates that although she can perform the task, her satisfaction with the results on the tasks is very low. These results indicate that Susan is aware of her disability, and she is not satisfied with the occupational outcome, even though she reports an ability to perform the rated tasks. Susan has received PT services in the past and is not familiar with OT or how it can help PwMS. Susan rated her FM scale at a 10, confirming that she perceives her FM status to affect her daily living tasks.

Donna (↑Performance, ↓Satisfaction, w/i the mean for FM skills). Donna is 27 years old and lives with her parents and brother in Queens, New York. Donna was diagnosed at 17 years old. She is very close with her family and interacts with them on a daily basis. Donna reported that she has lost friends over the years since her diagnosis and attributes this loss to her inability to keep up with the high energy activities. Her social network has changed, and she reports that she currently has three very supportive friends from work. She also has a boyfriend and stated, “He is very understanding because one of his family members has an autoimmune disease.” Donna reported that she does not go out to clubs or bars, but will go out to a diner to eat. She reported that she is able to perform her self-care tasks with active symptoms of visual deficits and numbness and tingling of hands and arms. She reports that she is unable to form a fist and will compensate when typing or manipulating papers. Donna states that her hands interfere with her daily tasks “a little bit,”, but then reported that her daily tasks are affected by her hand weakness daily, particularly her writing skills, manipulation of tools, difficulty with clothes fasteners (e.g., buttons). Donna does not receive OT intervention, but after given a description of OT, she expressed an interest in receiving it.

Donna’s FM skills match her statement of “a little bit,” but her self-awareness as to her rating of perceived satisfaction is linked to her expression of symptoms rather than her FM results. Donna presented with better FM results within all four subtests scoring within the mean performance range. Her average rated scores for the COPM resulted in a higher score with her perceived performance (10), but low in his perceived satisfaction (4.6). Donna self-rated her FM skills at a 7 regarding their influence on her occupations adding consistency to the results of her testing and interview.

Fran (↑Performance, ↑Satisfaction, below or w/I mean for FM skills). Fran is 21 years old and was diagnosed with MS at 17 years of age. Fran lives with her husband and son in a downstairs apartment from her parents and brother. Fran reported that her family is very supportive during her flare ups, but her dad did not understand her symptoms and diagnosis for some time. Fran has maintained the same friends since high school but has been less social due to her symptoms. She reported that can be angry at her friends because they have not been supportive at times and leave her out of activities. Due to her exacerbated symptoms, she was unable to attend her high school prom and required an escort to her graduation. Fran reported that her main concern is caring for her son, but childcare has been difficult as her symptoms have progressed. Fran stated, “I thought I was dying,” when she discussed her first attack. She reported that she was relieved to reach a diagnosis, but very upset because of the sudden onset of symptoms. Similar to Susan, Fran attributed her onset of symptoms to her pregnancy. She also reported her awareness of a high incidence of MS in Suffolk County, Long Island. Fran reported that her fatigue affects her job as a medical assistant and at times unable to perform her job due to her FM deficits. She is required to manipulate needles, but frequently drops objects due to hand fatigue and a low spatial awareness. It is when she feels that her hands are tired that she will ask for assistance or a stand in at work. Fran is currently a nursing student as well and expressed concern regarding her ability to perform her duties as a nurse after she graduates due to her FM status. Fran has accepted that she may need assistive equipment in her future. She reported that her neurologists never suggested her receiving OT or PT services but would want to have the interventions.

Fran’s FM scores fell mostly in the low to average range, and she rated her perceived performance and satisfaction high with an average score of 10 for each. Fran complained of weakness in her left hand and said that her FM deficits affect her daily tasks “tremendously.” Fran complained of a low spatial awareness of her hands with frequently missing her target of reach. She reported that she frequently dropped objects and that her writing skills worsened as her hand fatigued. She required frequent breaks from writing. Fran’s high perceived performance (10) and satisfaction (10) scores contradict her reports of FM difficulties during her daily tasks. She self-reported her FM rating at a 5, indicating that there was an average effect of her FM status on her occupations. These results indicated that Fran can perform her tasks and regardless of her FM difficulties, and she is satisfied with the outcome.

Wanda (≥ Performance, ≥ Satisfaction, ↓mean performance for FM skills). Wanda is 27 years old and was diagnosed with MS at 26 years of age. She lives in Brooklyn with her sister, and both are working professionals. Wanda interacts with her sister and speaks to her mother daily on the telephone. Her parents live out of the United States. Wanda’s social network consists of two friends, one of whom is relatively new. She reported going to bars after work and prefers to people watch or walk to lessen her stress. She reportedly stays private about her diagnosis. A major concern for Wanda was dating. She reported feeling that her MS will affect her future relationships, including marriage. Wanda reported to be active in remaining compliant with her medications and obtaining assistance if needed. She reported that her symptoms can be distracting at work because they result in pain, numbness, and tingling of her upper extremities. She reportedly drops her work tools due to tremors of her hands and upper extremities. She stated that she will ask her co-workers for assistance if her symptoms are affecting her work beyond her control. Wanda discussed how her experiences of constant symptoms affect her daily writing and ADL skills. She reported that she must focus on her grasp when holding objects in order to maintain a grasp.

Wanda’s scores fell below the mean performance range for her FM skills. Her average score for her perceived performance was lower (8.8) then the average score on the perceived satisfaction scale (9.4). Wanda stated, “MS is an ongoing process.” Wanda’s higher average score with her satisfaction indicates that she is satisfied with however she performs her tasks. Wanda rated her FM skills on her daily performance at a lower level of 2. She reported that this score is indicative of how she feels her symptoms interfere more with her concentration than her ADLs. This finding was a contradiction of her reported difficulties at work and with her daily living tasks. Her statement also showed her coping mechanism as acceptance with the progression of the disease.

Paul (↓Performance, ↓Satisfaction, ↓ mean performance on FM skills). Paul is 30 years old and was diagnosed with MS at 22 years old. He lives with his parents and reported that his family is very supportive. He reported that he has not told friends about his diagnosis unless they asked about his symptoms. He stated, “I don’t want sympathy and nothing like that.” He also reported that he tends to stay away from people who may be trouble because he may not be able to run from the problem if needed. Since his diagnosis he has developed a new social network within his MS support group.

Paul was active prior to his diagnosis until he noticed that he began to fall frequently. He reported that he lost vision in one eye and noticed that he was losing his balance. He reported that he is often fatigued and that heat slows him down. He stated that he can work, but his work is inconsistent. He works in construction and must “keep it light” because of his MS. He is currently not working. Paul currently exercises with walking and weights and feels this activity adds to his stability. Paul reported incorporating compensatory methods with his ADLs and manipulation or grasp of objects to continue his work and tasks within a day. He complained of frequently dropping objects and the need to focus on his hand skills. He stated, ". . . something small I'm grabbing, if it's–if it had some weight to it, it will bounce out my shaking hands. But if it doesn't have weight to it, I might fumble and things like that." Paul receives PT for his walking and balance and is prescribed to wear bilateral ankle foot orthoses. He does not wear the orthoses because he feels they impede on his walking ability, so he will use the wall for support. These are the only assistive devices he owns or uses.

Paul had scored below the mean performance on the FM testing and rated himself low on the perceived performance (3.2) and satisfaction (3.2) scales. He rated himself at an 8 on the self-report scale for FM status affecting his daily tasks. Paul's low scores on all assessments and self-reported rating of his FM status indicated that he is aware of his abilities in performance and is not satisfied with his results.

Member Checking Results

To improve the credibility and validity of the qualitative component of this dissertation study, member checking occurred following the analyzation of the transcribed interviews. A summary of the data collected from the semi-structured interviews (see Appendix N) was electronically sent to the 18 subgroup participants to check the authenticity of the findings. One participant requested a review through a telephone conversation because it was easier for him to talk rather than type. The summary included the key themes found within this study, such as relationship changes, FM skills related to self-care, productivity, and leisure tasks, fatigue related disability, knowledge of OT, and support.

The participants were asked to critically examine the findings, reflect on their own experiences, and agree or disagree with any of the given summary findings. Nine of the 18 participants responded. Six agreed with all of the founded themes and three agreed with 90% of the themes. One participant cited that the findings applied to her lived experiences with MS, except that her friends have remained loyal throughout her diagnosis with MS. Another participant cited that he disagrees with his FM skills interfering with his current ability to perform ADLs and work tasks, but agreed that fatigue plays a major role in self-care performance. Family and spousal support was universally strong with this group, except for one participant who cited that his relationship with his fiancé had broken off. He stated that he feels this break-up may have been due to his MS symptoms. Another participant stated that she mostly agreed, but not all of the findings applied to her. She continued to cite that MS is a "snowflake disease" because no two MS patients are alike and that although the findings may not all apply to herself, they may have been relevant to others she knows with MS.

