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Activity Strategy Workbook for Mothers Experiencing Multiple Sclerosis

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ACTIVITY STRATEGY WORKBOOK
FOR MOTHERS EXPERIENCING MULTIPLE SCLEROSIS

By

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Submitted to the Occupational Therapy Department

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In partial fulfillment of the requirements

For the degree of

Master's of Occupational Therapy



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This Scholarly Project Paper, submitted by Skylar Davis and Elizabeth Meyer in partial fulfillment of the requirement for the Degree of Master's of Occupational Therapy from the University of North Dakota, has been read by the Faculty Advisor under whom the work has been done and is hereby approved.

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May 4, 2010
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Title: Activity Strategy Workbook for Mothers Experiencing Multiple Sclerosis

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Degree: Master's of Occupational Therapy

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The purpose of this scholarly project was to create a resource for mothers diagnosed with multiple sclerosis (MS) to promote optimal success and independence in the motherhood role. The resulting workbook targets the mothering activities of individuals who have been newly diagnosed with MS and are raising young, pre-school aged children. The product provides education and guidance to optimize the mother's ability to care for herself and her child or children.

A comprehensive literature review was conducted to examine current best practice and treatment guidelines for MS, the influence of MS on both the parent and child, and also common symptoms and their effects on occupational functioning. The literature revealed a common underuse of energy promotion during the treatment of MS and an overemphasis on energy conservation strategies. Research also demonstrated a correlation between the mother's symptom level and her ability to provide care and nurturing to her child.

Specific focus was therefore placed on adapting mothering activities to balance energy conservation and energy promotion techniques according to fatigue fluctuations and symptom exacerbation. Emphasis was given to providing mothers with the opportunity to gain insight into the effectiveness of strategies used to carry out self-care, household management, and childcare activities. Guided by the Occupational Adaptation (OA) Model, the workbook promotes occupational mastery and skill generalization and is intended to be used as a supplement to occupational therapy (OT) services.

CHAPTER I

INTRODUCTION

Multiple sclerosis is a neurological disorder that affects 400,000 Americans, with 200 new diagnoses each year. Of those diagnosed, women are effected 2-3 times more than men. This has resulted in a large amount of mothers with MS who are raising children. Symptoms can vary with each individual and their disease process as there are several different forms and courses that this disease may take. A diagnosis of Multiple Sclerosis (MS) will influence family life and the ability to fulfill the motherhood role.

The relationships between MS course progression, type of symptoms experienced, and perceived severity of symptoms are influential factors in determining not only one's physical well being but mental and social health as well. Symptoms are variable among this population but can be characterized by physical state, such as muscle weakness, tremor, and spasticity, and also by affective state, like emotional or mood disturbances and pain (Snook & Motl, 2008). Fatigue is identified as the most prominent and debilitating symptom of MS with 96% of the population experiencing this symptom (Hemmet, Holmes, Barnes, & Russel, 2004).

Fatigue is often addressed through energy conservation techniques, therefore uniting engagement in occupation and influencing the perceptions of mothers in regard to their ability to participate in high energy activities. Individuals with MS perceive less physical ability than actual muscle fatigue with symptom exacerbation (Dettmers,

Sulzmann, Ruchay-Plossl, Gutler, & Vieten, 2009). This demonstrates that attention to a balance of energy conservation and energy promotion techniques may be indicated.

Multiple sclerosis symptoms also impact the mother's ability to provide care and nurture to her child or children. Mothers with MS are perceived by their children as showing a decreased amount of affection during periods of increased symptomology (Deatrick, Brennan, & Cameron, 1998). Mothers also worry about the need for their children to become their caregivers which may deprive them of childhood experiences (Prunty, Sharpe, Butow, & Fulcher, 2008).

