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The Effects of Multiple Sclerosis on Perceived Parenting Roles and Adolescent Coping

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The Effects of Multiple Sclerosis on Perceived Parenting Roles and Adolescent Coping

Alyssa Coundourides, Kendra Host, & Elizabeth Rexroat

A Research Project Submitted to the Graduate Faculty of the
Department of Occupational Therapy

GRAND VALLEY STATE UNIVERSITY

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Abstract

This research project focused on the effects of parental multiple sclerosis (MS) upon parenting roles and family coping. Specifically, the study was implemented to acquire insight into the primary research question: How do parents perceive familial role changes resulting from MS to impact coping of their adolescent children? The study also investigated the role of occupational therapy in assisting parents with MS to facilitate coping in their adolescent children. These concepts were investigated through a mixed methods design, using the Role Checklist to quantitatively assess participants' roles and values, and a focus group to qualitatively explore participants' lived experiences of parental role changes. Data analysis of the Role Checklist and focus group revealed three main themes: (a) MS symptoms that limit to role participation; (b) degree of understanding; and, (c) availability of support. Analysis indicated a discrepancy between the parental assessment of impact and actual impact upon roles changes. Although participants reported "minimal" impact, they also expressed low communication between parents and adolescents, thus indicating a potential lack of insight. The researchers conclude that occupational therapists should further address the implications of performance capacity deficits upon roles and interventions to facilitate positive coping within families with a parent with MS.

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Chapter One

Introduction

Introduction to Study

Multiple sclerosis (MS) affects 2.5 million people worldwide (World Health Organization, 2006). Particularly in Europe and North America, MS is the most prevalent neurological condition among young adults (World Health Organization, 2006). The World Health Organization (2006) stated that a diagnosis of MS typically occurs around age 30, includes more women than men, and is most common in Caucasians. Approximately 60% of people who have been diagnosed with MS for 20 years are no longer capable of fully ambulating and incur functional, physical, and financial difficulties in performing their traditional roles (World Health Organization, 2006). Multiple sclerosis creates a financial burden to individuals affected with this disease. Due to a 70% unemployment rate, people with MS collect disability compensation and welfare. Progression of the disease also causes role changes and affects the quality of life of individuals diagnosed with MS and their supporting family members (World Health Organization, 2006).

Background to Problem

The World Health Organization (2006) discussed four subtypes in the progression of MS: (a) relapsing-remitting subtype, constituted 80% of diagnoses; (b) secondary progressive subtype, acquired by 80% of people first diagnosed in the relapse-remitting subtype of MS; (c) primary progressive subtype, affected 10-15% of diagnoses; and (d) benign subtype. The relapsing-remitting subtype is characterized by relapses of sporadic and increasingly aggravated symptoms, followed by remission periods of varying duration. The secondary progressive

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subtype involves a progression of symptoms unrelated to relapse. Multiple sclerosis in the primary progressive subtype consists of progressive, vague, and slowly occurring symptoms. The benign subtype is typically retrospectively diagnosed and is related to the secondary progressive subtype. The benign subtype involves an absence or minimization of the acquired disability over the span of 15-20 years. Compston and Coles (2008) explained that individuals begin to show signs of MS at any subtype and progress to other subtypes. A diagnosis of MS is not always linear; the disease progression is different in each individual (World Health Organization, 2006).

The National Institute of Neurological Disorders and Stroke (2011) stated that MS is believed to be an autoimmune disorder affecting the ability of nerves to transmit impulses which impairs effective communication between the brain and body. Multiple sclerosis is manifested in a constellation of physical symptoms including: (a) numbness and tingling in appendages, (b) poor coordination and balance, (c) potential paralysis, (d) impaired red-green perception, (e) partial or complete loss of vision frequently accompanied by pain, (f) head movements that elicit shock-like pain, (g) speech impairments, (h) tremors, (i) fatigue, and, (j) dizziness (Mayo Foundation for Medical Education and Research, 2010; National Institute of Neurological Disorders and Stroke, 2011). The National Institute of Neurological Disorders and Stroke (2011) also asserted that an individual with MS can experience emotional and mild cognitive symptoms, including depression and memory decline. Symptoms vary in type and intensity for individuals and are often unpredictable in duration and frequency (Mayo Foundation for Medical Education and Research, 2010).

Previous research concerning the impact of MS upon parenting roles, responsibility changes, and self-perceptions lacks a focus on occupational therapy interventions to promote coping in the adolescent stage of the family life cycle (Courts, Newton, & McNeal, 2005;

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Deatrick, Brennan, & Cameron, 1998; Farber, 2000; Finlay, 2003; Lexell, Iwarsson, & Lund, 2011; Mazur, 2008). This research project aimed to bridge research gaps and further examined the impact that MS has upon the role of parenting.

Specifically, this project used a mixed methods research design to examine the familial role changes experienced by individuals with MS and the coping of their adolescent children. Participants included people who have been diagnosed with MS for at least six months who are parenting at least one adolescent child who is 12-17 years of age. The researchers assessed the phenomenon of participants' parental role changes and resulting coping of their adolescent children after a diagnosis of MS. Furthermore, the researchers sought to explore occupational therapy familial interventions to promote adolescent coping.

Significance

The impact of MS and acquired disability is reflected in previously conducted research such as Courts et al. (2005), Deatrick et al. (1998), Farber (2000), Finlay (2003), Lexell et al. (2011), and Mazur (2008). Existent research has demonstrated the occupational shifts and role changes in parents resulting from these acquired disabilities (Farber, 2000; Finlay, 2003; and Lexell et al., 2011). Additionally, previous research found social support and perceptions of others to influence the self-perceptions of parents with disabilities regarding their ability to fulfill parenting roles (Courts et al., 2005; Deatrick et al., 1998; Mazur, 2008). Further, research identified parental reactions and adjustment to such changes as affecting the well-being of their adolescent children (Bogosian, Moss-Morris, & Hadwin, 2010)

Problem Statement

This research project explored the impact of MS on perceived parenting roles and family adjustment. Based on Evelyn DuVall's eight stages of the family life cycle, the project focused

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on stage five: families with teenagers (Gavazzi, 2011). Specifically, it focused on the impact in coping abilities of adolescents between the ages of 12 and 17 years. This stage in the family life cycle involves increasing the flexibility of the family's boundaries in order to facilitate more independence in the adolescent, alteration of the parent-adolescent relationship, and altered focus on marital and parenting issues (Gavazzi, 2011). Despite the array of changes associated with the adolescent stage, Coles, Pakenham, and Leech (2007) communicated insufficient family-oriented treatments for families of parents with MS.

Purpose/Aims

The research study sought to provide insight into the familial role changes affected by a parental diagnosis of MS and impact upon adolescent coping. It also aimed to identify the role of occupational therapy in assisting parents to facilitate positive coping techniques in adolescent children.

Significance of Problem

The research study provided insight into the experiences of parents diagnosed with MS. Researchers examined the fifth stage, families with teenagers (between the ages of 12 and 17 years), in DuVall's stages of the family life cycle; many changes in family dynamics occur as the children in the family reach adolescence (Gavazzi, 2011). Studies have been conducted examining the roles of parenting both adolescents and children (Bogosian et al., 2010). Bogosian et al. (2010) found parental MS to impact the psychological well-being of their children; adolescents seemed to be more susceptible to adverse psychosocial reactions.

The research study could be significant to the field of occupational therapy because it has the potential to reveal further insight into the family dynamic of families living with a parent who has MS. A declaration from the Pan American Health Organization World Health

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Organization (2003) stated the need for more support offered to shared responsibility and active involvement in parenting roles. The committee noted that the family is the basic unit of society and it is entitled to comprehensive protection and support. The idea of providing direct support to the client and the client's family is crucial to occupational therapy. The results of the research study offered insight to occupational therapists to better assist families with a parent who has MS.

Although this study only examined the experiences of individuals with MS, the results may not only benefit the field of occupational therapy and clients living with MS, but also the family directly. By being able to better identify areas of perceived difficulty and maladaptive coping, families will be able to gain insight into the lived experiences of their loved ones who have MS and reciprocal impact upon the family. This may help them to develop effective compensatory strategies to best cope with the impact that the disease has had on the parents' ability to perform important parenting roles.

Results of this research project also revealed external factors that influence family function and dynamics for people who have MS. One such external factor includes economic factors. A study conducted by De Judicibus and McCabe (2005) examined the impact of financial costs and strains placed on families of individuals living with MS. De Judicibus and McCabe (2005) were particularly interested in how the financial costs and strains impacted the individuals' quality of life. The results of their study revealed the additional financial costs of MS placed a great amount of strain on the family as a whole, as well as on the family dynamic. It is possible that this research project may help to guide occupational therapists in adapting interventions to be more beneficial to the family as a whole. Study results may demonstrate areas

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of the parents' roles and family functioning that needs the most assistance at this point in the life cycle.

Research Question

Primary research question: How do parents perceive familial role changes resulting from MS to impact coping of their adolescent children?

Secondary research question: How can occupational therapy assist parents with MS in facilitating positive coping techniques in their adolescent children?

Key Concepts

The key concepts for this study were multiple sclerosis, the family life cycle, roles, adolescence, the Model of Human Occupation, and coping/adaptation.

Multiple Sclerosis: an autoimmune disorder affecting the ability of nerves to transmit impulses, and thus impairs effective communication between the brain and body (National Institute of Neurological Disorders and Stroke, 2011). The concept of MS in this study was referred to as the diagnosis the participants of this study must have had to participate in this study.

The family life cycle: the various stages of development of the family as a social unit (Pan American Health Organization World Health Organization, 2003). In this study, the family life cycle was used when discussing how mothers and/or fathers diagnosed with MS perceived their abilities related to parenting adolescent children.

Roles: Sets of behaviors as identified by the client as behaviors expected by society and influenced by culture (American Occupational Therapy Association, 2008).

Adolescence: is defined as children 12-17.

Model of Human Occupation (MOHO): The MOHO is a theory from the field of occupational therapy focusing on integration of the individual's motivation to engage in occupation (volition),

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the process of structuring occupations into roles and routines (habituation), and the basis of physical and cognitive processes (performance capacities) in order to engage in occupation (Cole & Tufano, 2008).

Coping/Adaptation: Response to occupational change to promote mastery in task and function in living (American Occupational Therapy Association, 2008).

Summary

As previous research has indicated, occupational role changes occur as a result of a diagnosis of MS, thus affecting family functioning as a whole (Bogosian et al., 2010; Farber, 2000; Finlay, 2003; Lexell et al., 2011). Existent research has also indicated that the role of parenting often became the occupational focus for parents with a diagnosis of MS (Lexell et al., 2011). Parenting roles and impact upon coping were evaluated within the adolescent stage of the family life cycle. Further, this study assessed the use of occupational therapy services in assisting parents to facilitate adolescent coping.

Chapter 2

Review of the Literature and Conceptual Framework

Introduction

The purpose of this chapter was to evaluate existing literature concerning multiple sclerosis (MS) as it relates to parenting of adolescents and the role of occupational therapy in developing effective family-centered interventions. Through a search of the Summon and CINAHL databases, research was largely focused on the adjustment of adolescents, suggesting that maladaptive coping, psychological distress, anxiety, and depression are more common in children of parents with MS (Bogosian et al., 2010; Yahav, Vosburgh, & Miller, 2007). Such findings indicate a need for interventions to facilitate positive coping and adjustment strategies for adolescents (Coles, Pakenham, & Leech, 2007). This chapter focuses on the impact of MS on parenting roles, the adjustment of parents who have MS, the adjustment of adolescents who have a parent diagnosed with MS, and existing interventions. The frame of reference for the study, the Model of Human Occupation (MOHO) and the psychometric properties of proposed methodology tools are further explained in this chapter.

Review of the Literature

Multiple sclerosis and adjustment.

Cahill, Connolly, and Stapleton (2010) evaluated the effect of MS upon occupational adaptation. Participants consisted of seven women who had been diagnosed with either relapsing-remitting or progressive MS for at least five years. Adaptation, specifically occupational competence and identity, was assessed through the Occupational Performance History Interview-Second Version, the Occupational Questionnaire, Role Checklist, and the Modified Interest Checklist (Cahill et al., 2010). These authors presented the results in terms of

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performance capacity, interests, and roles, respectively equivalent to performance capacity, volition, and habituation, the subsystems of the MOHO theory (Cole & Tufano, 2008).

Cahill et al. (2010) utilized a small, convenience sample of women with MS from within a specific geographical context in Ireland. Such limitations may be addressed by ensuring trustworthiness through member checking and provision of explicit participant and procedure information. Also, the scope of the study was simultaneously narrowed, yet enhanced, by examining only relapsing-remitting and progressive subtypes. The specific focus limited the applicability of study findings to only relapsing-remitting and progressive MS, but provided functional, occupational information concerning these two subtypes. Cahill et al. (2010) suggested further research to involve longitudinal studies of an MS subtype regarding occupational adaptation with a greater population sample.

The results of Cahill et al.'s (2010) study revealed changes in performance capacity, interests, and roles resulted from MS and adversely affected occupational competence and identity. Results demonstrated decreased physical performance capacities that caused occupational competence deficits. Decreased occupational identity, another potential result of physical capacity disruptions, suffered as well, as manifested in a loss of satisfaction in an employment role. Evidently, Cahill et al. (2010) identified a relationship between occupational adaptation, MS, and the concepts of the Model of Human Occupation: performance capacity, volition, and habituation. The Model of Human Occupation is a theoretical reference within occupational therapy that is used to guide practice (Cole & Tufano, 2008). Cole and Tufano (2008) define performance capacity as underlying physical and cognitive processes; volition as the motivation underlying engagement in occupation; and habituation as the structuring of

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occupations into roles and routines. The following subheadings further address these findings and supply additional supporting research.

Volition: Motivation for occupation.