Summary

This investigator assessed the relationships between FM skills and occupations for a sample of 40 YAwMS in the northeastern region. Using an independent two-sample *t* test to find the differences between the FM testing and COPM, no significant differences between the GPBT and COPM performance and satisfaction were identified. There was a trend for a difference (.051) between hand dominance of the GPBT fast and slow groups and perceived performance. The results of the independent *t* test leads to the assumptions that speed does not affect the perceived satisfaction with the dominant or non-dominant hand and that speed leads to differences in the perception of performance with the dominant hand. Hand dominance had no relationship to the speed or participants' performance of tasks. Using a Spearman correlation analysis, relationships were found between several components of the PPBT, GPBT and COPM performance and satisfaction. Correlations were found with the PPBT assembly and non-preferred hand and the COPM perceived satisfaction ($p < .01$) and performance ($p < .05$) scores. Also, a correlation was found between the PPBT preferred hand and the COPM perceived satisfaction ($p < .01$), but not perceived performance. The GPBT dominant hand had a correlation with the COPM perceived satisfaction ($p < .01$), but no correlation between GPBT dominant hand and satisfaction has been found. The Spearman correlation findings showed that with improved fine motor skills of the dominant hand, participants were perceiving greater satisfaction. Also, as coordination improved with the PPBT assembly subtest, participants showed improved perceived satisfaction and performance.

Eighty eight percent of the participants were right handed, (females = 24 and males =11). All five of the left-handed participants were females. All, male and female participants scored below the mean performance norms in the preferred, non-preferred, and assembly, according to the PPBT subtest means. In contrast, for both hands, two of the 11 male (21%) and five of the 20 female (60%) participants scored above the mean performance norms for young adults, according to the PPBT manual. The overall average score for the both hand domain was above the mean performance for both genders. The PPBT both hands scores were calculated by adding the right and left side scores to achieve a both hand total score, therefore, possibly resulting in higher scores, but not necessarily better manipulative skills.

The results of this study were found to be consistent with previous studies in which there were concerns for PwMS in performing their daily tasks, but there is limited research showing how FM skills have influenced daily occupations to the extent to which this investigator has examined. Kierkegaard et al. (2012) found that FM dexterity skills are important predictors of problems in daily tasks perceived performances in PwMS who are ambulatory.

Writing, typing, and household duties were the common reported problematic occupations on the adapted COPM for this study population. The COPM results showed that the level of importance of FM tasks for young adult’s daily performance at home, work, or school to be the most important. The overall higher ratings of level of importance in these three areas were suggestive that these participants perceived their FM skills as related to productivity to be very important. These findings were consistent with the expected occupational roles of this population as a student and employee. The COPM results showed the perceived performance scores to be higher than the perceived satisfaction with most participants. The low ratings in perceived satisfaction within home, work, and school problem areas had an implication that there were FM issues interfering with tasks that were considered very important to the daily productivity.

Interviews presented emergent themes that confirmed the participants’ descriptions of their FM performance during self-care, productivity, and leisure tasks. Themes included the relationship changes, disease attributions, FM deficits that affect daily performance, avoidance of assistive equipment, and a lack of knowledge of OT interventions.

Merging of the quantitative and qualitative data from 18 interviewed participants were suggestive of a relationship between the FM scores and perceived performance and satisfaction scores of the adapted COPM. The majority of the participants (13) performed poorly on the FM testing and scored themselves high on the perceived performance and low on satisfaction, indicating that although they were able to perform the tasks, they were not satisfied with the outcome of their performance.

Chapter 5: Discussion

Introduction to the Chapter

This dissertation study sought to answer the question “How the FM status of YAwMS relate to their perceived occupational performance and satisfaction and lived experiences”? The aim of this two-phase, explanatory mixed method study was to measure FM status from a sample of YAwMS (*n* = 40) using the PPBT and GPBT and identify perceived occupational performance and satisfaction using the COPM. Those quantitative findings led to interviews with a low scoring subgroup of the population (*n* = 18) to explore the lived experiences of YAwMS.

It was hypothesized that YAwMS will not be satisfied with their occupational performance in their self-identified problem areas as related to their FM status.

Discussion and Interpretation of Results

In the first phase, two valid and reliable assessments, the PPBT and GPBT, were used to determine the FM skills status of YAwMS. The assessments measured performance on individual hands, both hands, assembly, and speed. The finding that most (88%) of the participants scored below the mean performance for individual hands and assembly is consistent with the findings of a previous study using the PPBT with adolescents with MS. Squillace et al. (2015) found differences with manipulation and dexterity of the adolescent population with MS using the PPBT.

The findings of the low scores on PPBT and GPBT individual and assembly hand performance and speed low scores help describe why the participants reported that writing, typing, manipulating small objects, and household duties were most problematic for them. It was reported that PwMS and other neurological disorders demonstrate FM deficits that affect manual dexterity while performing daily tasks (Gorniak et al., 2014). Activities of daily living tasks involved with self-care, productivity, and leisure use the coordination of hand movements in order to manipulate objects or tools to complete the tasks. When tasks require one hand or if one hand is slower, then the task will be difficult to perform.

With the PPBT assembly subtest, the participants were required to use two hands cooperatively to manipulate and coordinate the peg assembly. The complexity of the bilateral assembly task resulted in lower scores for nearly all participants.

With the PPBT both hands subtest, participants were required to use both hands working independently and parallel to each other to perform this component of the test. Scoring for the both hands component involved calculating a sum of each hand score for an overall summary score. This calculation formula resulted in a higher overall score for the both hand PPBT subtest. This scoring may explain the considerable differences between the PPBT subtests of individual hand, assembly, and both hand scores.

Participants reported frequently dropping objects or low strength within their hands as a common symptom during and after an exacerbation. Coordination of digital and hand forces is important in the successful completion of daily living tasks (Gorniak et al., 2014). Squillace et al. (2016) found weaknesses with right hand two-point pinch strength in a study for adolescents with MS. A dysfunction in FM skills or coordination, including object dropping, decreased intrinsic hand strength, and low manipulation of tools, can negatively affect the ability to perform daily tasks that require FM skills (Gorniak et al., 2014). Krishnan and Jaric (2008) found lower scores of task performances and coordination as measured by static and dynamic manipulation grip tool devices. A relationship was found between walking speed, manual dexterity, cognition, and ADL performance using independent assessments for each domain (Kierkegaard et al., 2012). They found that walking speed and FM skills are important predictors of activity levels and participation, signifying these skills as important factors in daily living skills. Manual dexterity and walking are reported to be predictors of perceived problems in ADL performance for PwMS (Kierkegaard et al., 2012). The findings of this dissertation study presented confirmatory evidence that FM testing is important in determining changes in performance over time.

The hypothesis that YAwMS would have low satisfaction with performance involving FM skills was confirmed and corroborate findings in the literature (Gorniak et al., 2014; Lexell et al., 2006; Lexell, 2009; Lexell et al., 2014; Tal-Saban et al., 2014). Gorniak et al. (2014) found a correlation between impaired upper extremity movements and PwMS perception of their overall functional abilities. In this study, YAwMS were unsatisfied with performance on 34 age-related activities involving FM skills required for self-care, productivity, and leisure. These findings are consistent with Lexell (2009) who found that PwMS have mostly had problems with self-care and some with household tasks and that many needed financial and practical help in order to manage their daily life skills. Tal-Saban et al. (2014) found that at one point during the disease process there is a relationship between motor coordination and the influence of the symptoms that will influence daily functioning. Squillace et al. (2015) states that FM symptoms correlate to other physical findings and their relationships to participation in daily life activities.

The finding that one third (35%) of the participants scored their perceived performance higher than their perceived satisfaction indicates that although they felt they can perform the task, their level of satisfaction with the way they complete the task was low. This is consistent with Lexell et al. (2006) who identified ratings of perceived performance and satisfaction for occupations of PwMS. They found that the perceived difficulties in chosen occupations were rated as unsatisfactory with their performance.

Occupations most frequently identified and given a low perceived satisfaction score by participants were shaving and applying makeup, printing, writing or typing letters, manipulating small objects, household care, and managing fasteners. These are core occupations requiring FM skills for this age group. This finding is consistent with Lexell et al. (2014) who reported that in a group of 43 PwMS, the most reported problems were in the areas of self-care (63%) and productivity (24%). These participants scored themselves low in their perceived satisfaction with an average of 3.03 for self-care and 4.15 for productivity on a rating scale of one to 10.

In this dissertation study, only three of the 40 participants scored themselves high (10) on both the performance and satisfaction regardless of their lower FM scores. One participant indicated that she was satisfied with the performance of the tasks regardless of the degree that FM symptoms interfered with tasks performance (see Table 9.). In spite of poor performance, this individual’s optimism may be explained through the concept of compensation.