The subsequent chapters provide an overview of the background research and product development. Chapter two includes the review of literature and provides an overview of the identified problem and current research on the topic of mothering while experiencing multiple sclerosis and best practice for this population. Chapter three, methodology, includes a detailed description of how the literature review informed the creation and design of the activity strategy workbook. The guiding model is identified and the application process is also described in this section. Chapter four provides an introduction to the product of the activity strategy workbook for mothers experiencing MS while a full copy of this workbook can be found in the appendix. The project summary is located in chapter five, which consists of the project purpose and brief overview, limitations of the product, proposals of how the product could be implemented, and future recommendations for product application and improvement. A complete list of research used in the creation of this scholarly project is provided at the end.

CHAPTER II

REVIEW OF LITERATURE

Multiple Sclerosis is a disabling neurologic disorder that affects 400,000 Americans, with 200 new diagnoses each year. Of those diagnosed, women are effected 2-3 times more than men. MS occurs with the demyelination of the nerve fibers in the central nervous system which complete the brain, spinal cord, and optic nerves. Although the exact cause of MS is unknown, it is generally accepted as an autoimmune disorder. As the myelin of the nerve fibers is affected, sclerotic material, or scar tissue, is formed, giving the disease its name. This scar tissue interrupts and slows the neurological transmission of information. The area in which scar tissue is formed dictates symptoms experienced. With different types of diagnoses, symptoms can vary with each individual and their disease process. Although symptoms do not present uniformly, the most common symptoms are fatigue, pain, numbness, gait disturbances, bladder and bowel dysfunction, visual problems, vertigo, sexual dysfunction, spasticity, cognitive deficits, and psychosocial issues such as depression and emotional changes. (National Multiple Sclerosis Society (NMSS), 2010)

Symptoms and severity are dependent upon the course of illness experienced by the individual. There are four disease courses, each with differing manifestations of course progression: relapsing-remitting, secondary-progressive, primary-progressive, and progressive-relapsing. Most common, as experienced by 85% of individuals with MS, is

the relapsing-remitting course of MS. This is characterized by periods of relapses, flare-ups, and periods of normalcy at which point individuals can return to baseline functioning. Of those diagnosed with this course of MS, 10% will progress to secondary-progressive MS in which the disease course worsens at a more steady rate. Primary-progressive MS is experienced by approximately 10% of individuals with MS and symptoms present with slow decline of function with no distinct exacerbations. The rarest form of MS, experienced by only 5% of individuals, is the progressive-relapsing course in which chronic symptoms and exacerbations are present throughout the disease progression without periods of plateau or remission (NMSS, 2010).

The relationships between MS course progression, type of symptoms experienced, and perceived severity of symptoms are influential factors in determining not only one's physical well being but mental and social health as well. MS symptoms are variable among this population but can be characterized by physical state, such as muscle weakness, tremor, and spasticity, and also by affective state, like emotional or mood disturbances and pain (Snook & Motl, 2008). The negative effects of these symptoms may be further aggravated by treatable yet persistent medical conditions that occur due to medication side effects or physical inactivity, for instance depression, thyroid disease, or anemia (NMSS, 2010).

Hemmet, Holmes, Barnes, and Russel (2004) examined the common perceptions of MS patients regarding specific symptoms and their impact on health-related quality of life. All respondents reported more than one symptom related to MS. However, fatigue was identified as the most prominent and debilitating symptom of MS with 96% of respondents reporting its presence (Hemmet et al., 2004). Of those experiencing fatigue,

88% reported the symptom to be moderate to severe in intensity. Those diagnosed with the disease often face a fatigue that is unique to MS: lassitude. Lassitude can be characterized as fatigue that occurs daily, worsens as the day goes on, and is often made worse by the presence of heat (NMSS, 2010). Fatigue is categorized to signify either a lack of physical or mental energy as both are detrimental to optimal execution of tasks (NMSS, 2010). The idea of fatigability signifies a decline in performance during functional tasks that require high levels of cognitive processing or physical capability (Andreasen, Spliid, Andersen, & Jakobsen, 2009). Fatigue is related to decreased self-esteem, poor sleep, poor quality of life, decreased symptom management, higher disability level. (Dettmers, Sulzmann, Ruchay-Plossl, Gutler, & Vieten, 2009)