Results regarding the interests of participants presented by Cahill et al. (2010) indicated fatigue and motor symptoms as causing a shift in both the approach to interests as well as the interests themselves. All participants reported maintaining interests, primarily those that were sedentary and require low energy. Of the interests maintained, participants reported adapting the intensity or duration to sustain engagement. Such adaptations occurred over time as the participants gained insight into the symptoms of MS and resulting implications on their lives. Additionally, participants communicated a shift in their interests and a discovery of new, less physically demanding activities, such as listening to music. Due to physical symptoms and inaccessibility of facilities, such as swimming pools, participants also experienced an abandonment of previous interests.

As a means to gain insight into coping abilities, Ehrensperger et al. (2008) conducted semi-structured psychiatric interviews with 44 parents diagnosed with MS, their partners, and their children. Interviews with the children included the Thematic Apperception Test, story stems, and drawings of family members, while the parental interviews consisted of a battery of five subtests: “alertness”, “go/no go”, “divided attention”, “shifting of attention”, and “visual scanning” (p. 1107). Collectively, the interview results were used as a means to measure coping abilities. Further, to assess the influence of physical disability, depression, and cognitive ability resulting from MS, Ehrensperger et al. (2008) paired the interviews with neuropsychological and physical assessments of all participants.

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In regard to the parent with MS, the interviews revealed that emotional and neuropsychological functions were found to directly influence coping capacity, in both positive and negative ways. Furthermore, the results indicated a mutual influence of the healthy parent's and children's coping; the most significant predictor of the children's coping abilities was the healthy parent's coping reaction. Reciprocally, the parents' coping was related to the children's. Although the sample size was small due to the difficulty of administering the interviews to all family members, Ehrensperger et al. (2008) further established the relationship between parents and children's psychological well-being. Future research should contain a larger sample with a greater range of disabilities as a potential means to identify baseline coping factors and insight into the experience of individuals with more severe progressions of MS (Ehrensperger et al., 2008).

Habituation: Roles and routines.

Cahill et al. (2010) further discussed the impact of MS upon occupational adaptation specific to changes in work and personal roles. Physical symptoms affected participants' ability to complete work tasks, resulting in accommodations by employers. Unfortunately, participants also experienced a decrease in their work role satisfaction after receiving adaptations such as reduced hours and perceived the job to have shifted from a meaningful career to simple employment. Personal role changes were also expressed. Participants reported a loss of friend roles related to activities, such as sports, due to an inability to sustain participation. Also, a reversal in care-providing roles occurred for some cases in which an elderly parent adopted the self-care needs of their child. Furthermore, participants reported that MS altered their expectations for future roles, specifically stating marriage and childbearing as unfulfilled roles.

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Cahill et al. (2010) established a link between physical symptoms of MS, meaningful activities, and roles; physical changes dictated an adaptation in roles and the comprising activities.

Role alteration and divergence were additionally discussed in Finlay's (2003) phenomenological case study chronicling the experience of a mother's first year post-diagnosis of MS. Finlay (2003) interviewed the participant accompanied by an existential-phenomenological approach for analysis. Finlay (2003) examined the mother's occupational shift in focus away from work-related activities towards parenting activities. The mother also addressed the compartmentalization of her post-diagnosis life, stating that a discrepancy existed between her roles as a mother, advocate, and person with MS. Ultimately, the participant desired to continue in her role as a mother and disassociate her identity from her diagnosis of MS. The study comprehensively illustrated the importance of the parenting occupation as the mother's effort to preserve her pre-diagnosis identity and value.

The importance of maintaining a parenting role was further supported by the findings of Lexell et al. (2011). The study consisted of six women and two men with children; although participants were obtained from the same rehabilitation facility, there was sufficient variability to promote trustworthiness of the findings (Lexell et al., 2011). Lexell et al. (2011) conducted semi-structured, open-ended interviews with participants to document the occupational adaptations made by people diagnosed with MS. Interview results found that participants prioritized occupations that contributed to the family's well-being, rather than their personal well-being.

The diagnosis of MS extends beyond the individual; MS affects the parenting and marriage roles of the diagnosed parent as well as the non-diagnosed spouse. Courts et al. (2005) conducted a one-meeting focus group with eight men and four women whose spouses were

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diagnosed with MS. Although participants were acquired through convenience sample, Courts et al. (2005) indicated the results yielded generalizable information to the participant population. Courts et al. (2005) found that the spouse without MS usually assumed the caregiver role, which changed the couple's marital roles and increased their overall amount of family roles. Research findings indicated that men often helped their wives with MS in an attempt to protect and conserve their wives' energy, while the wives advocated for independence in their husbands with MS (Courts et al., 2005). This study demonstrated the dynamic effect MS had upon families and the presence of gender differences in the adjustment process.

Performance capacity: Cognition and physical function.

Cahill et al. (2010) explored the impact of MS upon performance capacity. Specifically, fatigue, motor abilities, sensation, and aspects of performance capacity were affected by MS. Six of the seven participants reported fatigue as negatively impacting occupations. Performance deficits related to motor abilities were reported by all participants, evidenced by a variety of symptoms, including decreased walking abilities, stiffness, soreness, and muscle weakness. Three participants reported experiencing decreased sensation of their lower limbs. Cahill et al. (2010) related performance capacity limitations to affected occupations; results showed fatigue as particularly limiting to participants' roles as employees.

Providing further elaboration upon functioning as related to MS, The National Institute of Neurological Disorders and Stroke (2011) reported MS to be a disease with a constellation of erratic symptoms manifesting from mild to severely debilitating. Although a mild condition is more prevalent, severe symptoms include difficulties with communication, cognition, and motor skills. According to the National Institute of Neurological Disorders and Stroke (2011), a cure does not exist for MS, but there are treatments for the symptoms. The drug Novantrone is used to

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treat advanced or chronic MS, and Ampyra is used to assist walking (National Institute of Neurological Disorders and Stroke, 2011). The National Multiple Sclerosis Society (2012) also stated use of corticosteroids as a means to treat severe inflammation that occurs during an exacerbation.

Despite availability of medications, many people with MS choose not to seek treatment because of the adverse side effects and potential risks of medications (National Institute of Neurological Disorders and Stroke, 2011). Non-medicinal interventions can also be utilized, including physical therapy, occupational therapy, neuropsychology, and social work. Such approaches can assist in management of the chronic disabling effects, energy conservation techniques, and avoidance of over-exertion (Compston & Coles, 2008; National Institute of Neurological Disorders and Stroke, 2011). Therapeutic approaches can help to improve function and safety; the use of complementary and alternative techniques, such as diet supplements or yoga, are also an additional option (National Multiple Sclerosis Society, 2012). Unfortunately, the success of such non-medicinal treatment is largely dependent upon the stage of disease progression, is unsupported with adequate research, and frequently is not cost-effective (Compston & Coles, 2008). Due to inefficacy of medicinal and therapeutic treatments such as occupational therapy, there is a need for further research into applicable interventions for people with MS.

Psychological treatments focusing on family well-being were studied by Coles et al. (2007). Coles et al. (2007) noted the existence of treatments to promote adjustment for children of parents with disabilities, yet also found there to be a lack of interventions specifically for children of parents with MS. Furthermore, a review of existing interventions conducted by Coles et al. (2007) indicated many flaws in the corresponding research, some of which included

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insufficient participant samples, infrequent use of follow-up measurements, and an absence of theoretical guidance. To counter the deficit in quality research regarding interventions, Coles et al. (2007) implemented a psychosocial intervention for children of a parent with MS. The intervention aimed to provide education concerning MS, to facilitate social support, and to promote adaptive coping strategies. This longitudinal, psychosocial intervention was implemented at a six-day camp attended by children 9-14 years old (n= 20). Parents and children completed questionnaires based upon several scales. The children's evaluation included an assessment of: MS knowledge, stress appraisal, coping strategies, and family functioning; parental questionnaires contained: adjustment, family functioning, and parental-perception of children adjustment. Although Coles et al. (2007) could not ascertain clinical significance, the results demonstrated statistically significant decreases in distress, stress, caregiving impact, limitations in activity, and increases in social support and knowledge concerning MS as a result of the intervention. Coles et al. (2007) acknowledged their findings to be limited by a small sample size without a control group and advocated for future research to apply the intervention in different contexts using randomized control trials.

Multiple sclerosis and parenthood.

Parents diagnosed with MS face unique challenges as compared to their counterparts with and without disabilities (Olkin, Abrams, Preston, & Kirshbaum, 2006). Olkin et al. (2006) examined the discrepancies between the parent-child relationships and responsibilities of parents with (n= 273) and without (n= 48) disabilities who parented adolescents aged 11-17 years. Information was acquired through three separate surveys, each designed for the study, to target three populations: parents with a disability parenting teenagers; teenagers of parents with a disability; and parents without a disability parenting teenagers. Olkin et al. (2006) expressed an

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attempt to include people with many types of disabilities in the study. However, also acknowledged a resulting propensity toward people with physical or systemic disabilities, as well as a narrow diversity of ethnic populations.

Although the results indicated no significant discrepancies between parents with and without disabilities in the amount of household chores for which the adolescent was responsible, a distinction in income was evident. Olkin et al. (2006) concluded that families of parents with disabilities on the average produced an income \$15,000 less than the families of parents without disabilities. Further divisions of resources and implications were found among the disability groups, the most remarkable of which related to MS. In comparison to other disability groups, parents with MS were distinctly more likely to fatigue, had a higher frequency of diagnosis after the birth of their children, increased prevalence of a non-disabled partner, and had the greatest susceptibility for job loss. Such factors indicate a higher need for psychosocial and financial support.

Effects of MS, such as fatigue, loss of balance, pain, incontinence, loss of vision, sexual dysfunction, digestive difficulties, and cognitive impairment, impact one's ability to work and carry out their family roles. Parents with MS feel that their illness in some way has impacted their children (De Judicibus & McCabe, 2004). This study was interested in examining whether children and adolescents of parents with MS were at an increased risk for psychopathology. Thirty-one parents with MS (5 male, 26 female) who were between the ages of 29 and 53 years participated in the study. The time since diagnosis was different among participants; range of diagnosis was less than one year to 19 years. The participants also were asked to describe the current state of their MS, in which two participants stated their MS as benign, 28 described their MS as relapsing-remitting, and one did not respond. Parents provided information regarding their

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children, and 24 male children (4 to 16 years) and 24 female children (5 to 16 years) were included in the data (De Judicibus & McCabe, 2004). The study concluded that children of parents with MS did not seem to vary from community norms of children of parents without MS. However, using the Goodman's impact score, the children were found to be over three times more likely than a community sample to be perceived by parents as having clinical status difficulties (De Judicibus & McCabe, 2004). De Judicibus and McCabe (2004) stated that the impact scale rates the levels of distress of the child and hindrances to the child's ability to function in their home life, friendships, classroom learning, and leisure activities.

Paliokosta et al. (2009) conducted a study to explore how disclosure of information regarding a parental diagnosis of MS may be correlated with family dysfunction and mental health problems in children. It was hypothesized that children's lack of awareness concerning parental diagnosis may be associated with increased levels of children's anxiety and impact on family function. Parental factors such as depression were also taken into account. Such factors have been related to family communication regarding parental illness. The study involved 56 families recruited from five neurological clinics of major hospitals or medical facilities in Athens, Greece. It is important to note that researchers did not distinguish families based on clinical course of MS, as such information was not made available by the neurologists.

Results of the Paliokosta et al.'s (2009) study suggest that children and adolescents who were given "partial information" concerning the parental MS diagnosis presented higher scores on the Child Behavior Checklist when compared with the other two groups ("no information" and "total disclosure"). Also, scores on the Youth Self Report were significantly higher for children and adolescents who were given "partial information" in the area of "social problems." The Child Behavior Checklist (CBCL) was completed by all parents, while the Youth Self

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Report (YSR) was completed by all children 11 years of age and older. The CBCL is comprised of 113 items and the YSR is comprised of 118 items. All items on both instruments pertain to behavior and feelings that respondents rate based on a three-point scale. In this scale, “0 = not true”, “1 = somewhat or sometimes true”, and “2 = very true or often true” (Paliokosta, et al., 2009, p. 68). These ratings are then combined and associated with eight clinical syndromes: Withdrawn, Somatic Complaints, Anxious/Depressed, Social Problems, Thought Problems, Attention Problems, Delinquent Behavior, and Aggressive Behavior. The results of this study suggest that children given “partial information” demonstrate increased social difficulties as compared with the other two groups. One unexpected finding was that the group given “no information” regarding parental multiple sclerosis seemed to perform psychosocially similarly to the group given “total disclosure.”

Overall, findings support that communication around parental MS in the family may be a major contributing factor for psychosocial problems of children and adolescents. They also support the idea of the importance of communication regarding parental illness with respect to ‘how, what, and how much’ (p. 73) information is disclosed, rather than whether or not there is communication in general. These findings are consistent with previous research. For example, Pedersen and Revenson (2005) found that high levels of communication, a family identity not related to the illness, and the ability to effectively redistribute family roles are related to more positive family functioning when a parent is diagnosed with an illness. Two limitations to this study were that only parents with mild impairment from MS were used, and that children and adolescents who were given “no information” did not complete the YSR self-report (Paliokosta et al., 2009). Other limitations to this study are that data was collected through self-report

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measures, and that this was a cross-sectional study, therefore, it does not observe any changes in adjustment over time.

Adolescents and adjustment.

Adolescents of parents affected by MS have difficulty establishing a positive psychosocial adjustment to their parent's condition (Bogosian et al., 2010). Bogosian et al. (2010) conducted a systematic review of 20 studies (19 published, 1 unpublished) of literature concerning the psychosocial adjustment of children and adolescents of a parent diagnosed with MS. Although the two studies concerning children (7-11 years old) yielded inconclusive results, all studies regarding adolescents (11-18 years old) revealed an adverse psychological effect. The adolescents reported high MS-related anxiety, a negative effect on social interactions, decreased family structure functionality, and decreased engagement in cultural and cognitive pursuits. Additionally, Bogosian et al. (2010) found parent-reports to indicate the adjustment of children as coinciding with the psychological state of the affected parent. The psychosocial and social relationships of children suffered when their parent exhibited increased depression and symptoms of MS. Despite the conclusions of Bogosian et al. (2010), a review of 20 studies is too small to declare strong, causal generalizations from the results. Twenty studies indicate an insufficient source of knowledge.