Table 10

Variations of FM and COPM Test Results

P/Non-P/Assembly		Speed		Perceived	
		Dom	Non-Dom	Performance	Satisfaction
↓Mean	88%	63%	68%	68%	High 25%
w/i Mean	0	37%	13%	Aver 35%	Aver 30%
↑ Mean	12%			Low 25%	Low 45%

Note: ↓mean=below mean. W/i mean= within mean. ↑mean=above mean. Percentages are representative of the percentage of participants that scored within the category.

Table 10 illustrates the combined results of the FM and COPM testing. Young adults with MS in this study who performed above the mean (12%) but rated perceived performance low range (25%) indicated less satisfaction with their performance of occupations that require FM skills.

Recalling that the vast majority (88%) demonstrated impaired FM performance, nearly half (45%) of the participants fell within the low range of perceived satisfaction with their occupational performance. Those scoring within the low satisfaction range (45%) were not satisfied with how they perform their tasks that required FM skills. This group's perceptions were consistent with their performance. For others who scored below the FM skill means, they rated their perceived performance (40%) and satisfaction (25%) within the high range. This group appreciated that they were able to perform the task at all. This finding is consistent with Lexell et al. (2014) who explained that upon admission to a rehabilitation center, PwMS rated themselves higher in perceived performance than perceived satisfaction.

Conceptual Framework for Findings

Impaired FM performance was related to low satisfaction within occupations, such as self-care (grooming, dressing, and childcare), productivity (house hold tasks, school and work), and leisure (quiet recreation) tasks. This study's conceptual framework describes how the interaction of the physical, emotional, and social environments of YAwMS can influence their sense of wellbeing. Figure 10 is a graphical representation of the experiences of the study participants. The quadrants represent the person (YAwMS; Quad 1), the occupations of concern (self-care, productivity, and leisure; Quad 2), environmental considerations or barriers (Quad 3) and social and emotional status (Quad 4).

In this study, YAwMS presented with substantial FM deficits that affected their occupational performance in the areas of self-care, child-care, household, school, and work. These FM symptoms of MS influence their physical, social, and occupational environments, which for the majority, led to a lower perception of their overall wellbeing and hopes for the future.

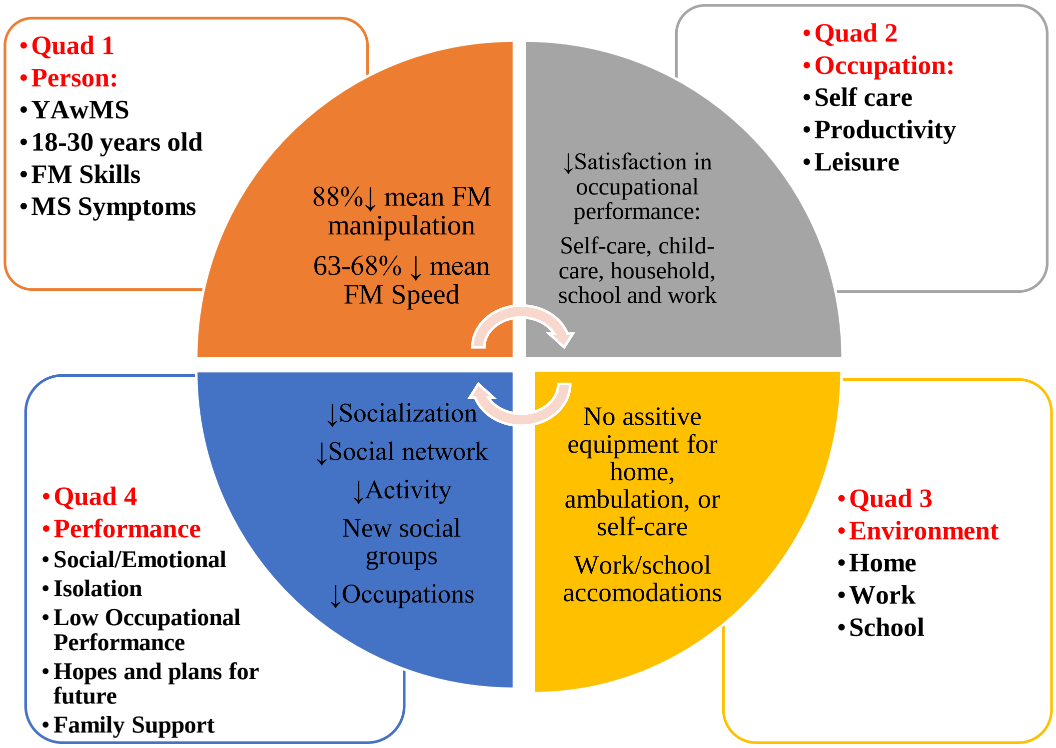

Figure. 10. Conceptual framework for findings.

The PEOP is a framework that describes the influence of functional and contextual context within occupational performance (Christiansen et al., 2005) and has further explanation of the findings of this study (see Chapter 1, p. 28). In this study, YAwMS reported changing or adjusting the context in which they perform. The interaction of physical and social environments with cultural norms and values, created a healthy quality of life.

When applying this conceptual framework to YAwMS, the interaction of the FM deficits, occupations, and environment can lead to avoidance of difficult tasks, lower socialization, and affect their hopes or plans for the future. The outcome of this interactive cycle produced a reduced quality of life as well as an overall decreased sense of wellbeing. Young adults with MS may be psychologically vulnerable if they experience emotional stressors, such as low self-esteem, embarrassment or shame due to memory loss, low concentration, physical impairments, and isolation from peers. Poor coping mechanisms can build on this vulnerability and lead to further changes in their self-care, productivity, and leisure tasks.

Symptoms of FM impairment for YAwMS led to a change in occupations, thereby influencing individuality, including the context in which they perform their occupations. Christiansen and Townsend (2010) described context as situational factors that influence the things people do and how they perform their tasks. Some participants were no longer able to meaningfully engage within the context of their home environment. For example, a young mother was unable to care for her child to the standard she felt appropriate due to the effect of her MS symptoms (e.g., diaper changing and play tasks). The context of person-environment interaction influences the engagement of occupations and the meaning that is derived from the occupation for that individual (Lexell, 2009; Lundmark & Branhom, 1996). The recognition of the effects of their impairments may lead to a change in self-perception. This change in self-perception may foster stronger efforts in maintaining their normal routines and achieving their expectations of performance. This continuation of meaningful occupations may further lead to positive outlook and an increased self-esteem during their occupational engagement (Lexell, 2009). Lexell (2009) reported that engagement in occupations generates a better living experience and positive quality of life for those with MS.

Contextual factors enhanced or dampened occupational performance outcomes of these YAwMS. Interviews with participants of this study found such factors within additional themes not associated with FM performance, but which affected quality of life. These additional themes are in contributing symptoms of MS; age-related milestones; environmental influence on performance; and living arrangements, including support systems, emotional status, and coping mechanisms, were explained within the quadrants of the conceptual framework of this study.

Quadrant 1: Person

Contributing symptoms of MS during and after an exacerbation. Many participants reported how their FM deficits affected their occupational performance during and after their MS exacerbation. Many discussed difficulties with manipulation of writing and simple household tools when they were experiencing their MS symptoms. Some also mentioned their concerns of lasting symptoms after an MS exacerbation, fearing that the symptoms would become a permanent part of their functioning skills. If these symptoms were lasting, their occupational performance may require assistance, thus possibly leading to environmental adaptations and emotional and social compromise. Depression may be the result of the realization that their occupational skills are changing. This depression has the potential to lead to social isolation.

Participants reported many other MS symptoms in addition to FM deficits. During or following a flare up, some symptoms may linger and contribute to difficulties with task performance. A common concern of participants was visual impairment. Optic neuritis, a symptom that is classified as a type of MS relapse, results in visual disturbances like blurred vision, visual fatigue, and double vision (Jasse et al., 2013). These symptoms occur with an attack and slowly subside. Participants described these symptoms saying, “I lost my eyesight,” “I drive with one eye,” and “I put makeup on with one eye.” Loss of vision could lead to a secondary or tertiary symptom, such as an eye infection from rubbing the eyes or feelings of depression due to the visual deficits.

Some participants stated that their first experiences with MS symptoms included lower extremity weakness, foot drag, ataxia, spasms and, most often, loss of balance. Participants said, “I forgot to walk” or “My legs stopped working.” Standing or ambulating for long periods of time required assistance with equipment or another person due to fatiguing of the lower extremities. “It stopped me from working because I was doing retail, and I can’t stand that long. Once I walked after a good 20 minutes, my feet felt heavy and tight.” Another said, “My legs are extremely weak; I get tired much more easily.”

Other MS symptoms were described as headaches, tremors, speech delays, vertigo, and fatigue, which affected some of the participants daily. “Every day is something,” one participant said when describing coping with the symptoms.