The significant presence of MS related fatigue has been found to be a negative influence on several behavioral, emotional, and physical aspects of the individual. Fragoso, Da Silva, and Finkelsztejn (2009) explored the correlation between fatigue due to MS and its effects on the individual's self-esteem. When accounting for and minimizing other variables that could possibly affect one's self-esteem, study participants reported levels of decreased self-esteem secondary to the experience of fatigue. Similar findings that substantiate the relationship between depression and decreased quality of life were uncovered by Glanz et al. (2009). These discoveries highlight the negative impact of fatigue in the psychosocial aspects of the symptomology of MS. Additionally, there is a correlation between overall quality of life in MS patients as impacted by disability, fatigue, and quality of sleep. The major influence of the disease severity, as characterized by fatigue and decreased quality of sleep, demonstrated an inverse effect on quality of physical and mental health (Ghaem & Haghighi, 2008).

Fatigue has also been found to be a detrimental force on cognitive symptoms. Cognitive deficits can occur in early MS which include problems in information processing, verbal and spatial memory, and verbal fluency (Andreasen, Spliid, Andersen, & Jakobsen, 2009). Andreasen et al. (2009) uncovered a relationship between fatigue and discrete levels of decreased processing speed in MS patients who experience mild to moderate symptoms. Of those who experience these cognitive symptoms, deficits in verbal fluency and ability to generate and retrieve words were related to lower health related quality of life (Glanz et al., 2009). Furthermore, lower deficits in word production were also correlated to overall better mental health including fewer depressive symptoms as depression has a negative influence on verbal fluency (Henry & Beatty, 2006).

Poor role performance is a consequence of the presence of these negative symptoms as compounded by the various environmental and behavioral factors experienced by the individual. These symptoms operate as sources of information on the individual's level self efficacy which can be described as an individual's sense of personal ability to attain desired goals (Webster's Dictionary, 2010). Overall symptoms, including motor symptoms, correlate with the level of self efficacy. For example, physical symptoms such as weakness and balance problems may negatively influence engagement in physical activity as the individual may perceive these symptoms as inhibiting participation in activity; with decreased self efficacy there is a reduction of physical activity (Motl & Snook, 2008). However, there are also behavioral variables that inhibit activity level. A sense of not being able to control one's symptoms may lead to ineffective management of both physiological and affect symptoms as lower levels of self efficacy decrease likelihood of the individual to seek out and utilize coping strategies

(Motl & Snook, 2008).

Bandura's theory of reciprocal determinism has been applied to self efficacy issues among ill individuals. The bi-directional relationship outlined by this theory demonstrates that the separate factors of behavior, the individual, and the environment can be manipulated to elicit change in the desired areas in order to produce an overall change in behavior. Self monitoring of daily symptoms along with physical activity and its effects on these symptoms can lead to a higher sense of control of disease process, and therefore a higher sense of self efficacy. With the perception of increased ability to perform necessary tasks, an individual is more likely to engage in interventions that allow engagement in the everyday occupations that are required to fulfill life roles such as mothering (Motl, Snook, McAuley, & Gliottoni, 2009).

Mothers also have the advantage in their ability to follow through with physical exercise recommendations as they have decreased disability level with higher energy and greater mobility. They have also less experience with "learned non-use," and their role responsibility requires a higher energy level and motivation level of them. Parents especially need more energy due to their higher energy lifestyles; when the dominating symptom of fatigue impacts this lifestyle, it disrupts the ability to parent as is required for best child care. Combating fatigue should be the central focus MS intervention as doing so will inversely benefit overall quality of life for MS patients. A comprehensive evaluation can help identify the factors contributing to fatigue and make it possible to develop an approach suited to the individual's needs. In creating holistic treatment, it is importance to consider the diverse variables and correlations that affect the disease disorder and its impact on quality of life as specific to the role of mother.