When a parent has a chronic somatic disease such as MS, all family members have to cope with changes in the affected parent, such as changes in physical appearance, functional impairments, decline in the parent's autonomy and independence, as well as the threat of death (Diareme et al., 2006). Diareme et al. (2006) addressed the impact of parental somatic illness on members of the family and their psychosocial functioning. The study group consisted of 56 families in which one parent had MS. In each family, both parents and a child who was randomly

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selected (aged 4-17 years) took part in the study. The comparison group consisted of 64 families with children who were of similar age and gender to the children in the study group; however, the parents did not have a chronic somatic illness. Diareme et al. (2006) found that children of parents with MS exhibited greater emotional and behavioral problems than children of similar age and gender whose parents have no chronic somatic illness. It was also found that children of mothers who have MS have greater problems than children in the comparison group (Diareme et al., 2006).

MS not only affects the diagnosed parents, but also has the potential to impact the partner and children in various ways (Steck et al., 2007). Steck et al. (2007) investigated the risk factors that are found to be associated with psychological problems in families with a parent affected by MS. Participants for the study were recruited from university hospitals, specifically from: Hamburg, Germany; Athens, Greece; and Basel, Switzerland. Findings from the study state that approximately 59% of all patients and 20% of the partners evaluated themselves as being depressed, and the depression score was higher with MS or symptomatic parents than in healthy parents (Steck et al., 2007). The duration of the disease has been found to have a significant impact on the severity of depression on the ill parent as well as the healthy parent. In this study, parents were asked to evaluate their children's psychological well-being, and children over the age of 11 were asked to complete a self-report regarding their psychological well-being. The results found that the parents with MS rate their children as needing either counseling or treatment; however, healthy parents did not rate their children as having higher relevant problems (Steck et al., 2007). It is thought that depressed parental couples overestimate mental health problems, whereas healthy parents and adolescents underestimate the risk of mental health

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problems (Steck et al., 2007). Overall, Steck et al. (2007) suggest that children of parents with MS exhibit a need for counseling or treatment due to psychological problems.

Ireland and Pakenham (2010) conducted a study to investigate relationships between youth adjustment and three sets of potential predictors: parental illness/disability characteristics, youth caregiving, and parent-child attachment. They associated poorer adjustment in youth with higher emotional and behavioral difficulties, lower prosocial behavior, and poorer physical health in youth. It was hypothesized that more negative caregiving experiences, lower perceived choice in providing care, and lower parent-child attachment security would be associated with poorer youth adjustment. The other aim of the study was to investigate differences between children of parents with physical illness/disability and children of a parent with mental illness based on youth adjustment, parental illness/disability characteristics, youth caregiving, and attachment. The researchers predicted that youths of a parent with mental illness would demonstrate poorer adjustment than youths of a parent with physical illness/disability.

Ireland and Pakenham (2010) noted that the youths' perceived choice in providing care, as well as variables relating to diverse caregiving experiences were explored in the study as predictors of youth adjustment. With regard to the parent-child attachment aspect of this study, the attachment theory was used. Weinfield, Sroufe, Egeland, and Carlson (1999) state that "According to attachment theory, variation in the quality of parental care leads to differences in the quality of attachment, which can be classified as either more or less secure" (p. 633). Parental illness may impact the parent's ability to respond sensitively to the child's needs. Therefore, characteristics of parental illness/disability, youth caregiving contexts and experiences, and parent-child attachment security were hypothesized to be predictors of youth adjustment.

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A total of 81 youths between the ages of 10 and 25 years with a parent with either a physical illness/disability or mental illness was used in the Ireland and Pakenham (2010) study. Physical illnesses/disabilities included were spinal or back impairment, MS, and cancer. Mental illnesses included were depression, bipolar disorder, and psychotic disorder. Results suggested that negative caregiving experiences and lower perceived choice in providing care were related to poorer youth adjustment. It was noted that perceived maturity, isolation, and choice in caring were found to be the strongest caregiving predictors of youth adjustment. It was also found that lower parent-child attachment security was not associated with poorer youth adjustment. However, post hoc analyses suggested that increased attachment security was significantly related to longer parental illness duration, greater functional impairment, increased worry about parents, fewer activity restrictions, less caregiving discomfort, and greater caregiving confidence. Therefore, researchers concluded that parent-child attachment security was more strongly related to youth caregiving than to adjustment. The results also showed that gradual illness onset was found to be the strongest predictor of poorer youth adjustment. Also, youths of a parent with a physical illness/disability indicated higher levels of worry about the parent, while youths of a parent with a mental illness indicated greater caregiving discomfort. The most significant limitations to this study were the relatively small sample size, the broad age range of youth participants, and the reliance on youth perceptions/self-report.

Pedersen and Revenson (2005) reviewed literature on three domains of youth well-being: psychological distress, problem behavior, and positive well-being. Overall, the literature reviewed revealed that youths were at greater risk for anxiety, depression, and low self-esteem if their parents were ill. They were also at greater risk for increased problem behaviors. However, Pedersen and Revenson (2005) noted that few of the studies reviewed

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moderated participants' gender, cognitive development, and age at time of parental diagnosis.

This lack of moderation may have impacted the quality of the data collected.

Yahav et al. (2007) compared the psychological distress and parental-child relationships in a cohort of adolescents aged 10-18 of parents with MS (n= 56) to a control group of adolescents of parents without a disability (n= 156). Using the YSR and Separation Individuation Test of Adolescents, Yahav et al. (2007) indicated that the children of parents with MS demonstrated higher anxiety and depression levels than did their control group cohorts. Further, adolescents of a parent diagnosed with MS acknowledged feelings of parental dependence and heightened separation anxiety as compared to the control group. Such feelings indicated a delay in development of an identity independent from their family, a natural process of adolescents. These findings of Yahav et al. (2007) accentuate psychological well-being as a resulting factor of importance for families affected by MS.

Mazur (2008) examined the perceived amount of positive and negative events related to parental disability. Participants included 19 parents (males: 3, females: 16) with a variety of acquired disabilities (10 had a diagnosis of MS) and their adolescent children. Mazur (2008) obtained demographic information concerning family members, household roles, and disability-related health history. The frequency and perception of disability-related events were measured with the Parental Disability Events Profiles for Parents and Children (PDEP-P; PDEP-C). Generally, the PED-P quantifies the types of disability-related events and respective occurrence rate (Mazur, 2008).

To measure parental adjustment, Mazur (2008) administered the Brief Symptom Inventory 18 to assess depression and anxiety and the Parenting Sense of Competence Scale for satisfaction and perceived efficacy in fulfillment of the parental role. Mazur (2008) utilized

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parental and adolescent report to evaluate adolescent adjustment. Using The Child Behavior Checklist, Mazur (2008) accessed the parental perspective concerning adolescent behavioral tendencies to internalize or externalize problems and school performance. Mazur (2008) obtained adolescent report for internalization tendencies and school performance using: The Children's Depression Inventory to examine depression; anxiety from the Revised Children's Manifest Anxiety Scale; aggression with the Youth Self-Report (YSR) Aggression Scale; school performance from the YSR; and self-worth sub-scale Self-Perception Profile for Adolescence. In general, higher amounts of positive events were reported, however, parents were more likely to report negative events than were the children (Mazur, 2008). However, an interesting result was the adolescents' reports revealed a lower self-esteem and concealing problems from parents, yet such feelings were not acknowledged in the parent reports. This lack of acknowledgement by the parents reveals that perhaps they are not aware of these issues; this indicates a discrepancy between the parents' and adolescents' perspectives. Mazur (2008) acknowledged the research to be merely correlational, thus although there is a report discontinuity, the source or direction of the discrepancy cannot be determined. Additional limitations included a limited sample size, primarily non-Hispanic white, middle class families, and a small sample size (n=19 families).

Application to the Field of Occupational Therapy

Model of Human Occupation.

The Model of Human Occupation (MOHO) was first developed by Gary Kielhofner as a master's thesis in 1975 and further refined into a theoretical framework (Cole & Tufano, 2008). It is still relevant in occupational therapy practice; a study by Wook Lee, Taylor, Kielhofner, and Fisher (2008) indicated therapist use of the MOHO to guide approximately 80% of practice. According to Cole and Tufano (2008), the MOHO emphasizes the relationship between the

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internal and external environments as engaging and reciprocal. The internal environment, the person, is composed of three associated concepts: volition, habituation, and performance capacity. Volition constitutes motivation for occupation and includes one's personal causation, values, and interests. Habituation includes the habits and roles that comprise individual lives. Furthermore, performance capacity reflects the musculoskeletal, neurological, cardiopulmonary, and symbolic systems of a person. Thus, the MOHO views the person as part of a continuous interaction with the environment, impacting volition, habituation, and performance (Cole & Tufano, 2008).

Positive effects of occupational therapy intervention.

As previously mentioned, Cahill et al. (2010) examined the impact of MS upon the volition, habituation, and performance capacity of seven women, and found adaptations in all three areas. Such results denote the prevalence of MS symptoms as spanning one's interests, roles, and physical capabilities. Further, Cahill et al. (2010) supported the function of occupations as a therapeutic means to adaptations. Although all aspects relating to the person were influenced, participants adapted by acquiring new interests, modifying performance to maintain previous activities, and matching roles to performance capabilities. Thus, adaptation in volition, habituation, and performance capacity can be facilitated in people diagnosed with MS.

Further assessing occupational changes, Bourland, Neville, and Pickens (2011) utilized the MOHO as a means to interpret the phenomenological results of quality of life assessments among stroke survivors. Application of the MOHO helped to view quality of life as a transient and multifaceted concept, revealing occupational loss and changes in performance capacity. A resulting discrepancy between individuals' desires and actual abilities affects perceived quality of life. Conversely, the MOHO affords insight into the transition from pre-morbid to post-morbid

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occupational status and facilitates development of new occupations. Comprehensively, participation in occupations and quality of life are actively related. Therefore, occupation fosters an increasing sense of control, and thus identity.

In a retrospective study, Eklund (2007) assessed the perceived control and occupational performance among individuals with mental health issues. Specifically, the research aimed to establish a clinical understanding of control within occupational performance as it was presented in the MOHO. Eklund (2007) defined perceived control to be a feeling of accountability for one's actions. Perceived control was measured using The Locus of Control Scale (LOC) and The Mastery Scale to assess attributions of control and self-mastery. The study was based on two previously collected data sets from studies conducted by Ecklund. The first data set was collected with 74 outpatient clinic patients with severe mental illness. The second data set was collected three years later from 103 outpatient clinic patients with severe mental illness at a different outpatient clinic.

Results based on the LOC and The Mastery Scale indicated perceived control to be related to occupational performance as well as to occupational satisfaction. Thus, the amount of control that individuals feel they have has a reciprocal impact upon their occupational performance and satisfaction. One limitation to this study was that healthier patients in the first data set were not included in the sample because the researchers wanted to focus on patients who had more recently visited the outpatient unit. Inclusion of these patients may have made a difference in the observed results. Another limitation was that the sample was limited to specific demographics seen at the two clinics and, therefore, it may be argued that results may be difficult to generalize.

Reliability and Validity or Trustworthiness

Reliability and validity.

Reliability and validity are psychometric properties of quantitative instruments (Kielhofner & Fossey, 2006). Reliability refers to the consistency of information yielded across different applications of the instrument. Validity examines the accuracy of the instrument in obtaining the intended information. Establishing reliability and validity assists in the development and implementation of quantitative instruments.

The Role Checklist.

The proposed study used the Role Checklist, developed by Gary Kielhofner, to obtain insight into roles and perceived importance to participants (Kielhofner et al., 2008). Kielhofner et al. (2008) described the Role Checklist as an assessment based on the MOHO used as a means to measure perception of occupational role participation and associated value. The assessment encompasses past, current, and expected future roles of adolescents and adults. The Role Checklist provides insight into role patterns and resulting influences upon participation. It may be completed independently or in a group; the Role Checklist is conducive to discussion concerning roles and meaning, thus after completion it ought to be discussed with an occupational therapist or other group members.

Kielhofner (2008) asserted that assessments for the MOHO are well researched and contribute to the psychometric properties as well as the improvement of such assessments. Self-report measures such as the Role Checklist are still developing, and are most useful to facilitate conversation between therapist and client to establish feasible priorities. Oakley, Kielhofner, Barris, and Reichler (1986) initially evaluated the Role Checklist for psychometric properties and found adequate test-retest reliability and indicated a need to assess for validity.

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Trustworthiness.

Coster (2006) explained trustworthiness to entail reliability and validity of qualitative inquiry. Specifically, trustworthiness involves establishing the credibility, transferability, dependability, and confirmability of qualitative methodology. According to Morse, Barret, Mayan, Olson, and Spiers (2002), trustworthiness requires use of “negative cases”, peer debriefing, prolonged engagement, persistent observation, audit trails, and member checking.

Focus groups.

The study used the Role Checklist to stimulate conversation within a focus group. According to Krueger and Casey (2009), a focus group consists of participants who share key characteristics in which the researcher facilitates focused discussion concerning a specified topic. Discussions are intended to identify commonalities and differences in participants’ experiences and perceptions. Focus groups on a specified topic are typically conducted across several different groups of participants to ascertain general similarities and patterns.