One participant said, “They laid me off because I was unable to perform my duties that were asked of me.” Ben-Zacharia (2011) stated that loss of concentration, memory loss, delayed thought processes, and depression are secondary and tertiary symptoms that can also affect daily functioning and keep PwMS from working or changing work due to a lack of confidence in job performance.

Fatigue as a major role in task completion. Eighty percent of PwMS experience fatigue daily, worsens with heat, has unexpected arrival, interferes with physical and daily function, and worsens as a day progresses (Khan, Amatya, & Galea, 2014). “I'm too tired to do anything. Like literally I could sleep all day if I could,” stated a participant who described how fatigue had an effect on her functional tasks, such as caring for her child and work. Another said, “I am always tired. Fatigue is a killer.”

For most participants, fatigue had affected socialization, and many reported that they stopped engaging in tasks with friends due to the fatigue. One participant shared, “Fatigue is the biggest thing. So, like, sure, the hangout sounds fun, but I don’t have the energy to do that.” One participant stated that rather than participating in activities with her friends, she isolated herself. She said, “I should be doing what my friends are doing,” but because of her physical limitations and low energy levels, her social activities were affected. Fatigue is one reason as to why PwMS stop working or do not participate in social activities (Lundmark & Branholm, 1996).

Fatigue was related to weaknesses in maintaining a grasp on objects. One participant said, “Sometimes I was dropping it [cigarette] more often like I wasn’t conscious of how tight I was holding it, and I was just dropping it more often.” “I would be holding something, and my hand just decides to let it go without me wanting to that does happen.” General household duties were reported on the COPM as an important and common task for the participants, but this task required assistance from others due to fatigue. “I would do that [house cleaning] with some help.”

Child care was related to fatigue issues by participants who were mothers. One participant shared, “Like if I’m feeling well, and it’s time to dress them, or if I feel like I am tired, I will get help from my mom.”

A common theme in this study was the effect of fatigue on occupational performance. Fatigue has been shown to affect occupational functioning, including self-care, productivity, and leisure tasks (Stroud & Minihan, 2009). There is some disagreement regarding the effects of physical activity on YAwMS. Those with MS who have general chronic fatigue and motor fatigue may experience exhaustion when engaged or finished with a physical activity, which can lead to a flare up of MS (Lexell, 2009). On the contrary, Yeh et al. (2015) found that physical activity for adults with MS is a harmless intervention with no side effects or serious adverse events and will not increase the possibly of an exacerbation. PwMS who claimed to be more independent with their daily living skills were less fatigued and more satisfied with their ADLs and leisure tasks (Lundmark & Branholm, 1996; Lexell, 2009). It has also been suggested that reduced symptoms, such as chronic fatigue, combined with regular exercise and physical activity may increase the quality of life for those with MS (Stroud & Minahan, 2009).

Symptoms of MS that can cause physical limitations may play a role in reduced well-being, quality of life and social isolation (Kayes et al., 2011). The quality of life for those with MS may be a leading factor in how they perform their self-care, productivity, and leisure skills.

Quadrant 2: Occupations

Occupations and age-related stages of life. The participants' ages ranged from 18 to 30 years old. Developmentally appropriate occupations involve the development of meaningful relationships, careers, and education for this group. Unexpected flare-ups brought questions regarding a future spouse or intimate relationships for some of the participants. One participant stated, "I'm in that age for the first time; hopefully, I will get over this–just like, oh, how do I want this to affect my socialization, dating life?" Some participants were engaged at the time of the data collection and had partners who were supportive in their journey with MS. The married participants acknowledged the assistance they received from their spouses. One said, "My husband takes care of me. He keeps me grounded." This participant was concerned with the potential effect of medications on conceiving a baby. Despite believing "I wasn't [supposed] to be normal and have kids," she continues to pursue having a family.

Quadrant 3: Environment

Environmental influence on performance. The environment in which the YAwMS lives and performs their occupations may exist without assistive equipment, adaptations, or accommodations. This lack of assistance or adaptation also contributes to worsening in occupational performance (Lexell et al., 2011). On the contrary, if YAwMS receive treatment for their FM deficits and their environment was adapted and included assistive devices or accommodation, their occupational performance may improve. These remediations can further lead to competence within their tasks, better self-esteem, and confidence within their socialization activities and result in a healthier overall wellbeing and quality of life.

Quadrant 4: Performance

Support systems effect on performance. All the participants in this study were living with family members or significant others at the time of the data collection. Many said that although they wanted to live independently, they felt secure living with their family and the family's support. It is age appropriate developmentally for YAwMS to develop support systems independent of family through friends and social networks. The diagnosis accompanying the occupational performance can interrupt this age appropriate stage.

Approximately 30% of PWMS need home support, and 80% of that support is usually a family member or informal caregivers (Buchanan & Huang, 2011). One participant discussed being homeless prior to his MS diagnosis. He now lives with his father, but their relationship is strained. Although the relationship is not strong he says that his father tries to help him when his symptoms flare up. This participant also describes his friends as acquaintances and will call his brother in law or ex-girlfriend for support.

> He is concerned when I hit rock bottom. He thought I was going to be disabled for the rest of my life. He was going to buy me a hospital bed and all that stuff, but the doctor said your son can walk. I can walk, but I'm not going to be 100% where I used to be before (Danny, 26, diagnosed at 24 years).

Some participants described how their parents have become very involved with researching of MS symptoms and treatments. Family members have attended support groups to maintain current information on medications for MS. The diagnosis came with an initial response of shock or concern and parental involvement increased. One participant said, “My mother didn't want to believe it at first, what is–but then she started going to groups with me, like, MS groups and things like that, hearing more about it.″

Participants’ families maintained age-appropriate expectations, including obtaining an education for their YAwMS. Other participants described their family members as safeguarding or protecting them discouraging independence and interfering with a productive future. Some participants reported that their overprotective parents interfered with their attempts to achieve personal goals.

Emotional status on performance. There has been evidence to show one’s perceived identity and competence is affected by the disability associated with the disease, thereby affecting the performance of occupations (Lexell, 2009). Symptom-related occupational limitations caused emotional stress on YAwMS. Participants frequently used words like anxiety, anger, frustration, denial, sadness, stress, and fear to express their emotional experiences since their MS diagnosis. Most participants expressed fear of the future due to the disease’s effect on their physical skills and independence. Participants were concerned about the unpredictability of the disease. One participant said:

> It’s just so unpredictable how this can play out and I think that’s what I have a hard time dealing with. But at the same time, because it’s so unpredictable, it could just be okay and I’ll just be–hopefully, Copaxone will work and I’ll just stay on this for a really long amount of time and I won’t have another flare-up, it could go that way, too, right? So, when we say it’s unpredictable, yeah, it’s always easy to just focus on something

> bad happening but also, it could be something good happening (Tim, 28, diagnosed at 16 years).

Some participants said they did not look up information about MS because reading about the potential future frightened them. Others said that by associating with others who were more impaired then they were forced them to deny the reality of their diagnosis. One said, “I hear from people who are, you know in a wheelchair, and I’m like, that freaked me out, so I push that aside.” In some cases denial prevented them from seeking the appropriate care. “I try not to look into that because all it's going to do is make me more anxious about everything I guess.”

The physical deficits that PwMS face are often precursors to the psychosocial stressors that follow due to the adjustment to physical limitations, slow decrease in independence, less social interaction, and potential loss of work (Krischner & Lara, 2011). Participants experienced anger and frustration because of their decrease in their physical abilities and functional skills. Many said they had continued to work or attend school; however, they required accommodations. One said, “I get angry that I can’t do things.” Some participants said they felt embarrassed by the decrease in their ability to articulate their thoughts creating frustrated feelings at work.

Coping mechanisms. Participants coped in a variety of ways. For some, faith and religion played a positive role. One said, “Jesus is alive in me and helped me through a lot so many things that I’ve been through.”

Although many participants cope with their MS by staying private about their condition and handle the symptoms privately, they will also adjust to the affect the disease has had on their lives. Many also accept the diagnosis of MS and their future regarding the disease. For some participants, maintaining contact with social support networks, such as MS support groups, has helped with coping with the disease's symptoms and progression. For one participant hearing from a long time MS survivor was helpful. She said the following:

> I met a guy the other day at work, one of my patients. He was 40, in his mid-40s, he's had MS since the early 80s . . . and that was before all the medications that we have now and that makes me feel better about it. He takes—he does an infusion every month, but in the 80s, they didn't have that so it's like, it must have been so miserable for him back then . . . that makes me feel better about it . . . knowing that, if God forbid something significant like that happens to me I can come here or call, and he'll help me (Ginger, 27, diagnosed at 19).

A method of rejecting their victimized identity and regaining their self-identity, PwMS will have an opportunity to continue to set life goals and successfully engage in familiar occupations without disruption (Lexell, 2009).

Occupational Therapy Practice Implications

Overall Implications and Relation to the OTPF

Occupational therapists (OTs) have an important role in addressing the effect of FM deficits in relation to the occupations of YAwMS. With the OTPF (AOTA, 2014), occupational therapists have a reference point in understanding the relationship between the effect of FM skills of YAwMS and the meaningful occupations they perform within their age group.

The OTPF (2014) presents how performance skills in terms of bodily functions are key component in successful participation in occupations. An understanding of performance skills shapes the understanding of how occupations are completed and performed (OTPF, 2014). Occupational therapists must consider the physical functioning of YAwMS when attempting to encourage participation in occupations.

Occupational Therapy Evaluation and Treatment Considerations

The findings of this study have presented OTs with additional considerations during assessments for YAwMS. Based on the results of this study, OTs should carefully examine the fine motor deficits that influence the participation in occupations of YAwMS and collaborate with the patient in identifying occupational performance issues that affect their roles and occupations.

This investigator also found inconsistencies between YAwMS's perception of their performance and satisfaction and influencing their decisions about accepting assistive devices or accommodations. Occupational therapists must consider these differences in perception in developing client-centered treatment plans.

Occupational therapists can develop personalized goals that address the individual's self-care, productivity, and leisure needs. Strategies can be developed with a focus on the person, specific client-related occupations, and the environment in which those tasks occur (Finlayson et al., 2013). The symptoms of MS that cause fatigue, visual and cognitive deficits, psychosocial and emotional issues, and impaired upper extremity functioning require specific interventions that include the therapeutic use of self, task specific training, and patient education. Occupational performance, participation and quality of life can be obtained through the OTs use of restoration, remediation, compensation, and environmental adaptation (Finlayson et al., 2013).

Occupational therapy client-centered strategies can be implemented to help in reducing the psychosocial stressors that are associated with a decreased sense of self and independence. The OT and client work together on goals that enhance their personal mental health and optimal occupational functioning through the utilization of resources and functional occupational goals. Setting goals that are achievable and measurable will promote a sense of success and encouragement for YAwMS who struggle with psychosocial issues due to impairing symptoms of MS. Occupational therapists can advocate for support services that go outside of traditional therapeutic services, such as resources for MS community-based programs and goals that are client-centered around active and productive lifestyles, despite occupational challenges they may face (Finlayson et al., 1998).

Education has also been affected for YAwMS. Attending a higher education facility has been difficult for some due to physical limitations, such as fatigue or deficits in motor planning. Fortunately, the availability of online courses has afforded three of the participants an opportunity to gain an education in accounting, medical billing, and teaching. Occupational therapists can offer resources in helping a YAwMS find educational or vocational training programs that would be conducive to their needs due to physical limitations they may have.

Occupational Therapists Working with Families/Caregivers

Family members or friends who are non-paid health care workers play an important role in assisting their loved one to cope with the effects of MS. This role places stress on that caregiver’s personal and physical daily life as well (Buchanan & Huang, 2011). Through health programs and support groups, OTs can provide education on balance within the context of the lives of YAwMS, including balance between environment and meaningful occupations. Occupational therapists can provide encouragement for active participation in meaningful occupations that can lead to more satisfied and fulfilled life roles (Yu & Mathiowetz, 2014). Occupational-based education for caregivers of those with MS will provide support and resources for the family member. Occupational therapists can offer education programs for caregivers to help them learn to manage their own responsibilities and health care or self-preservation needs (Finlayson et al., 2008).

Occupational Therapy on the Interdisciplinary Team

Yu and Mathiowetz (2014) reported that PwMS could benefit from goal directed therapies, such as multidisciplinary rehabilitation programs, which specifically include functional performance skills. High intensity programs may offer short-term benefits, but lower intensity programs, such as rehabilitation outpatient programs may have longer lasting results for improvement towards a quality of life (Yu & Mathiowetz, 2014). The role of the OT is recognized within a multidisciplinary team approach when treating PwMS, but the effects of OT interventions cannot be delineated from the effects of the entire team involved in the intervention program (Yu & Mathiowetz, 2014). A better understanding of the long-term effects of specific OT related interventions is needed. Buchanan et al. (2009) found age related differences in the utilization of therapeutic interventions. It was reported that a larger percentage of older PwMS received either occupational or physical therapy than YAwMS (Buchanan et al., 2009). This difference may explain the findings in this dissertation study regarding the lack of participant knowledge of OT interventions.

Interprofessional education for multidisciplinary teams within neurological clinics would provide further knowledge about the role of OTs on a rehabilitation team, adding to a well-rounded team approach in the intervention of a YAwMS. Discussions with team members about goal-directed tasks involving energy conservation techniques, equipment needs, home adaptability, and psychosocial support will provide a better understanding of the need for OT within a team approach. Other multidisciplinary rehabilitation team goals include engagement of tasks incorporating upper extremity skills that improve occupational performance outcomes. It has been found that training in functional tasks resulted in improvement in overall occupational tasks as opposed to just therapeutic exercises (Yu & Mathiowetz, 2014). Although OTs' focus is on functional and occupational performance, they also incorporate therapeutic exercises that involve low intensity and repetitive exercises to improve endurance for mobility and functional tasks (Yu & Mathiowetz, 2014).

Occupational therapy can offer specific training or rehabilitation interventions for a multidisciplinary team that possibly contribute to upper extremity motor functioning improvements, thereby resulting in better FM skills during functional tasks. There has been limited evidence found in specific functional training programs, but certain motor learning methods may be appropriate for YAwMS. Although variability of interventions and training programs within rehabilitation disciplines have led to limited research within the MS population, Yu and Mathiowetz (2014) found improved motor functioning and coordination following a constraint-induced movement intervention for the upper extremities.

Implications for Further Research

Future researcher should further explore FM skills and occupations of YAwMS. They should focus on symptomatic issues such as fatigue, cognitive and visual issues, and psychosocial problems that influence the performance of occupations. There have been several studies performed with PwMS regarding their occupations, performance, and participation (Lexell et al., 2006; Lexell, et al., 2009; & Lexell et al., 2014), but there has been limited research linking FM skills and occupations of individuals with MS and more specifically, YAwMS.

These findings have contributed to the knowledge base regarding how FM deficits of YAwMS relate to occupational performance. The finding of no significant differences between the GPBT, which measured speed, and the COPM, which measured perceived performance and satisfaction, indicated that future research includes larger sample sizes to detect statistical significance. The large effect size within the dissertation study may be the result of the small size of the sample (Slavin and Smith, 2008).

It is recommended that future research measure FM tasks that require manipulation of writing tools because they were frequently identified as a problem. Future researchers should assess specific task-related occupations within self-care, productivity, and leisure. Further research will aid in the development of appropriate occupational therapy interventions, including environmental adaptations, towards a more independent and functional occupational life.

Exploration of physical activity as it relates to fatigue and ADLs is needed to provide informed practice to address the functional abilities of YAwMS. This research is particularly important due to the level of activity considered developmentally appropriate within this age range. Yu and Mathiowetz (2014) found in a systematic review that interventions for PwMS given by OTs have showed direct effects towards their target goals, but limited research has been done to investigate the long- or short-term effects of OT interventions and that there is a necessity for more research on the usefulness of OT interventions for PwMS.

Occupational therapy researchers should develop assessment tools that address functional abilities that are related to upper extremity motor skills. This research may further lead to occupational outcome studies that will provide the evidence needed for appropriate OT-related rehabilitation services for young adults and all PwMS.

Reduction in overall quality of life, including physical and psychosocial health issues, has affected caregivers of those with MS (Finlayson et al., 2008), which raises the issue of caregiver support systems. Future research should investigate the role of OTs in ameliorating caregiver stress.

Limitations and Delimitations

There are several limitations to this study. The sample size of the study was small, despite the power analysis being appropriate for the study. The population was a convenience sample from local neurological clinics. In retrospect, it may have been useful to interview all of the study participants to understand the full experience of YAwMS.

Testing was constrained by participants' physician appointments, resulting in completing the peg board tests in one trial. Previous history with using the PPBT had shown little variation in the results when testing with one or three trials. In a study for test retest reliability, Gallus and Mathiowetz (2002) reported that one-trial administration of the PPBT is an adequate reliable assessment for PwMS. Justification for this administration would also be the one-trial completion of the GPBT, which would add consistency between the two tests.

Due to the focus of this study on FM performance, only items that required FM performance were used as a part of the COPM assessment. Two items that were somewhat related to FM tasks, managing responsibilities and learning new tasks, required more explanation on how they relate to FM needs.

There is a lack of research available on the topic of FM skills involving the occupations of YAwMS. Although few researchers discussed occupational performance, engagement and participation (Lexell et al., 2014; Lexell et al., 2011; Lexell, 2009; Lexell et al., 2006), there is a paucity of research in which a relationship between FM skills and the occupations of YAwMS is discussed.