Hyde, Howlett, Brady, and Drennan (2005) advocated that focus groups can be a valuable means of acquiring otherwise inaccessible information, such as insight into the social processes of participant groups. However, it can be challenging to ensure trustworthiness in focus groups. This is due to the subjectivity of researcher interpretation, the range of opinions expressed within specific groups and resulting dominant viewpoint, accuracy of information shared by participants, and presence of cross-checking methods. Hyde et al. (2005) determined that trustworthiness is influenced by how researchers address such issues. Particularly, Hyde et al. (2005) recommended use of post-interview questionnaires as a means to cross-check validity and measure trustworthiness. Focus groups have a potential to provide a more natural setting, and are

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thus conducive to participant expression; carefully constructed trustworthiness measures can maximize the utility of focus group research.

Summary and Implications for the Study

Multiple sclerosis impacts occupational adaptation due to changes in physical performance capacities, interests, and roles (Cahill et al., 2010). Furthermore, research indicated parental and adolescent perceptions, coping capabilities of other family members, and physical symptoms as influential in maintenance of interests and occupational adaptation of people diagnosed with MS (Cahill et al., 2010; Ehrensperger et al., 2008; Mazur, 2008). Multiple sclerosis also affected the importance and execution of current roles, as well as expectations for future roles for the person diagnosed as well as their family (Cahill et al., 2010; Courts et al. 2005; Finlay, 2003; Lexell et al., 2011). Research has indicated many factors that influence the psychosocial impact of MS upon the parenting role including, financial resources, physical symptoms, information available to children, and communication (De Judicibus & McCabe, 2004; Olkin et al., 2006; Paliokosta et al., 2009; Pedersen & Revenson, 2005). In addition to the parental role, families are also affected; children of parents with MS, and particularly adolescents, exhibit heightened incidence of anxiety, depression, behavioral problems, and maladaptive coping (Bogosian, et al., 2010; Diareme et al., 2006; Ireland & Pakenham, 2010; Pedersen & Revenson, 2005; Yahav et al., 2007). Further, research reveals a discrepancy in the perceptions of parents' view of their children's adjustment as compared to children's self-reported adjustment (Steck et al., 2007).

Despite extensive research into the impact of MS upon the adolescent stage of the family life cycle, Coles et al. (2007) expressed a lack of family-oriented interventions to facilitate coping in adolescents of parents with MS. In an effort to counter this deficiency, Coles et al.

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(2007) implemented an intervention program for children at a summer camp. The study indicated an improved psychological well-being of the participants, however it did not incorporate the parents into the intervention and is not easily replicated. Thus, there is a need to develop family-centered interventions to assist in adolescent adjustment in response to parental MS. Therefore, this study assessed parental perceptions of parenting an adolescent, as well as familial adjustment to role changes based on a parental diagnosis of MS. The study aimed to investigate how occupational therapy can assist parents with MS in facilitating positive coping techniques in their adolescent children.

Chapter 3

Methodology

Introduction to Methodology

As a means to evaluate the perceptions of parents with MS parenting adolescents, this study utilized a mixed method approach, using role changes quantified from the Role Checklist and qualitative information from the focus group. This chapter will entail a detailed review of the methodology of the proposed research study. This chapter will address: the study design and associated procedures, location, participant population, instrumentation that will be utilized, reliability and validity of proposed methods, and possible limitations of the methodology.

Study Design

According to Corcoran (2006) a mixed methods design involves the simultaneous use of quantitative and qualitative methodologies. Specifically, this study utilized a concurrent nested design in which the qualitative data is the predominant source of information. Corcoran (2006) asserted that such a design is used as a means to measure two dimensions of the same question; in this case the quantitative aspect objectively measured parental roles while the qualitative piece addressed the subjective aspects of roles.

In this study, Role Checklist was utilized for the quantitative aspect, although structured in a self-report manner, the researchers used this tool to determine prevalence of past, present, and future roles, as well as a ranking of the value assigned to each role (Corr & Wilmer, 2003). The focus group served as the qualitative measure; Kielhofner et al. (2008) advocated for use of the Role Checklist as a means to promote conversation, a tool to be discussed with an occupational therapist or others who have completed it. Due to this application of the Role Checklist, a mixed methods approach was conducive to the needs of the research project. The

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participants independently completed the Role Checklist prior to the focus group and referenced it in order to facilitate discussion throughout the focus group. Similar topics included in the Role Checklist were discussed in the following focus group.

The Role Checklist was used to quantify participants' perspectives on their engagement in and importance of their roles, while the focus group identified commonalities among the participants' parenting roles and experiences. Also, the Role Checklist is a self-report measure, thus it provided insight into the roles and occupations discussed within the focus group (Kielhofner, 2008). Application of a focus group following the Role Checklist is supported in the discussions of Bloor, Frankland, Thomas, and Robson (2001) concerning the usefulness of focus groups as a means to examine the underlying meanings regarding group opinions and reactions. Research with focus groups allows further examination of data beyond an objective, informative level; focus groups promote the examination of underlying reasons for group norms. Bloor et al. (2001) also discussed the utility of focus groups in mixed-methods research to establish triangulation and active participant involvement. Triangulation is described by Bloor et al. (2001) as a contrast of results obtained from different means, that may be improved by pairing focus groups with another measure, such as the Role Checklist.

Study Site and Population

Study site.

The focus group occurred at a location that was the most convenient for participants involved.

Participants.

Upon approval from Grand Valley State University's Human Research Review Committee, a pilot group made up of a convenience sample of participants was recruited. The

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researchers also contacted the Michigan Chapter of the National Multiple Sclerosis Society for approval to solicit participants for the proposed study through their website. After approval from the Multiple Sclerosis Clinical Advisory Committee, the organization placed an advertisement online. Recruitment through publications and advertisements is advocated for by Bloor et al. (2001) as a means to access less common or marginalized populations. The submission form to utilize the National Multiple Sclerosis Society to recruit participants is included in Appendix A. Morgan and Krueger (1997) recommend facilitating at least two focus groups to promote diversity in the data, however, due to time constraints, it was not feasible for researchers to conduct a focus group using participants recruited from the Michigan Chapter of the National Multiple Sclerosis Society. Therefore, the data collected was based on the information from the pilot group.

Through phone call and e-mail, researchers were able to recruit participants whom they knew met the inclusion criteria for the study. Further information concerning the date and time of the focus group were provided to the participants via phone conversation and email. In order to be eligible to participate in the study, participants must have had a diagnosis of multiple sclerosis for at least six months and parenting at least one adolescent child in the home between ages of 12 and 17. The adolescent did not need to be the biological child of the parent participating; adoptive parents, stepparents, foster parents, and grandparents were eligible to participate in the study. Subtypes, stage, and exacerbation of MS were not considered as inclusion nor exclusion criteria. Participants could be any age and either gender. Inclusion criteria are specified in Appendix B. Participants completed a Pre-Interview Survey to assess eligibility, as advised by Bloor et al. (2001) for participation requiring multiple inclusion criteria (see Appendix C).

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Equipment and Instruments

The Role Checklist is a non-standardized measure; the items are primarily used as a means to facilitate conversations and identify client priorities (Kielhoefner, 2008). The focus group questions also are non-standardized, created by the researchers to stimulate conversation based on the Role Checklist. A total of nine questions were asked, and group discussion took approximately 60 minutes to complete. A sample of the Role Checklist and focus group script are included in Appendices D and E.

Validity/Reliability

An original evaluation of psychometric properties of the Role Checklist demonstrated test-retest reliability but acknowledged a need for established validity (Oakley et al., 1986). More recent analysis has indicated self-report measures for the MOHO assessments, such as the Role Checklist, as needing further research (Kielhoefner, 2008).

Trustworthiness

Hyde et al. (2005) expressed subjectivity of interpretation, dominance of opinions, information accuracy, and use of cross-checking as influential to focus group trustworthiness. Hyde et al. (2005) also acknowledged that the influence such issues have upon trustworthiness is determined by the researcher's approach; thus, the researchers of the proposed study implemented several methods to ensure trustworthiness. The researchers used interview training, piloting, reflexivity, triangulation, and audit trail methods to ensure trustworthiness.

Firstly, interview training occurred. Each of the three researchers practiced interviews with standardized questioning and probing under supervision from their committee chairperson. Trustworthiness was also achieved through triangulation of data methods and data gatherers. Triangulation of data methods refers to the use of multiple sources to acquire information. The

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study used both the Role Checklist and results from the focus group discussion to arrive at conclusions. Triangulation of data gatherers occurred when each of the researchers independently analyzed the data and compared results to achieve a consensus. Audit trails were maintained concerning data gained through the study, explanations of theoretical background to the study, procedures for data collection, documentation of decisions about data collection and interpretation, personal reflections, and copies of procedures for the study. Finally, Hyde et al. (2005) proposed use of post-interview questionnaires as a means to assess the trustworthiness of participant responses. Thus, researchers utilized a post-interview questionnaire in the proposed study to promote trustworthiness (See Appendix F).

Procedure

After approval from the Human Research Review Committee of Grand Valley State University, the researchers contacted the Michigan Chapter of the National Multiple Sclerosis Society regarding participant recruitment. After the completion and approval of the research request (Appendix A), an inquiry was posted on the website of the National Multiple Sclerosis Society containing general information and inclusion criteria for the study, a request for participants availability, and researcher contact information. The advertisement also informed participants of an incentive, one participant would be selected at random to receive a \$100 Visa Card. Eligible participants were asked to contact the researchers with preferred dates and times for the study to occur. Researchers would then select the time that accommodates the majority of those interested. In order to promote participant attendance at the focus groups the researchers would remind participants through an e-mail of the date of the study, as recommended by Bloor et al. (2001). This e-mail would also entail the pre-interview survey, the Role Checklist, and informed consent form to print and complete prior to arrival at the focus group (See Appendices

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C, D, G). Participants would be prompted to contact the researchers if they did not have access to a printer and the forms would be mailed to their house. If participants were uncomfortable distributing their address, forms would be provided upon arrival to the study for completion. An example of the e-mail that would be sent out is available in Appendix H. As previously mentioned, time constraints did not allow the researchers to use participants from the Michigan Chapter of the National Multiple Sclerosis Society. Therefore a pilot group was conducted using the same methods that would have been used for the formal focus group.

The focus group was held at a location that was most convenient for the participants involved. In this case, the location was the home of one of the participants. The focus group took place in the dining room of the home. Researchers ensured that the room was kept private for the duration of the focus group discussion. There was a refreshment table in the room with water, coffee, and snacks. Participants were seated facing each other around an oval table. Two of the researchers led the discussion, and were sitting opposite each other and among the participants. The third researcher was seated off to the side and documented the conversation as it occurred. Two audio recorders were used during the session to record the conversation.

Upon arrival, participants were greeted by the researchers, thanked for their participation, and offered refreshments. Next, they received an envelope containing the post-interview questionnaire and researcher contact information (See Appendices F and I). Each envelope and its contents were labeled with an identifying number which researchers referenced participants to maintain confidentiality. Participants were asked to take a seat and enjoy refreshments while waiting for other participants to arrive.

The audio recorders began once all participants had arrived; the researchers introduced themselves, explained the study, and provided a schedule of the study's events. The researchers

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began speaking from a script, found in Appendix E. Next, the researchers facilitated the focus group. Two researchers posed questions based upon the script in Appendix E and facilitated resulting conversation while the third researcher documented the discussion. Researchers probed participants for elaboration when appropriate.

Following the focus group, the researchers instructed the participants to complete the post-interview questionnaire to assess the validity of respondents' answers (see Appendix F). The researchers exited the room to minimize coercion effects. A participant notified the researchers once everyone was completed. The researchers returned to the room, collected the envelopes containing the participants' post-interview questionnaire. At the conclusion of the focus group, researchers expressed gratitude for participant involvement.

Data analysis.

The Role Checklists were used to compile quantitative information regarding participants' past, present, and future role engagement and value ranking assigned to such roles, as demonstrated in Corr and Wilmer (2003). Corr and Wilmer (2003) utilized the Role Checklist with people who had experienced a stroke as a means to determine actual engagement in roles. Such an analysis provided depth to the qualitative, interview piece, of their study. Corr and Wilmer (2003) calculated the proportions of participants engaged in each level of role engagement as well as the assigned value; the researchers of the proposed study will do the same. The Role Checklist provided a measure of role changes as related to MS while the focus group allowed for elaboration upon the role changes and impact upon adolescents.

Bloor et al. (2001) advocated for transcription of audio recordings as a means to allow an accurate, in-depth analysis of the focus group. The transcription process required: (a) transference of all words as they occurred, not correcting for speech mistakes;

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(b) documentation of all oral communication, such as laughter; and, (c) consistent identification of recorded responses to correct participant. Such efforts were taken to ensure an accurate written representation of the focus group events.

Further analysis involved indexing data, storing and retrieving data, and interpretation of the results (Bloor et al., 2001). Indexing involved categorizing results according to themes, broadly at first, then narrowing to specific sub-categories. Researchers of the study completed indexing as the first step following data transcription, to identify prevalent similarities among participant responses. Data storage and retrieval required organizing all responses according to their indexed category. Bloor et al. (2001) proposed storing data using a filing system, researchers of the study printed transcribed notes and stored in binders according to indexed categories. The final step of the data analysis process described by Bloor et al. (2001) involved interpretation using a step-by-step analytic induction approach. Researchers of the study assessed indexed responses to form commonalities and discrepancies to derive conclusions. Data were stored in the Cook-DeVos Center for Health Sciences for three years following analysis.

Limitations.

Bloor et al. (2001) discussed several limitations that naturally accompany focus groups, including participant selection, the group processes, and confidentiality of focus groups. Firstly, researchers were not able to conduct a formal focus group with participants from the Michigan Chapter of the Multiple Sclerosis Society. Therefore, the researchers were only able to conduct one pilot group of three participants, limiting the generalizability of the results. Also, the participants in the pilot group were a convenience sample. This means that the results were not able to be fully representative of the target population. In addition, our convenience sample presented geographic, gender, and ethnic limitations in regards to lacking diversity in such areas.

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Bloor et al. (2001) explained the importance of creating a group dynamic among participants to foster participation of all participants, low feelings of dominance or submission among participants, and reassurance of confidentiality are important. However, Bloor et al. (2001) also acknowledged such phenomena are unpredictable and thus difficult for the researcher to control. Hence, the unpredictability of group composition and dynamics are an inherent limitation of focus groups. Further, Bloor et al. (2001) explained focus group size to be an influential, but also uncontrollable, limitation. Small groups may create a sense of comfort and facilitate conversation, while conversely lower participant numbers may limit discussion. Thus, the small size of the focus group presented limitations. On the other hand, larger groups may not allow for all participants to express their opinions and may be too large for researchers to manage. One further limitation that is inherent to focus groups, is ensuring participant confidentiality. Researchers asked that participants respect the confidentiality of other group members as this was a responsibility of the participants and was outside of researchers' control.

Summary

The study entailed a mixed methods approach utilizing the Role Checklist and a focus group to examine the perceptions of parents with MS parenting adolescents. The study was conducted with a pilot group of participants at a location that was most convenient for the participants. Trustworthiness was achieved through interview training, reflection of researchers, triangulation of data collection and analysis, utilization of a post-interview questionnaire, and audit trails. In the following chapter the researchers discuss data analysis of the Role Checklist and focus group.

Chapter 4

Results/Data Analysis

Techniques of Data Analysis

Data analysis of the pilot focus group entailed the following: transcription training with the committee chair; transcribing data; independent researcher development of themes; collective researcher refinement and negotiation of themes; collective development of codes and code book; and, member checking. To begin, Dr. Cynthia Grapczynski instructed the researchers in the processes of data analysis to include: (a) transcription recording all utterances of researchers and participants; (b) use of note cards to identify themes; (c) individual development of themes and collective integration; and, (d) member checking with phone calls to participants to ensure accuracy of themes. Bloor et al. (2001) supported the recommendations from the transcription training with the following advice: transcription of all words and sounds; indexing of discussion according to themes, beginning generally and progressing to specific content; and, organization of all responses according to indexed category. While independently listening to an audio recording of the focus group, the researchers independently transcribed by typing into a Microsoft Word document. The researchers transcribed sections of the focus group and compiled the sections into one, cohesive document. To protect the identity of participants, they were identified using their initials.

Next, the researchers printed the document and independently read through the transcription using red pens, green permanent markers, and highlighters. To emphasize portions of the text, researchers underlined and highlighted recurrent topics and key statements made by participants. Additional emphasis was placed on segments of the text by writing questions and connections in the margins. After independently reading and marking the transcription, the

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researchers used note cards to indicate potential themes for each question, stating key words each participant used, and potential themes based on the question. Collectively the researchers reviewed the general themes they independently generated and decided on three overarching themes based on the prevalence: fatigue; understanding; and, availability of support. Next, together the researchers coded the transcribed data, coding entailed selecting participants' statements related to one of the themes; color coding each statement in the transcription document according to the theme; and copying the statements to a new Word document organized according to the three themes. Throughout this process, the overarching themes were further developed as follows: Theme 1 MS symptoms that impact role performance; theme 2 understanding of the meaning of the MS diagnosis; and, theme 3 availability of support.

Once the coded document was compiled, the researchers collectively developed subthemes for each overarching theme based on coded information. Subthemes for theme 1 included (a) MS symptoms that impact parenting; (b) MS symptoms that impact familial relationships; and, (c) prioritization of family roles around symptoms. Subthemes for theme 2 included (a) self-insight; (b) children's expected insight; (c) best interests of child; and, (d) children self-directing insight. Subthemes of theme 3 included (a) presence of informal supports; (b) presence of formal supports; (c) knowledge as limiting and liberating; and, (d) need for further support. A codebook was created to record each of these themes and subthemes (Appendix K). Subsequently, the rationale and supporting quotations for themes and subthemes were compiled for this chapter. To ensure accuracy of themes, the researchers attempted to contact each participant by phone to tell them of the themes developed; despite multiple attempts only one participant was successfully contacted and reported concordance with themes.

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Characteristics of Subjects

The focus group was composed of three participants, two males and one female. Inclusion criteria were met for all of the participants. Each participant had one adolescent between the ages of 16 and 17, and length of diagnosis varied from 8-12 years. All three participants were married and resided with their adolescent full-time. Because the focus group was a pilot study, the participants knew the researchers and each other.

Results

Data analysis involved analyzing quantitative results of the role checklist and qualitative findings of the focus group. Tables 1, 2, and 3 report the findings of the Role Checklist for participants' past, current, and anticipated engagement in roles, as well as the value associated with these roles. Information from the Role Checklist completed by each participant was compiled into Table 1 for comprehensive comparison. Analysis of the focus group presented three overarching themes: Theme 1 MS symptoms that impact role performance; theme 2 understanding the meaning of the MS diagnosis; and, theme 3 availability of support. Themes and subthemes are detailed below.

Role Checklist findings of interest.

Results from findings discussed can be found in Table 1. While all participants reported current engagement in the roles of worker and family member, they also indicated these roles as very important. With five categories, all participants acknowledged roles as "quite" or "very important", looking after my home; doing things with my friends; and, doing things with my religious organization; having hobbies; and, doing things with a wider group. Of these roles indicated as quite or very important, three were indicated as being currently engaged in by all participants: looking after my home; doing things with my friends; doing things with my

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religious organization. However, only one participant currently engages in the roles of having hobbies, and none reported doing things with a wider group, although all participants noted these roles as quite or very important. Further, one participant stated they would like to participate in hobbies as a future role, while two participants want to engage in doing things with a wider group in the future. Only the roles of student (n=2), volunteer (n=1), and looking after someone (n=1) were selected by some participants as not important.

Table 1: Compiled Findings of the Role Checklist

	Time Engaged in Role			Importance of Role		
	Used to do this	Doing this Now	Would like to do This	Not Important	Quite Important	Very Important
Student	✓✓✓	✓		✓✓	✓	
Worker		✓✓✓				✓✓✓
Volunteer		✓✓	✓	✓		✓✓
Looking after someone	✓	✓	✓	✓		✓✓
Looking after my home		✓✓✓			✓	✓✓
Doing things with my friends		✓✓✓	✓		✓✓	✓
Doing things with my family		✓✓✓				✓✓✓
Doing things with my religious organization		✓✓✓			✓✓	✓
Having a hobby/hobbies	✓	✓	✓		✓✓	✓
Doing things with a wider group(s)	✓		✓✓		✓✓✓	
Different roles...						
Would like to: go to graduate school			✓		✓	

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Table 2: Details of Participants' Past, Present, and Future Roles

	Used to do this	Doing this Now	Would like to do This
Student	3	1	
Worker		3	
Volunteer		2	1
Looking after someone	1	1	1
Looking after my home		3	
Doing things with my friends		3	1
Doing things with my family		3	
Doing things with my religious organization		3	
Having a hobby/hobbies	1	1	1
Doing things with a wider group(s)	1		2
Different roles...			
Would like to: go to graduate school			1

Table 3: Value Placed by Participant on Each Role

	Not Important	Quite Important	Very Important
Student	2	1	
Worker			3
Volunteer	1		2
Looking after someone	1		2
Looking after my home		1	2
Doing things with my friends		2	1
Doing things with my family			3
Doing things with my religious organization		2	1
Having a hobby/hobbies		2	1
Doing things with a wider group(s)		3	
Different roles...			
Would like to: go to graduate school		1	

Theme 1: MS symptoms that impact role performance.

Physical symptoms related to MS, such as fatigue, decreased performance capacity and ability to engage in occupations related to roles. Fatigue was found to be impactful to the

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participant's ability to participate in family occupations. It was reported that energy was most frequently depleted in the evening, but also unpredictably, thus limiting engagement. In response to the second question, participant A referred to energy levels as a "gas tank"; "you know it's like a gas tank- you're going fine and all of a sudden "boomp" no energy- I can't move I can't...uh...I don't want to do anything." This analogy was used throughout by all participants.

Subtheme 1: MS symptoms that impact parenting.

Decreased role performance due to MS symptoms is perceived by the parent to most affect themselves. Participants reported a decreased participation in familial occupations due to performance capacity limitations. Specifically, participants experienced fatigue, peripheral neuropathy, lack of coordination, and feeling of a "fog." As a result, participants must withdraw from involvement in family occupations and activities. Participants perceived such withdrawal as most impactful to themselves; each participant acknowledged feeling that the withdrawal was more hurtful to themselves than their family. One participant stated: "I would have some mornings where I just couldn't even get out of the fog." Additionally, a participant confirmed: "there are times when the fatigue hits and...um...I am not really able to be a part of something I need to be a part of but...the biggest person it hurts is me."

Subtheme 2: MS symptoms that impact familial relationships.

Decreased role performance due to MS symptoms creates a psychosocial barrier between parent and adolescent, and parent and significant others. Participants discussed the impact of their emotional reactions to physical symptoms as a barrier to relationships with their adolescents and significant others. Specifically, participants reported that increased irritability and aggravation resulting from physical symptoms exacerbated existing conflict. Further, participants expressed difficulty in interacting with their adolescents while experiencing such agitation.

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A participant stated: “I would snap at times, probably at the weirdest times, I would snap at the kids or something like that...probably because of that the fatigue.” Participants also stated conflicts arising between them and their adolescents due to performance capacity deficits, thus limiting ability to perform parenting roles. Specifically, they reported difficulty in emotional regulation when interacting with adolescents. One participant discussed difficulties with homeschooling a child, stating:

I was homeschooling him and...he would be tired or I would be tired it was just hard to try to find the time and for both of us to be patient at the same time. Um to both of us to be feeling well enough to sit down to do what we needed to do sometimes difficult.

Another participant acknowledged relational tension:

I do get a little more aggravated at times because...I have peripheral neuropathy in my feet at times, and well its always there but it's a little worse sometimes, and...if that's kinda bugging me...a fuse is short sometimes that's probably the biggest impact on our relationships period.

Subtheme 3: Prioritization of family roles around symptoms.

Decreased role performance due to MS symptoms causes the individual with MS to prioritize certain roles as more important than others. Due to performance capacity deficits, participants' family roles take precedence over other productive, social, and leisure pursuits. This was discussed as an ongoing struggle, “my house fell apart after oh my gosh, we're just starting to get it back together...” One participant credited fatigue specifically as impacting occupational involvement and priorities, saying: “I would say the fatigue factor works for me with that, especially I mean having late night volleyball practice really stinks...” As a result of symptom

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interference, adolescents or significant others often assume responsibility for these roles. One participant described the need for assistance: “yeah especially recently... theres just things I... physically am not able to accomplish at my home. So, you know, you have to have somebody come and do it...” An example of role assumption was provided by one of the participants, discussing how her spouse took over responsibilities for den leader while their son was in Boy Scouts:

But it definitely was a change in the way I was interacting with my son at the time because I was no longer as involved with that area. It's active. You know, I wasn't doing the campouts and stuff, my husband worked campouts, but um with all the other parts of it and all the um just coordinating and arranging and all the stuff that I was doing um and actually spending the time with him and this would have been great. Um, and all of a sudden I just wasn't there.

Theme 2: Understanding the meaning of the MS diagnosis.

Knowledge and insight affect one's ability to accept and adapt to role changes. Participants expressed insight regarding the implications of their physical symptoms of MS upon their daily lives, yet they indicated “minimal impact” upon their role as parents. However, participants stated a familial understanding of the parent's performance capacity, although they did not formally address these capacities with their children. As a result, a shared but assumed understanding of roles exists among family members and the parent with MS. Participants reported adolescents' further interest in learning about the condition to acquire greater understanding.

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Subtheme 1: Self-insight.

Role engagement is determined by the individual's acceptance and understanding of their diagnosis of MS. Participants expressed self-insight regarding the implications of MS and the resulting manifestations in their lives, both in terms of parenting roles as well as general occupational engagement. One participant stated, in relation to caring for her mother-in-law: "If it happened 10 years ago that would have been a different story." Participants demonstrated an understanding of the tasks within their capabilities. Participants experienced a process of acquiring insight, one participant explained their process and support:

Probably, I probably would have gotten more [support] if I'd let more people know. I just, I pretty much kept it to myself. Overall, it's like, based on what I do, see a lot of people with a lot of problems, so, so I tend not to complain about it, myself in any way just because I've seen... I've seen such different things, bad things in a lot of cases. I say, I never say "why me?" about it.

Another particularly telling statement provided understanding into how the participant came to cope with their diagnosis:

I've come to live with it because I know there is nothing you can do about it I mean there's no no cure for it so you just really have to cope with it is is what its like and I think I probably learned to cope with the aches and pains and if I have an exacerbation or something it's like okay alright let's get through this one hopefully it it will be a short one and won't you know be a long lasting effect type exacerbation but I think I've dealt with it a lot more now or I'm dealing with it better than I did in the beginning...

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Subtheme 2: Children's expected insight.

From the parents' perspective, children are assumed to understand the implications for MS and adapt accordingly. Participants described their children as "understanding" the implications of parental MS, yet they acknowledged that such understanding was also assumed. A participant described: "my other kids were a little bit older at the time and didn't...I don't think it impacted them much...they just understood that I couldn't always get up and drive late at night and go somewhere or pick them up." One participant had never formally shared his diagnosis with his daughter, while the other two participants had discussed the diagnosis, but not pertaining to role changes. The participant who had not informed his daughter explained that he believes that she knows:

She's 16 and she's not...she's very intelligent and she sees some stuff round the house and things and she see's all the things I get in the mail and and...and all that and she knows I was coming to this today. Yeah she is.

Regarding the impact of his condition upon roles, he further stated:

I don't think...the only thing I don't know what kind of impact this is but I think um she doesn't necessarily expect me to do certain things just automatically we never never really discuss but I just don't think that she necessarily expects me to jump in and do things like when she was younger she understands now that she is a teenager

Subtheme 3: Best interests of child.