Recommendations

This study indicated that FM skills of YAwMS play a role in their occupations in terms of performance and outcome of occupations. To further evaluate the FM skills and occupations of YAwMS, it is important to initially gather the FM status of YAwMS between the ages of 18 to 30 years. Following an accurate assessment of the FM status, it is important to further assess the FM skill while engaging in occupational tasks, such as dressing, writing, typing, or grooming. The combined assessments would offer a more thorough approach to treatment within the areas of self-care and productivity, including work and school, and leisure for this population.

Occupational therapists who work with YAwMS or future educators and clinicians should address the entirety of the conditions influencing the performance of this population during a crucial time in their lives. Attention to the social and emotional symptoms is equally as important as attending to the physical symptoms in that social conditions also play an equal role in occupational performance outcomes. Including family-centered goals within the treatment plan will create a better understanding within the dynamic of the family support. These goals will reduce enablement and encourage independence for the young adult with MS.

It is also important to understand the types of MS and the symptoms associated within each type. This information will help in choosing the appropriate assessment and guide the development of an effective treatment plan.

Summary

This dissertation study investigated the connection between the FM skills and occupations in self-care, productivity, and leisure tasks, of YAwMS. Regarding the FM status, the results showed low scores for individual manipulation and coordination of the PPBT and slow speed for the GPBT. On the COPM, the perceived performance scores were relatively higher than the perceived satisfaction scores, indicating that although this population can perform the task, they may not be satisfied with the outcome of how they performed the task. Correlations were found between perceived performance and satisfaction scores and components of the PPBT and GPBT, but no significant correlations with perceived performance and dominant or non-dominant hand of the GPBT, possibly due to the overall higher scores on the performance component of the test.

The population age range was chosen for this study because of the many life changes that occur at this age. Although the problems that were chosen were individual to each participant, this study showed that this population can perform most tasks, but would prefer to better perform the task. This finding was particularly important for those beginning a new career, already involved in their career, caring for their family and children, and maintaining independence.

All the participants lived with family members or spouses, but preferred to not receive assistance with their ADL and IADL skills. Independent living would require a young adults with MS to perform their daily occupations, but it is important for young adults with MS to recognize their limitations to be more productive and independent in their personal and social lives.

Finally, the most effective approach is a multidisciplinary approach in which the medical team members work together in creating goals that will help the participants reach their greatest potential. For OTs, it is important that interventions include the clients' entire context of person and environment, life experiences within their daily tasks, and personal goals in every aspect of their occupational life. These client-centered goals include the client in the development of a personalized treatment plan that is designed to maximize the client's occupational performance with their self-care, productivity, and leisure tasks.

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Appendix A

Clinical Course of Multiple Sclerosis

Clinical Courses of MS

Subgroup	% of MS	Subgroup Description
Relapse-remitting MS (RRMS)*	85%	acute episode, partial or full recovery, return to disability status prior to episode;
Secondary-progressive MS (SPMS)*	65%	after RRMS; progression w/w-o relapses; minor remissions & plateaus;
Primary-progressive MS (PPMS)*	10-15%	consistent progression w/ w-o remissions; minor or temporary improvement;
Progressive-relapsing MS (PRMS)*	5%	progression from onset; full/partial recovery to prior level of disability (O'Connor, 2002).

*****Note*. Subgroups of each classification of MS: RRMS: also referred to as benign if there is little or no progression over time with little disability; single attack progressive MS also referred to as SPMS if there is a single attack followed by a progressive stage; PPMS/PRMS is also referred to as malignant or fulminant MS due to the rapid progression of the disease leading to significant disability or death soon following diagnosis; transitional MS is referred to those within the transition from RRMS to SPMS due to its gradual progression (O'Connor, 2002).

Appendix B

Expanded Disability Status Scale

(Tarver, 2015)

0 Normal neurological exam (all grade 0 in Functional Systems (FS); cerebral grade 1 acceptable).

1 No disability, minimal signs in one FS (i.e., one grade 1 excluding cerebral grade 1).

1.5 No disability, minimal signs in more than one FS (more than one grade 1 excluding cerebral grade 1).

2.0 Minimal disability in one FS (one FS grade 2, others 0 or 1).

2.5 Minimal disability in two FS (two FS grade 2, others 0 or 1).

3.0 Moderate disability in one FS (one FS grade 3, others 0 or 1), or mild disability in three or four FS (three-four FS grade 2, others 0 or 1).

3.5 Fully ambulatory but with moderate disability in one FS (one grade 3 and one or two FS grade 2) or two FS grade 3, others 0 or 1, or five FS grade 2, others 0 or 1.

4.0 Fully ambulatory without aid, self-sufficient, up and about some 12 hours a day despite relatively severe disability consisting of one FS grade 4 (others 0 or 1), or combinations of lesser grades exceeding limits of previous steps. Able to walk without aid or rest some 500 meters (0.3 miles).

4.5 Fully ambulatory without aid, up and about much of the day, able to work a full day, may otherwise have some limitation of full activity or require minimal assistance; characterized by relatively severe disability. (Usually consisting of one FS grade 4 (others 0 or 1) or combinations of lesser grades exceeding limits of previous steps. Able to walk without aid or rest for some 300 meters (975 ft.).

5.0 Ambulatory without aid or rest for about 200 meters (650 ft.); disability severe enough to impair full daily activities (e.g., to work full day without special provisions). (Usual FS equivalents are one grade 5 alone (others 0 or 1); or combinations of lesser grades usually exceeding specifications for step 4.0.)

5.5 Ambulatory without aid or rest for about 100 meters (325 ft); disability severe enough to impair full daily activities. (Usual FS equivalents are one grade 5 alone (others 0 or 1); or combinations of lesser grades usually exceeding specifications for step 4.0.)

6.0 Intermittent or constant unilateral assistance (cane, crutch, or brace) required to walk about 100 meters (325 ft.) with or without resting. (Usual FS equivalents are combinations with more than two FS grade 3+.)

6.5 Constant bilateral assistance (canes, crutches, or braces) required to walk about 20 meters (65 ft.). (Usual FS equivalents are combinations with more than two FS grade 3+.)

7.0 Unable to walk beyond about 5 meters (16 ft.) event with aid, essentially restricted to wheelchair, wheels self in standard wheelchair a full day and transfers alone; up and about in wheelchair some 12 hours a day. (Usual FS equivalents are combinations with more than one FS grade 4+; very rarely pyramidal grade 5 alone.)

7.5 Unable to take more than a few steps; restricted to wheelchair; may need aid in transfers, wheels self but cannot carry on in standard wheelchair a full day; may require motorized wheelchair. (Usual FS equivalents are combinations with more than one FS grade 4+.)

8.0 Essentially restricted to bed or chair or perambulated in wheelchair; but may be out of bed much of the day; retains may self-care functions; generally has effective use of arms. (Usual FS equivalents are combinations, generally grade 4+ in several systems.)

8.5 Essentially restricted to bed for much of the day; has some effective use of arm(s); retains some self-care functions. (Usual FS equivalents are combinations, generally grade 4+ in several systems.)

9.0 Helpless bed patient; can communicate and eat. (Usual FS equivalents are combinations, mostly grade 4.)

9.5 Totally helpless bed patient; unable to communicate or effectively eat/swallow. (Usual FS equivalents are combinations, almost all grade 4+.)

10 Death due to MS.

Appendix C

Flyer for Recruitment

Research Participants Needed

If you are:

- Between the ages of 18-30 years
- Diagnosed with Multiple Sclerosis
- In remission past one month
- Curious about how your symptoms are affecting your functional skills

If you have:

- 30 minutes to volunteer before or after your MD visit
- 30 minutes for a possible telephone questionnaire
- An interest in helping to investigate the FM skills of YAwMS…

Then this is the study for you!! Your participation was totally at your convenience—before or after your MD appointment within a small office space, or within the comfort of your own home! All data was taken within one visit with the investigator and, if selected, a telephone or face to face interview.

This study involves the investigation of the FM status of those with MS between the ages of 18-30 years. These findings were further investigated in how they are linked to your occupations (self-care, work, leisure), through use of standardized assessments and a semi-structured interview.

There are no significant risks associated with this study and you was given a small token of appreciation of $25 gift card to cover your time during the testing.

If you are interested in participating in this study, please contact xxxxxxxxxxxxxx or xxxxxxxxxxxxxxx.