From the parents' perspective, parents included or withheld information regarding their diagnosis, prognosis, and lifestyle implications, in accordance to the best interests of the child. One participant overtly stated: "I was surprised at how my kids...we didn't necessarily talk about it-it wasn't to hide it but it was to not make it be a big thing that was uh that was scary and

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negative or whatever.” To further validate the desire to protect their child, another participant elaborated:

I never wanted... to burden her with that or the chance that of geez Daddy’s got something that he could die from or something... because really that’s not really necessarily the case... I never wanted to put that on her.

Participants explained withholding information from their children as an effort to protect them and expressed refraining as a means to avoid burdening or scaring their children. Regarding the decision process to communicate with their children, one participant asserted:

We never formally addressed it with our kids not that I can remember... I’m sure my wife spoke with to them about it but... I just didn’t want to burden them with it... but then you know they...I’m sure they think about it...wonder could they possibly get it and I know we’ve talked that with them and said you know it’s... it’s not passed that way you know...don’t worry... you think it’s not...

Subtheme 4: Children self-directing insight.

From the parents perspective, children applied and expanded knowledge of parental condition to gain better understanding. Although participants reported minimal conversations with their children about the impacts of MS, after the children recognized the implications for their lifestyles and adapted, they independently sought more information. In times of conflict with children, a participant described his children as turning to his wife for further information: “I know they talked to Karol at times saying ‘geez, what, my God, what the heck you know. Was it this bad?’ Ya know, and Karol would try to console them...” One participant

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felt that their children would intentionally seek further information:

If there was a project they would always pick something that either had to do with heart disease or MS because without us ever talking about it and I would just find out that they that they that was something they were interested in because they...I think they wanted to know more and they wanted to get the information and then with my son it's like he never would...the the younger one would never show he...he doesn't share very much with us so ya know you look through his book bag or you look through whatever and find a report on MS and it's like wow I didn't know you were aware I didn't know you cared I didn't know ya know and I guess that's that would be encouraging.

Theme 3: Availability of support.

Formal and informal supports are perceived as valued by individuals with MS, especially when first diagnosed, yet may be expanded to address the needs of the family. Participants discussed the varying levels of formal and informal supports received as related to their diagnosis of MS. While the formal support participants utilized was self-solicited, the informal support was offered through family and friends. Although participants stated satisfaction with their current service provision, they felt that people who are newly diagnosed and with more acute forms of MS would further benefit from services. Participants expressed a need for conversations concerning the implications of MS at the family-level, facilitated by a professional.

Subtheme 1: Presence of informal supports.

The assistance of family and friends are beneficial to individuals with MS and their families. Participants acknowledged the use of informal supports, stating family members, friends, neighbors, and a personal religious faith as helpful in coping with their condition.

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Informal supports were naturally in place; participants did not feel the need to seek it out. One participant described the availability of informal supports as:

If we needed anything with the kids, or anything, they would help...it's like I almost had that kind of support if I needed it. I'm not big for, at asking for it, but it was there. It was nice to know that there were people that would pick that up.

Additional informal supports were identified to help with coping:

We have good strong families and strong faith background and I think that that helps tremendously in being able to deal with any adversity in your life period, let alone this, and you realize in essence you... were blessed to be able to function the way we function... the strength of our family backgrounds and everything and our close family really helps in our ability to cope with ya know any feelings of frustration and anger that we come upon us so at least for me so...

Subtheme 2: Presence of formal supports.

Although occupational therapy services are limited, the assistance of organizations in providing education regarding MS is beneficial. Drug companies, healthcare professionals, and medical institutes composed the formal supports utilized by participants. None of the participants reported receiving occupational therapy services. The drug company Biogen was acknowledged as particularly helpful:

I mean they're compassionate, pretty much. Even dealing with them on the phone when you're refilling a prescription they wanna make sure if you have questions for the pharmacist. They definitely do provide support. And if you have a question, or if you have a need, you certainly could ask it. I've not done that...

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Subtheme 3: Knowledge as limiting and liberating.

Education pertaining to MS may be adaptive or maladaptive, depending upon the amount and relevance. Participants reported the process of acquiring knowledge about MS and the resulting lifestyle implications to be ambiguous. One participant and their family encountered distress while acquiring information after the initial diagnosis:

Because, in the beginning, when I was first diagnosed... my wife, just freaked out, literally freaked out. Then of course she started reading the Internet, and when you read the Internet it gives you the worse case scenario on everything and ya know, I was gonna go blind, I wasn't gonna be walking, I wasn't gonna be doing this, ya know. and then we have friends who are nurses that are like "uh-stop reading the Internet, okay, just don't go out there because you are reading the wrong stuff."... you hear "plaque on brain," on nerves and your brain, and "what, what, what, what?" and you do, you read that Internet at home... you drive yourself crazy because you know there's so much information out there and you can't...you just can't absorb it all, just look at it with a clear mind because you are distraught, and your spouse has this got this disease and oh my god, could this happen, this happen, this happen, but yeah, if there were services out there I think that would be very beneficial for families. Absolutely.

Participants expressed fear and anxiety of incorrect or extreme information acquired through informal resources, such as the Internet, or information available from formal sources to be inapplicable. When participants gained appropriate information it was relieving and comforting. However, the process to gaining appropriate information was self-directed, one

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participant described difficulty despite being directed toward an institute:

Because at the Mellen center they had that little library at the time... And, I remember going in there and just pulling pamphlets... some of them weren't helpful and some were...some were geared towards children, some were geared towards spouses, and some were geared towards caregivers. But we were never really directed in that.

Subtheme 4: Need for further support.

Further formal and informal supports are necessary, particularly education pertaining to MS after an initial diagnosis. Although participants acknowledged they did not feel a need for support currently, direction and information would have been helpful initially after their diagnosis. Particularly at the familial-level, participants recommended further information regarding MS to alleviate fear and to understand the process.

One participant described the need for further support for those diagnosed such as his:

nieces that are...you know...by marriage...that do have the disease that are much younger than me and whose functionality has decreased because of the disease. So... and...you would hope that for them, that there would be more programs, public and private, for them to take advantage of because, especially when they're new mothers and that's got to be scary being in their twenties and having a huge change in your life. You know, what kind of support are you going to be looking for?

Another participant described a specific service needed:

Like a facilitator to facilitate conversation in the family, and and, uh, point the conversation in the right direction like you said. And steer away from the scary stuff and concentrate on the positive.

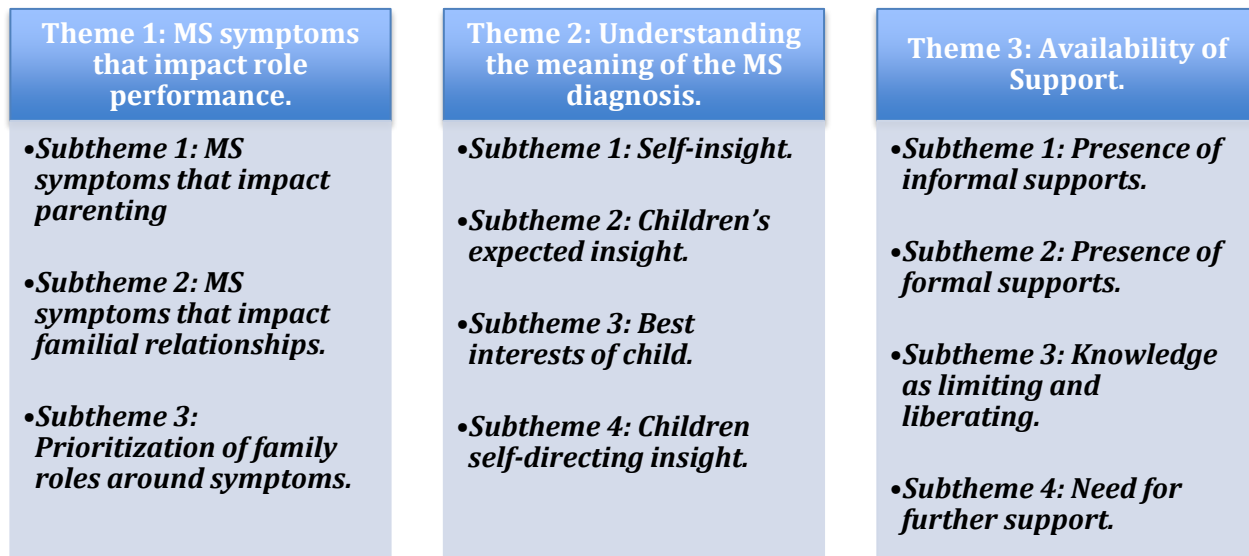
Other Findings of Interest

Refer to the “Results” section for all findings.

Summary

Data analysis of the focus group involved training, transcription, coding, independent and collective researcher review, member checking, and composition of a codebook. The results of such analysis resulted in the development of three overarching themes: Theme 1 MS symptoms that impact role performance; theme 2 understanding the meaning of the MS diagnosis; and, theme 3 availability of support. Based on the prevalence and collective participant agreement of supporting quotations, subthemes for each overarching theme were also developed. Subthemes for theme 1 entailed MS symptoms that impact parenting; MS symptoms that impact familial relationships; and, prioritization of family roles around symptoms. Subthemes for theme 2 included self-insight; children’s expected insight; best interests of child; and, children self-directing insight. Subthemes of theme 3 included presence of informal supports; presence of formal supports; knowledge as limiting and liberating; and, need for further support. Role checklist. Comprehensively, the themes, subthemes, and role checklist illuminate the lived experience of parents with MS, the impact upon perceived role performance, and implications for families with adolescents. The implications will be further explored in Chapter 5, providing discussion of the results and study conclusions.

Figure 1: Themes



Chapter 5

Discussion and Conclusions

Introduction

Data collection and analysis of the focus group and Role Checklist led to further understanding of the influence of MS upon parental roles for those individuals with MS who are parenting adolescents. Specifically, the focus group led to development of three overarching themes: MS symptoms that impact role performance; understanding the meaning of the MS diagnosis; and, availability of support. Percentages and proportions of engagement and value for roles were calculated based on the Role Checklist. Findings suggested that although the participants indicated valuing the roles in which they currently engage, a discrepancy was discovered regarding a reported high level of importance, yet a lack of current engagement in hobbies and wider groups. This chapter will entail a discussion of the findings, apply the results to the practice of OT, identify and address limitations of the study, and provide suggestions for future research concerning MS.

Discussion of Findings

The researchers initially posed a primary research question and a secondary research question. The primary research question stated: How do parents perceive familial role changes resulting from MS to impact coping of their adolescent children? This question was addressed throughout the focus group; participants reported a “minimal” impact of role change upon adolescent coping. Although the impact was indicated as minimal, based on themes developed from the focus group discussion and the Role Checklist it seems that the impact of role change on coping may be greater than the participants’ awareness. The secondary research question asked: How can occupational therapy assist parents with MS in facilitating positive coping

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techniques in their adolescent children? While the need for further supportive services was addressed by participants, occupational therapy specifically was not acknowledged. However, assessing the needs described by participants, occupational therapy would be a relevant service. Participants particularly identified individuals recently diagnosed with MS and those with acute cases as requiring more services. Further, participants stated a need for a professional to facilitate conversations concerning the diagnosis and implications of MS at the family-level.

Theme 1: MS symptoms that impact role performance.

While participants stated symptoms as having a minimum impact upon roles, and maintained this belief throughout the focus group, discussions suggested an impact of which participants may not be aware. As evident in the first theme, participants reported fatigue, peripheral neuropathy, lack of coordination, and feeling of a “fog” as limiting to participation in familial occupations. This distancing participants experienced indicates the subtle implications of MS; while such physical symptoms are overtly related to MS, other, more subtle familial impacts exist. For example, participants discussed situations in which they felt irritable as a result of the fatigue, and conflicts consequently developed. Previous research has recognized occupational shifts and role changes occurring due to acquired disabilities, as shown by Farber (2000), Finlay (2003), and Lexell et al. (2011).

Despite participants’ awareness of such subtle implications, they were unaware of the larger connections to roles and coping. For instance, while participants reported an overall “minimal” impact of MS upon adolescent coping and roles, participants conversely discussed specific roles that had changed. One participant explained how the familial morning routine became the responsibility of her children when she experienced fatigue, stating it to be a “major role change” for her daughter. Although the specific role change was acknowledged, an

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awareness of the impact on overall coping and roles was not expressed. These issues resulting from performance capacity deficits not only create communication barriers between participants and their adolescents, but also further limit insight into the parent-child relationship regarding actual coping and roles. The impact of MS symptoms upon roles and lifestyle was evidenced in Cahill et al. (2010) in which participants reported adapting and developing interests and roles in accordance with performance capacities. While participants in the current research study stated the effects of changes in familial occupations, specifically withdrawal, as most impactful to themselves, clear communication regarding the impact upon adolescents has not been established. Thus, the participants cannot truly know if the adolescents perceive the distancing and role changes to be “minimal”.

In order to maintain engagement in roles within their performance capacity limitations, prioritization of roles occurred. According to the Role Checklist, although participants do not currently engage in hobbies and doing things with a wider group, these roles were rated as valued. This indicates that there is a discrepancy between what the participants want to do and can do, demonstrating prioritization of engagement in occupation. Within the focus group, participants acknowledged leisure pursuits and instrumental activities of daily living (IADLs), such as home management and managing community mobility as part of parental roles. However these roles were prioritized to be less important to other familial roles. While the female participant did acknowledge a tangible role change for her children, the other participants indicated role changes as more significant to spouses. This may be due to the previously existing roles of participants. The gender of the two participants may impact their primary roles: The female traditionally has more family-oriented roles than the male. Thus, perhaps the female participant's role change more directly affected her children because her roles more closely

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center around her children. Regardless of the role assumption of her spouse, the change ultimately more directly impacts her children. Based on this finding, the researchers speculate that the impact of role change would be far greater among single parent households where the parent is primarily responsible for parenting roles.

Theme 2: Understanding the meaning of the MS diagnosis.

Discussion within the focus group revealed the process in which participants and their families gained insight into the diagnosis of MS and the implications for their lifestyles. This process affected their perceptions of MS, roles, and ability to cope. Understanding started at the personal level for participants and they accordingly assumed their children to have the same insight. This personal understanding of the reality of MS has enabled participants to cope with the impact, and has thus contributed to their adolescents' coping. These findings are supported in the literature, Bogosian et al. (2010) determined through a systematic review the psychosocial functioning of children and adolescents to be affected by the state of the parent with MS. Specifically, when parents with MS experienced increased symptoms and depression the social relationships and psychological well-being of their children was impacted. Another factor that may impact the level of coping of the adolescents is the level of knowledge and awareness of the child. One participant stated that he had never discussed the diagnosis with his daughter, while the other two participants reported having acknowledged the diagnosis with their children but not frequently discussing the implications. Limited communication regarding the diagnosis and its impact upon familial roles may influence the coping of adolescents; there may be discrepancies between what the parents assume the adolescents understand and what they actually understand.

Participants explained limited communication with their adolescents as an effort to protect the best interests of their children, participants wanted to avoid undue stress and worry.

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Although the participants were well-intentioned with limiting the information provided to their children, this may be maladaptive. Limited understanding on the part of the adolescents may also restrict their ability to adapt to the role changes. Although the information the adolescents received from their parents was limited, participants reported the adolescents as seeking out their own information regarding MS. Perhaps the participants perceived the adolescents to have “minimal” reactions and adaptive coping because they did not ask questions of them, but initiated acquiring further information from other sources. Conversely, this may actually be a sign of maladaptive coping; perhaps the adolescents use self-directed learning as a means to cope. Although the participants stated “minimal” impact of MS upon adolescent coping, and perceived their children to have an understanding of the condition and implications, Paliokosta et al. (2009) demonstrated the importance of purposefully informing children about MS. Further, Pedersen and Revenson (2005) found adaptive family coping to coincide with communication, family identity, and role sharing. This may indicate that there is a need for increased communication between parents with MS and their children, and also a need for professionals to help facilitate this communication.

Theme 3: Availability of support.

To help facilitate coping participants discussed use of informal supports for emotional support and to help fulfill parenting roles. Informal supports included: family members, friends, neighbors, and religious faith. Such supports were naturally present, such as family and friends, or initiated by those providing the support. Informal supports provided a sense of reassurance that if help was needed, a resource would be available. Use of formal support was less common, participants were private about their conditions, and also felt that the available supports were not appropriate for their level of functioning. However, participants may also be unaware of the

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potential benefits of formal supports and the availability for people in remission of symptoms or with a mild case. Further, participants may be uninformed regarding how to access relevant supports. The researchers believe that formal supports may help facilitate more positive coping for parents and adolescents. Within the focus group participants discussed the power of knowledge to be limiting or liberating. Inapplicable information regarding MS induced unnecessary worry for participants and their families. However, information specific to the participants' individual symptoms was found to provide relief and appropriate insight into the prognosis of their diagnosis of MS.

Participants' input regarding the availability of support speaks to the secondary research question: How can occupational therapy assist parents with MS in facilitating positive coping techniques in their adolescent children? While participants overtly stated a need for further supports, they did not discuss occupational therapy specifically, nor did the researchers reference occupational therapy as an additional support or service. The researchers were interested in the participants awareness of available services. One participant expressed a need for a professional to facilitate conversations with families concerning the implications of parental MS upon family roles. Although not stated, this would be an optimal position for an occupational therapist to educate families. This question will be further addressed in the "Application to OT Practice" section.

Application to OT Practice/Administration/Education/Theory

Current occupational therapy treatment for individuals with MS includes the following: education regarding energy conservation, avoidance of over-exertion, compensatory techniques, adaptive equipment for activities of daily living, and building activity tolerance. (Forwell, Copperman, & Hugos, 2008; Compston & Coles, 2008; National Institute of

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Neurological Disorders and Stroke, 2011). Therapeutic services can be supplementary or alternative for treatment of MS. While such interventions address the performance capacity deficits and teach compensatory techniques, there is a lack of interventions to address coping at the family-level. Coping and psychosocial issues are included within the occupational therapy practice framework. Specifically, occupational therapists are qualified to address familial coping within the functioning of emotional regulation and social performance skills, with outcomes focused on role competence and participation (American Occupational Therapy Association, 2008).

Administration/education.

In order to create programs appropriate for families of parents with MS, physicians must first understand the role of occupational therapy within this population. With increased awareness individuals may be referred to such services. For example, participants in the study referenced The Mellen Center for Multiple Sclerosis, part of the Cleveland Clinic, as a resource to which they were directed upon being diagnosed. Occupational therapists are employed at the Mellen Center, however none of the participants were referred for occupational therapy services.

Upon reviewing the Mellen Center's description of occupational therapy services provided, the scope includes a biomechanical approach to interventions designed to remediate and compensate for underlying strength and range of motion needed for ADLs, such as: dressing, eating, toileting, and bathing (Cleveland Clinic, 2012). While this may be an appropriate approach for individuals experiencing an exacerbation or with a more acute type of MS, this excludes individuals with less acute types. Individuals functioning similar to the participants in this study may exhibit more psychosocial difficulties or role changes requiring skilled intervention. Currently, psychological counseling services are available for individuals receiving

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treatment for MS through the Mellen Center (Cleveland Clinic, 2012). However, the treatment is focused on the individual and the services are mainly initiated through patient request.

While individuals with MS are currently referred to occupational therapy and treated for physical symptoms, this indicates a deficit not only in the referrals to occupational therapy, but also in the approach of occupational therapy being provided. Such change could begin at the level of occupational therapists currently working within the medical model. According to Mesa, Anderson, Askey-Jones, Gray, and Silber (2012) occupational therapy has a relevant role in addressing mental health among individuals with MS, suggesting assessment of engagement in social roles and quality of life; changes in emotional, cognitive, and social well-being; levels of fatigue; and, difficulty with adjustment. Further Mesa et al. (2012) discussed use of the Canadian Occupational Performance Measure and Hospital Anxiety and Depression Scale to determine client quality of life and engagement in occupation. Recommended interventions included a focus on client and family education regarding the prognosis, course of the condition, interventions, and available community services.

Practice.

A study by Dennison, Yardly, Devereux, and Moss-Morris (2011) investigated the adjustment process of individuals recently diagnosed with MS and found that participants' perception of control and acceptance of MS was facilitated by positive information. The findings of Dennison et al. (2011) resonated with the focus group themes concerning knowledge as liberating. Furthermore, Dennison et al. (2011) portrayed adjustment as a transient process requiring continued adjustment as the condition progresses.

Dennison et al. (2011) described the focus of participants to include domination of either a wellness or illness perspective, stating that participants maintained the wellness

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perception in preference to the illness perception. Within this current research project, this may explain to the participants' response of "minimal" impact upon their children, the wellness perspective may not include an awareness of implications of MS upon role change. Also, Dennison et al. (2011) validated the initial and continued need for individuals with MS to receive support to facilitate coping. Additionally, among individuals with early stage, mild MS, results from Dennison et al. (2011) indicated the condition to be perceived as stigmatizing, with a general sense of fear and resistance to information and equipment regarding limitations. The fear of the stigma related to MS was reflected in the current research study in that participants discussed reluctance in making their diagnosis known to others for fear of the stigma associated with more acute subtypes of MS. For example, one participant stated that because his symptoms are not overt many people are not aware that he has MS. However, once other people do learn of his diagnosis, they interact with him differently than before. Thus, the professionals providing services and education must be aware of the audience's stage of acceptance; the individual with MS may not tolerate information about the further stages and the service would then not be therapeutic.

Falk-Kessler, Kalina, and Miller (2012) conducted a quasi-experimental pilot study to assess the effectiveness of a multidisciplinary approach, with an emphasis on occupational therapy, in fostering resilience among individuals with MS. Resilience, according to Falk-Kessler et al. (2012) is one's ability to cope with stressful events in a positive and adaptive manner. A stressful event may encompass the acquisition of a chronic condition, such as multiple sclerosis. The tool, the Resilience Scale, is used to measure resilience after an adverse event, and it was administered to participants before and after the multidisciplinary interventions. The multidisciplinary team included neurology, occupational therapy, physical therapy, nursing,

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social work, and psychology. Participation was optional, and scheduling conflicts, lack of transportation, and reluctance contributed to non-engagement in occupational therapy.

Occupational therapy intervention specifically included: community reintegration and socialization, engagement in roles and routines, positive coping techniques, education, and management of symptoms. The findings revealed occupational therapy to be a vital aspect of the multidisciplinary team. Specifically, participants that received occupational therapy services significantly increased in post-intervention resilience scores, as compared to participants that received all other multidisciplinary services except occupational therapy. In relation to the current research study, the work of Falk-Kessler et al. (2012) supports the researchers' conclusion of a need for further involvement of occupational therapy to address coping in the initial and ongoing treatment of individuals with MS and their families.

To examine the use of intervention beyond just the individual with MS, the researchers reviewed the findings of Coles and colleagues. Coles et al. (2007) discussed a psychosocial intervention program for adolescents of parents with MS. The intervention included education regarding MS, adaptive coping and encouragement of social support. The intervention demonstrated statistically significant decreases in distress, stress, caregiving impact, and limitations in activity, supplemented by an increased social support and knowledge of MS for the adolescents. Coles et al. (2007) completed the study in the context of a six-day camp for children between 9-14 years of age. Although the results propose an additional avenue of service for occupational therapy, it also emphasizes the need for development of alternative resources, as the camp setting is not conducive to the lifestyle of all families. The findings of Coles et al. (2007) support the researchers' conclusion that occupational therapy services could benefit the family as a whole, not just the individual with MS.

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Based on the results of our study, Dennison et al. (2011), and Falk-Kessler et al. (2012), occupational therapy needs to be involved in the multidisciplinary approach to treating MS. This study has acknowledged the need for further services for families with parents with MS, particularly to guide conversations concerning the implications of the condition. The researchers believe that such education would be a precursor to addressing role change and facilitating positive coping. Dennison et al. (2011) demonstrated the value of skilled education as a means to promote positive coping. Falk-Kessler et al. (2012) highlighted the importance of occupational therapy in fostering resilience to MS to increase engagement in daily roles. While these findings are individually valuable within occupational therapy, neither study addresses the individual in the greater context of their life roles. Further, although Coles et al. (2007) emphasized the positive impact of a psychosocial, family-oriented intervention, the setting is not conducive to generalization. Development of a multidisciplinary, family-oriented psychosocial intervention for families of parents with MS is necessary for comprehensive and quality care.

Theory.

The study results, in addition to the findings of Coles et al. (2007), Dennison et al. (2011), and Falk-Kessler et al. (2012) indicate the value of using role-oriented, holistic theories to frame the occupational therapy process. The Model of Human Occupation (MOHO) was the theoretical basis of this research project. According to Cole and Tufano (2008), the MOHO is a holistic approach to the OT process. The MOHO focuses on volition, habituation, and performance capacity, all of which are impacted by MS. The Role Checklist, part of the MOHO, was used with participants to demonstrate impact upon habituation and volition related to MS symptoms.

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The Role Checklist was used to facilitate conversation concerning performance capacity, habituation, and volition within the focus group. Use of this frame of reference was effective to assist researchers in understanding the implications of MS upon life roles, coping of parents, the indirect impact upon adolescents, and the role of OT within this population. The MOHO may be further integrated into OT practice with individuals with MS and their families to address psychosocial needs as well as role changes related to the diagnosis.

Limitations

The study presented several limitations. One limitation is that the study was only a pilot study and thus had a limited number of participants (n=3) and was a convenience sample. Due to the convenience sample, participants knew each other to varying degrees, and also knew one of the researchers. This may have affected the disclosure of participants within the focus group, although this was not expressed in the post-focus group questionnaire. Also, the focus group took place in an environment that was familiar to all participants and presented some natural distractions.

Another limitation was the limited range of symptoms with participants; they were all at similar, high levels of functioning. This caused low diversity in the responses and made role changes more difficult to identify. There was a disproportionate ratio of men to women in the research study: two males, one female. This may have impacted the types of roles discussed by participants.

Because the researchers did not thoroughly explain what was meant by key terms (roles, change, and support) as they related to the study, the terms to be interpreted differently by the participants than the researchers had anticipated. Additionally, it is possible that the researchers may have had personal biases and assumptions concerning individuals with MS. For instance,

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researchers' personal experiences with individuals with MS may have altered perceptions of the abilities and functioning of individuals with MS. Further, as occupational therapy students the researchers may understand the study's concepts differently than the participants. The concepts of roles, coping, and impact may be defined differently for the researchers. This difference in understanding may have impacted the interpretations of the data collected during the focus group.

Suggestions for Further Research/Modifications

Continuation of this current research study would require modifications to improve quality. Firstly, the researchers would recommend clarifying terms used in the focus group questions for participant understanding. Also, the accessible version of the Role Checklist contains a space for participants' name; this should be omitted for confidentiality purposes. Next, use of a pilot study in addition to a focus group would help to refine questions and procedures. Further, by conducting multiple focus groups, data saturation may be reached and multiple perspectives would be acquired to ensure data trustworthiness. Additionally, recruiting participants from diverse populations, ensuring representation of a range of ages and genders, would allow for better generalizability of results by increasing diversity in length of diagnosis, severity of symptoms, and ages of adolescents.

Based on the findings of this pilot study, the researchers suggest further investigation regarding challenges faced by parents with MS who are parenting adolescents. Specifically, there is a need for research involving the perspectives of the adolescents to further knowledge of the needs and potential interventions for this population. In order to facilitate coping with role change through occupational therapy, additional research concerning family-oriented interventions must occur.