Appendix D

Data Extraction Sheet

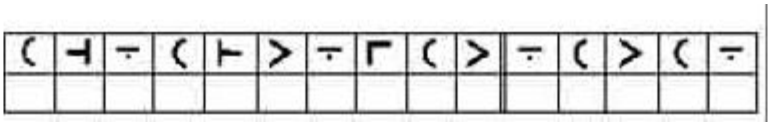
Initials	Date	DOB	AGE	Type	EDSS	Meds	Last Ex	LOI

Last Ex=last exacerbation
LOI=level of independence with ADLs; min, mod, max assist or Independent

Appendix E

Symbol Digit Modalities Test (SBMT)

Sample row from the SDMT



Appendix F

Symbols Digit Modalities Test Permission

November 28, 2016

Mary Squillance, DOT, OTR
Nova Southeastern University
xxxxxxxxxxxxxxxxxxxxxxxxxxxx

Re: *Symbol Digit Modalities Test (SDMT)*

Hello

This follows up your email of 21Nov'16, regarding permission to reprint selected items, the first row of symbols from the Symbol Digit Modalities Test (SDMT) Autoscore Form in your upcoming dissertation paper.

WPS permits your reprint of the requested items for the described purpose and indicated edition only, on provision that the following required notice appears in its entirety on each reprint that you make of the SDMT:

Sample items the SDMT copyright @ 1973 by Western Psychological Services. Reprinted by M. Squillace, Nova Southeastern University, for scholarly display purposes by permission of the publisher, WPS. Not to be reprinted in whole or in part for any additional purpose without the expressed, written permission of the publisher (rights@wpspublish.com). All rights reserved.

Please note that this authorization extends to paper-bound copies of your presentation as may be required, as well as reproduction by microfilm and any other media (digital, electronic or otherwise) as may be required.

On behalf of WPS, I appreciate your interest in this instrument as well as your consideration for its copyright. lt's our privilege to assist helping professionals, and I hope we can be of service to your future work.

Sincerely yours,

Sandra I. Ceja
Rights & Permissions Specialist
sceia@wpspublish.com
424.201.8857
SC:ad

Appendix G

COPM Adapted Score Sheet

COPM Categories Adapted	Sub Categories	Chosen Tasks for Assessment	Level of Importance
Self-Care			
	Personal Care	Managing fasteners	__________
		Opening containers	__________
		Maintaining nails	__________
		Shaving/Applying makeup	__________
		Dressing	__________
	Community Management	Using a telephone	__________
		Paying bills	__________
		Handling money	__________
		Shopping	__________
Productivity			
	Paid/Unpaid Work	Learning new tasks	__________
		Managing responsibilities	__________
		Preparing Resume	__________
	Household Management	Prep Food	__________
		Cleaning house (dusting, Kitchen, bathroom etc.)	__________
		Doing dishes/clear table	__________
		Doing Laundry	__________
		Minor house repairs (change bulbs)	__________
		Child care	__________
	School	Manipulating objects	__________
		Draw/cut/ paste	__________
		Print/writing	__________
		Note taking	__________
		Doing homework	__________
Leisure			
	Quiet Recreation	Knitting/sewing	__________
		Hobbies/collections	__________
		Creative Arts	__________
		Play cards/board games	__________
		Media tool manipulation	__________

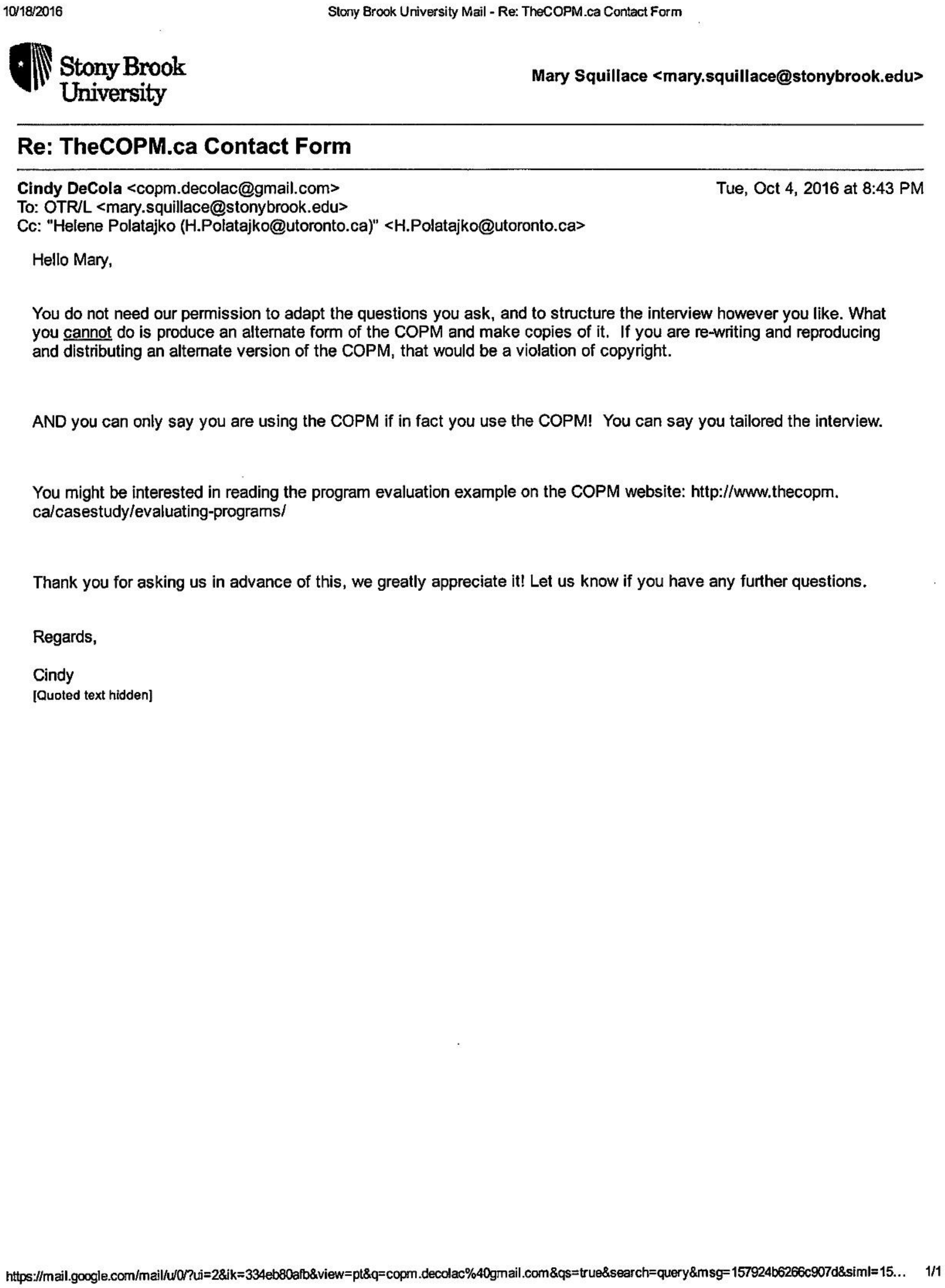
Active Recreation	Caring for pet	__________
	Dining out (utensil use)	__________
	Driving (car knobs)	__________
Socialization	Telephone manipulation	__________
	Hosting parties'	__________
	Writing letters	__________

Problems	Importance	Performance	Satisfaction
1.			
2.			
3.			
4.			
5.			

	Total Performance	Total Satisfaction
Total Scores		
Average Scores (total score/#problem (5)).		

Appendix H

Permission Letter to Adapt COPM Questions



10/18/2016 Stony Brook University Mail - Re: TheCOPM.ca Contact Form

Stony Brook University

Mary Squillace <mary.squillace@stonybrook.edu>

Re: TheCOPM.ca Contact Form

Cindy DeCola <copm.decolac@gmail.com> Tue, Oct 4, 2016 at 8:43 PM
To: OTR/L <mary.squillace@stonybrook.edu>
Cc: "Helene Polatajko (H.Polatajko@utoronto.ca)" <H.Polatajko@utoronto.ca>

Hello Mary,

You do not need our permission to adapt the questions you ask, and to structure the interview however you like. What you <u>cannot</u> do is produce an alternate form of the COPM and make copies of it. If you are re-writing and reproducing and distributing an alternate version of the COPM, that would be a violation of copyright.

AND you can only say you are using the COPM if in fact you use the COPM! You can say you tailored the interview.

You might be interested in reading the program evaluation example on the COPM website: http://www.thecopm.ca/casestudy/evaluating-programs/

Thank you for asking us in advance of this, we greatly appreciate it! Let us know if you have any further questions.

Regards,

Cindy
[Quoted text hidden]

https://mail.google.com/mail/u/0/?ui=2&ik=334eb80afb&view=pt&q=copm.decolac%40gmail.com&qs=true&search=query&msg=157924b6266c907d&siml=15… 1/1

Appendix I

Semi-Structured Interview Questions Guide

Start: Interviewer introduction of self and procedure of interview. Use code assigned to the participant and note on recording the code (e.g. "This is participant S1 for this interview on date.") Please indicate that the participant is not obligated to respond to any questions that may be uncomfortable, or they do not want to offer a response.