Conclusion and Summary

In conclusion, the role changes related to MS need to further be addressed at the family-level to facilitate coping of parents and adolescents. Such findings were found through the mixed methods focus group conducted to assess the two research questions. The primary research question posed: How do parents perceive familial role changes resulting from MS to impact coping of their adolescent children? The secondary research question inquired: How can occupational therapy assist parents with MS in facilitating positive coping techniques in their adolescent children? The primary and secondary questions were answered through the findings of the Role Checklist and the focus group. Through the focus group three themes emerged: (a) MS symptoms that impact role performance, (b) understanding the meaning of the MS diagnosis, and (c) availability of supports. This current study helped better understand role changes, family coping, and the need for occupational therapy with this population.

While participants stated “minimal” impact of role changes upon adolescents, communication regarding the impact of MS was limited between participants and adolescents, thus the parental assessment of impact may be discrepant from actual impact. This study revealed the need for incorporation of occupational therapy interventions addressing family coping and the deficits related to parental MS.

Further research needs to be conducted to determine the impact of parent role changes upon adolescent functioning to assess the impact of occupation therapy interventions to facilitate coping among families of parents with MS. Occupational therapists have a role within families of parents with MS to provide education regarding the implications of performance capacity deficits upon roles and interventions to facilitate positive coping.

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Appendix A
National Multiple Sclerosis Society Checklist

**Clinical Advisory Committee
Study Review Checklist**

Has the full protocol for the study been submitted for review? Yes___ No___

Has the chapter been provided with a copy of the approval statement from the
Proper IRB? Yes _____ No _____

What is the purpose of the study? Is the intent of the study clear?

What population will be targeted? _____

What is the eligibility criteria? _____

What safety measures are in place?

How will patient confidentiality be protected?

What is the funding source?

Is a disclaimer on forms? Yes _____ No _____

Does the disclaimer encourage participants to discuss their participation with their physician?

Yes _____ No _____

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Appendix B

Inclusion/Exclusion Criteria

- Diagnosis of multiple sclerosis for at least six months
- Parenting at least one adolescent child in the home between ages of 12 and 17
- The adolescent does not need to be the biological child of the parent participating; adoptive parents, step parents, foster parents, and grandparents may be included in this proposed study
- Subtypes, stage, and exacerbation of MS will not be considered in this study
- Participants can be any age and either gender

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Appendix C Pre-Interview Survey

1. How long have you been living with a diagnosis of multiple sclerosis?
2. Please indicate the number of adolescents you are parenting in each of the following age ranges:
_____ 12-13 years old _____ 14-15 years old _____ 16-17 years old
3. How often does the adolescent(s) live with you?
4. What is your current marital status?
5. Have you ever participated in a family therapy session related to your diagnosis of multiple sclerosis?
6. Have you ever received occupational therapy services related to your diagnosis of multiple sclerosis?

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Appendix D The Role Checklist












Role Checklist

















Name:














Date:








Roles.... 	Tick when you had this role 			Tick how important this role is to you 		
	I used to do this 	I am doing this now 	I would like to do this 	Not important 	Quite important 	Very important 
1. Student 						
2. Worker 						

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Roles ... 	I used to do this 	I am doing this now 	I would like to do this 	Not important 	Quite important 	Very important 
3. Volunteer  						
4. Looking after someone 						
5. Looking after my home   						
6. Doing things with my friend(s) 						

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Roles ... 	I used to do this 	I am doing this now 	I would like to do this 	Not important 	Quite important 	Very important 
7. Doing things with my family 						
8. Doing things with my church/ mosque/ synagogue etc... 						
9. Having a hobby/hobbies 						
10. Doing things with a wider group(s) 						

Roles ... MULTIPLE SCLEROSIS A 	I used to do this 	I am doing this now 	I would like to do this 	Not important 	Quite important 	Very important 
11. Different roles...						

Summary of Role Checklist:

The most important roles to me are 	I would like to do 

Based on the Role Checklist© Copyright 1981 and revised 1984, 2006 by Frances Oakley, MS, OTR/L, FAOTA. Adapted by Kim Bagues OT (UK) and Rebecca Wilson OT (UK), with permission.

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Appendix E Focus Group Script

“Hello everyone. Our names are Kendra, Libby, and Alyssa, and we are occupational therapy students at Grand Valley State University. We would like to thank you all for volunteering to take part in this study. Your time and input are greatly appreciated. Just to reiterate, this is a study about multiple sclerosis and how it impacts parental roles and adolescent coping. Occupational therapy helps to promote independence and engagement in meaningful occupations. Specifically to this study, we are interested in how occupational therapy can help people with multiple sclerosis who are parenting adolescents. Does anyone have any further question regarding the study before we get started?”

Can we have everyone introduce themselves? Just with your first name.

Now we’d like to move on to the discussion portion of the study.

1. Based on the Role Checklist that you all completed, what are some of your roles that have been most significantly impacted by your diagnosis of multiple sclerosis?
2. On a scale of one to ten, one being no change and ten being a significant change, please indicate the extent your parenting roles have changed since your diagnosis of multiple sclerosis?
Probe: Can you tell us in what ways have your roles changed?
3. Looking at the Role Checklist, think about the roles that are the most important to you. Of these “most important” roles rank order the changes that have felt the most significant for you. (Present cards from the Role Checklist and blank cards as well)
4. In what ways do you think your changes in parenting roles have impacted your adolescent?
5. Can you tell us about a situation in which your adolescent was affected by a reaction you had to your role change?
6. In what ways have your adolescents’ roles changed since your diagnosis of multiple sclerosis?
Probe: In what ways have you addressed your adolescents’ change in roles?
7. Can you tell us of a reaction your adolescent had in response to a role change?
8. Please describe any supports your family has received related to your diagnosis.

Lastly,

9. Please describe any supports that you feel would be beneficial for your family.
- For the purpose of the study in general, is there anything else that anyone would like to share?
Now we would like you take out the post-interview questionnaire from your packets. We are going to step out of the room and allow you all to fill out the survey. When the last person finishes, could he or she please come let us know that everyone has finished.
We’d like to thank you all again for participating in our study. If you have any questions or concerns, please feel free to contact us using the information provided.”

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Appendix F Post-Interview Questionnaire

1. Did you withhold information?
2. How comfortable did you feel sharing answers (please circle): uncomfortable, somewhat uncomfortable, indifferent, somewhat comfortable, or comfortable
3. How honest were you in sharing answers (please circle): not truthful at all, truthful to some extent, mostly truthful

Questions adapted from: Hyde, A., Howlett, E., Brady, D., & Drennan, J. (2005). The focus group method: Insights from focus group interviews on sexual health with adolescents. *Science and Medicine, 61*, 2588-2599. doi: 10.1016/j.socscimed.2005.04.040

Appendix G

Informed Consent Form

The Effects of Multiple Sclerosis on Perceived Parenting Roles

Principle Investigators: Alyssa Coundourides, Kendra Host, and Elizabeth Pollock

Faculty Chair: Cynthia Grapczynski, EdD, OTRL

We are inviting you to participate in our research study titled, “The Effects of Multiple Sclerosis on Perceived Parenting Roles and Adolescent Coping.” This study will include only those individuals who voluntarily choose to take part in it.

WHAT IS THE PURPOSE OF THE STUDY?

Through this research we are hoping to further understand how people with multiple sclerosis parenting adolescents help their children adjust to changes caused by the disability. Also, this research study will look at the role of occupational therapy in helping families of parents with multiple sclerosis.

WHO CAN PARTICIPATE?

You have been asked to participate because you meet the criteria for our study, a diagnosis of multiple sclerosis for at least six months and are parenting an adolescent child between the ages of 12-17. Marital status, gender, and age will not change participation in the study. Subtypes, stage, and symptoms of multiple sclerosis will not be considered for participation.

WHAT WILL HAPPEN IN THIS STUDY?

The study will occur in a neutral location. Participants will complete a pre-survey questionnaire and checklist before coming, this will take about 20 minutes. Participants will take place in a focus group for 90 minutes and a post-interview questionnaire for 10 minutes. Participants will only experience expenses related to transportation needs.

WHAT ARE THE RISKS OF THIS STUDY?

Although not intended, there may be some unforeseen risks. Possible risks with this study may be: (1) psychological distress due to a potentially sensitive topics, and (2) a breach of confidentiality by other participants. There are no other risks beyond those of everyday functioning.

WHAT ARE THE BENEFITS TO THE STUDY?

There are no benefits to participants, however the study may contribute to the education of the researchers.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

Your participation in this research study is completely voluntary. You do not have to participate. You may quit at any time without any penalty to you.

WHAT ABOUT CONFIDENTIALITY?

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Your name will not be given to anyone other than the research team. All the information collected from you or about you will be kept confidential to the fullest extent allowed by law. In very rare circumstances specially authorized university or government officials may be given access to our research records for purposes of protecting your rights and welfare.

WHO DO I CALL IF I HAVE QUESTIONS OR CONCERNS?

If you wish to learn about the results of this research study you may request that information by contacting any of the Masters-level research students: Alyssa Coundourides at Coundoua@mail.gvsu.edu, Kendra Host at Hostke@mail.gvsu.edu, and Elizabeth Pollock at Pollocel@mail.gvsu.edu. You may also contact GVSU's Human Research Review Committee at hrrc@gvsu.edu or by phone 616-331-3197.

WILL I BE REIMBURSED FOR MY TIME?

There will be no payment for participation in the research, although one participant will be selected at random to receive a \$100 Visa Card. The gift card will be purchased through the private funds of the three student researchers. There will be only one gift card for participants across all focus groups. The researchers cannot predict the total number of focus groups that will be held because it depends on participant response. After completion of the study the recipient will be selected from among all of the participants throughout the study. After selection, the gift card will be mailed to the recipient.

AGREEMENT TO PARTICIPATE

By signing this consent form below you are stating the following:

- The details of this research study have been explained to me including what I am being asked to do and the anticipated risks and benefits;
- I have had an opportunity to have my questions answered;
- I am voluntarily agreeing to participate in the research as described on this form;
- I may ask more questions or quit participating at any time without penalty.

_____ (Initial here) I have been given a copy of this document for my records.

Print Name: _____

Sign Name in ink: _____

Date Signed: _____

If you have any questions about this study you may contact the lead researcher as follows:

Kendra Host PHONE: (616) 648-8579 E-MAIL: Hostke@mail.gvsu.edu

If you have any questions about your rights as a research participant, please contact the

Research Protections Office at Grand Valley State University, Grand Rapids, MI

Phone: 616-331-3197

e-mail: HRRC@GVSU.EDU

This research protocol has been approved by the Human Research Review Committee at Grand Valley State University. File No. 12-194-H Expiration: July 30, 2013.

MULTIPLE SCLEROSIS AND PARENTING

Appendix H E-mail to Participants

Dear participant,

We would like to thank you for your willingness to participate in our research study. This e-mail serves to remind you of the study time and date: Month, day, year occurring at _____. We request that you print off and complete the following forms located in the email attachment prior to arrival at the study: pre-interview survey, the Role Checklist, and informed consent form. The **pre-interview survey** serves to verify participant eligibility for the study. The **Role Checklist** contains ten different role categories. For each category, you must check when you had the role and how important the role is to you. On the final page, please list the roles that were found to be most important to you, as well the roles that you would like to do. The **informed consent form** ensures you as a participant are aware of your role in the proposed study and voluntarily assent to participate.

We look forward to meeting you at the focus group. Once again, thank you for your time and efforts toward this research.

Sincerely,

Alyssa Coundourides, Kendra Host, and Elizabeth Rexroat

MULTIPLE SCLEROSIS AND PARENTING

Appendix I Researcher Contact Information

Alyssa Coundourides
(440) 554-7477
Coundoua@mail.gvsu.edu

Kendra Host
(616) 648-8579
Hostke@mail.gvsu.edu

Elizabeth Pollock
(231) 519-0017
Pollocel@mail.gvsu.edu

We would like to sincerely thank you for your participation in our study, your insight, time, and effort are greatly appreciated.

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Appendix J Advertisement

The Effects of Multiple Sclerosis on Perceived Parenting Roles Grand Valley State University

We are looking for volunteers with multiple sclerosis to participate in a focus group regarding parenting and multiple sclerosis. Participants will be entered into a drawing for \$100 Visa gift card. We are doing this study as a requirement to graduate from our occupational therapy program at Grand Valley State University.

To be eligible you must meet the following criteria:

- Diagnosis of multiple sclerosis for at least six months.
- Parenting at least one adolescent child in the home between ages of 12 and 17.
- The adolescent does not need to be the biological child of the parent participating; adoptive parents, stepparents, foster parents, and grandparents may be included in the proposed study.
- Subtypes, stage, and exacerbation of MS will not be considered in this study.
- Participants can be any age and either gender.

Location and time will be determined dependent on participant responses

If you are interested in this study and want to enroll, please contact Alyssa Coundourides (440-554-7477), Kendra Host (616-648-8579), or Elizabeth Pollock (231-519-0017).

Thank you for your consideration,

Alyssa Coundourides, OTS

Kendra Host, OTS

Elizabeth Pollock, OTS

Masters Program in Occupational Therapy

Grand Valley State University

Appendix K
Codebook

Theme 1: MS symptoms that impact role performance

Subtheme 1: MS symptoms that impact parenting

Subtheme 2: MS symptoms that impact familial relationships

Subtheme 3: Prioritization of family roles around symptoms

Theme 2: Understanding the meaning of the MS diagnosis

Subtheme 1: Self-insight

Subtheme 2: Children's expected insight

Subtheme 3: Best interest of child

Subtheme 4: Children self-directing insight

Theme 3: Availability of Support

Subtheme 1: Presence of informal supports

Subtheme 2: Presence of formal supports

Subtheme 3: Knowledge as limiting and liberating

Subtheme 4: Need for further support