Demographics:

Tell me about yourself:

Where are you from?

Probe: how long have you lived there?

Add probes as to their age and significant other or family. (e.g., who do you live with? who do you interact with on a daily basis?)

Tell me about your friends.

Who do you call when you are having a bad day?

How do you like to spend your free time?

How old were you when you received your first diagnosis?

What was that like for you? (probe. What were you thinking or feeling at that time?)

How do you think this news effected your family?

How do you think this news effected your social life?

Are your symptoms worse, better, or the same since when you were first diagnosed?

How have the symptoms affected your life and how you live your life?

Can you tell me about the first symptom you felt before your diagnosis?

What did that feel like for you?

Can you tell me about your first physical symptom?

**The following questions and probes may be related to the COPM responses:

Can you tell me how these symptoms effected your self-care skills, your work or your leisure skills?

Have you ever experienced difficulty when using your hands to manipulate small objects or tools? Probe: can you tell me your experiences with this difficulty?

What type of job do you have? (or how do you take notes in school? Do your symptoms effect the skills needed for your job, self-care or school work?)

Does your job require you to use your hands?

What do you know about MS?

On a scale of 1 to 10, how much is your FM skill effected by your symptoms related to MS?

How frequently are they effected?

How severe are your symptoms during or after an exacerbation?

During which tasks do you most notice your symptoms are affecting your performance?

Have you ever been referred to OT/PT intervention?

Has anyone ever spoken to you about adaptive equipment?

Are you aware of adaptive equipment that is available to you to help you with needed skills?

Have you tried adaptive equipment?

Probe: do you feel you need this equipment?

Probe: are you satisfied with the adaptive equipment?

What are your expectations of the future as you live with this disease?

Appendix J

Purdue Pegboard Score Sheet

For Model #32020A

Name: ________________________

Dominant Hand: Right or Left
Reason for Administering: ________________________Test

Administrator Name: _____________________

Test Date:

Scoring Grid Based on Number of Parts

	Trial One	Trial Two	Trial Three	Trial Average
Right Hand				
Left Hand				
Both Hands				
Right + Left + Both				
Assembly				

**taken from original Lafayette Instrument Company (2015, Model# 32020A)

Appendix K

Grooved Peg Board Test Score Sheet and Data Extraction Form

Initial:____________________

Age:______________________

EDSS Score: _________________

Hand Dominance R L

	Right Hand	**Left Hand**
Total # placed pegs		
Total # dropped pegs		
Total time		

Subjective comments:

Observation comments:

Appendix L

Letter of Agreement Neurological Associates SBU

Mary Squillace DOT, OTR/L
Clinical Assistant Professor
Occupational Therapy Department
Stony Brook University
Stony Brook, New York 11794-8206

Neurology Associates of Stony Brook University
xxxxxxxxx
xxxxxxxxx
Attention: xxxxxxxxx

Dear xxxxxxxx

Thank you for responding to my email regarding access to the Neurological Associates of Stony Brook Medical Center for my dissertation data collection. As previously discussed my dissertation is on the effects of FM deficits on the occupations of the young adult population with multiple sclerosis. This was a mixed method study that would require FM quantitative data to be taken as well as an open-ended interview. I was having the subjects perform as short cognitive test (approximately 3 minutes), two standardized FM assessments (approximately 15 minutes combined), a self-report on occupations (approximately 20 minutes or less), and if they are chosen to participate within the qualitative component of the study while at the clinic, at home or via telephone, they will engage in an open-ended interview regarding how their experienced symptoms affected their occupations (ADLs, Leisure, Work). The interview was a sub-population of about 10 subjects of the original subject pool of 40. I am looking for a total of 40 subjects between your clinic, other private neuroscience clinics that specialize in multiple sclerosis, MS support groups, and potential outside private participants. I am anticipating the data collection to begin in the spring, granted that my IRB submission is approved. The projected time to utilize your clinic would be in the spring and summer of 2017 if the dissertation processing continues at a smooth and productive pace.

As requested by my IRB review committee, I am sending this formal letter as a notification and request to use your clinic to recruit participants, review medical charts, and collect the necessary data for my dissertation. If you would so kindly contact me at xxxxxxxxxxxx or at xxxxxxxxx with your permission to use your clinic it would be greatly appreciated.

Thank you very much for your time and interest in this matter and I look forward to hearing from you.

Sincerely,

Mary Squillace DOT, OTR/L

Appendix M

Letter of Agreement South Shore Associates

Mary Squillace DOT, OTR/L
Clinical Assistant Professor
Occupational Therapy Department
Stony Brook University
Stony Brook, New York 11794-8206

South Shore Neurological Associates
Comprehensive Multiple Sclerosis Center @ South Shore Neurological Center
xxxxxxxxxxx
xxxxxxxxxxx
Attention: xxxxxxx

Dear xxxxxxxxxxxx

Thank you for responding to my email regarding access to the Comprehensive Multiple Sclerosis Center at South Shore Neurological Center for my dissertation data collection. As previously discussed, my dissertation is on the effects of FM deficits on the occupations of the young adult population with multiple sclerosis. This was a mixed method study that would require FM quantitative data to be taken as well as an open-ended interview. I was having the subjects perform as short cognitive test (approximately 3 minutes), two standardized FM assessments (approximately 15 minutes combined), a self-report on occupations (approximately 20 minutes or less), and if they are chosen to participate within the qualitative component of the study while at the clinic, at home or via telephone, they will engage in an open-ended interview regarding how their experienced symptoms affected their occupations (ADLs, Leisure, Work). The interview was a sub population of about 10 subjects of the original subject pool of 40. I am looking for a total of 40 subjects between your clinic, other private neuroscience clinics that specialize in multiple sclerosis, MS support groups, and potential outside private participants. I am anticipating the data collection to begin in the spring, granted that my IRB submission is approved. The projected time to utilize your clinic would be in the spring and summer of 2017 if the dissertation processing continues at a smooth and productive pace.

As requested by my IRB review committee, I am sending this formal letter as a notification and request to use your clinic to recruit participants, review medical charts, and collect the necessary data for my dissertation. If you would so kindly contact me at xxxxxxxxxxxxxx with your permission to use your clinic it would be greatly appreciated.

Thank you very much for your time and interest in this matter and I look forward to hearing from you.

Sincerely,

Mary Squillace DOT, OTR/L

Appendix N

Member Check Summary

Thank you very much for volunteering your valuable time in allowing me to test your fine motor skills and interview you. In my study, I started with three research questions about your hand skills, and one question about your experiences living with MS. Please read the question and the results that I found and:

- Let me know the extent to which you agree or disagree with the findings. Do they make sense to you?
- I need for you to let me know if you think I got it right or not.
- Please email me back your thoughts by Dec. 21, 2017 if possible.

My question when I began the research was:

> What are the lived experiences of the things you do and how you do them using your fine motor skills (hand and finger skills) as a young adult with MS?

Findings

- I've learned that for young people with MS, changes in relationships with friends have occurred when some friendships had slowly gone away, or any type of relationship had been changed to the status of acquaintances. This was because of young people with MS have limited energy and unpredictable MS symptoms.
- Intimate relationships were more stable, in that spouses and fiancés stayed by their significant other and gave maximum support.
- Family was the main source of support from the diagnosis to present.
- Common strategies to cope with symptoms have been to stay positive and avoid stressful situations. However, opposite to this idea, many of you avoided investigating information about MS for fear of learning too much about MS, and the progress of the disease in the future.
- Self-care and work, related to fine motor difficulties (problems using your fingers and hands), have been expressed through slower movements, writing or typing difficulty, dropping objects, and problems with holding or handling smaller objects, such as writing tools, and problems with household tasks.
- Feeling tired (fatigue) reduces fine motor skills needed for personal care, such as grooming, applying makeup or shaving. This also affects dressing skills, such as putting on pants.
- Changes occurred in concentration on tasks because of distractions from MS symptoms.
- Changes occurred in leisure tasks (relaxing tasks) from active to more relaxing tasks, such as watching TV, staying at home with friends and family, or simple drives. These more leisurely tasks have replaced the more active life style that many enjoyed before the MS diagnosis.
- The majority of you do not use medical equipment to help with daily tasks. A main reason given is that using equipment would mean that there are more problems or weaknesses related to the disease or simply that equipment is not

needed. For example, many view the use of a wheel chair to mean that this is how future will be for those with MS.

- Very few of you use physical therapy interventions and none used occupational therapy for MS related symptoms. Many of you did not understand occupational therapy or how it can help those with MS.

Once again, I truly appreciate your time and interest in this dissertation study. I could not have completed this study without your time and help! Have a very happy and healthy holiday season.

Sincerely,

Mary Squillace DOT, OTR/L