The variability of the MS disease course makes predicting future ability to complete tasks difficult for individuals who look to future life planning. Many factors influence the decision to become a parent when experiencing Multiple Sclerosis. Women have the concern of pregnancy's effect on symptoms experienced and possible apprehension of pregnancy related exacerbations and required time to recover from the birthing process.

Prunty, Sharpe, Butow, and Fulcher (2008) found that mothers considered concerns about health and well being, the well-being of the child, their ability to cope with parenting, societal attitudes, the timing and pressure of the decision, and the imagined experience of being a parent before pregnancy. In regard to their own health and well being, mothers had concern for the discontinuation of medications while breastfeeding. They felt as though the discontinuation of medication would adversely affect the management of symptom relapses. Acknowledging the continuous responsibility for meeting the child's needs, mothers questioned their ability to do so with the chronic symptom of fatigue.

The age of onset and the age of family planning often coincide. These simultaneous events make family planning even more pressured. A sense of needing to make the right decision is felt while still having uncertainties regarding the MS process. Overall, mothers may experience fears that their unknown symptoms will inhibit their ability to provide proper care for the child through necessary physical, emotional, or financial means. Women expressed fear of passing on MS to their child or children despite the small increase from 0-2% chance without a parent with MS to a 3-5% chance with a parent diagnosed with MS (Twork et al, 2007; NMSS, 2010). Specifically, the

symptom of fatigue is concerning as it may adversely affect the mother's ability to consistently complete household tasks and prevent the child from engaging in dangerous or harmful situations. There is future uncertainty of ability to maintain employment with the possibility of the mother's partner needing to support both mother and child during times of relapse. In considering the long term effects of MS symptoms and degenerating nature of the disease, mothers worried about the future need for their children to become their caregivers which may deprive them of childhood experiences (Prunty, Sharpe, Butow, & Fulcher, 2008).

Mother's concern for the well being of their child as an effect of the MS gene is unsubstantiated. Research studies have found that the rates preterm labor, birth weight, head circumference, and congenital malformations have shown no higher risks in the health of a child being carried by a mother with MS than those carried by non-diseased mothers (Weinreb, 2004; Abramsky, 1994; Mueller, Zhang, & Critchlow, 2002; Dahl, Myhr, Daltveit, & Gilhus, 2008). No extreme birthing measures were indicated beyond an increased necessity for cesarean section found (Chen, Lin, & Lin, 2009). With increased knowledge mothers may make an informed decision that does not rely on exaggerated and unsubstantiated fear for the child's wellbeing. This increased understanding may relieve the uncertainties and reduce pressure of family planning.

Although abnormal detrimental effects are absent from the birthing process, there is evidence suggesting the likelihood for increased MS symptomology in the mother within three months postpartum (Confavreux, Hutchinson, Hours, Cortinovic-Tourniaire, & Moreau, 1998). It is understood that mothers with MS experience a lifestyle that is atypical to the general population. However, Crist (1992) has shown no statistical

difference in the methods of interactions between dyads of mothers and daughters in which the mother is either non-affected or diagnosed with MS. This study demonstrated that children may not experience a negative impact in their social and relational development with their mothers despite the mother's chronic illness. Although the motherhood role will likely require an adaptation when one experiences a chronic illness, it does not create a uniquely negative parent-child interaction during the execution of occupational tasks. Mothers and daughters, regardless of the presence of MS, exhibited similar and reciprocal behavioral responses during task and play activities. For instance, as mothers were more receptive, so were their daughters. Crist (1992) viewed behavioral responses to categorize into three interaction composites. Directive behavior is described as a command series; receptive behavior signified the use of praise and collaboration, while dissuasive behavior indicated negative interactions between mother and daughter with independence noted during work and play tasks. In order to generalize the data gathered from contrived interactions, mother and daughters completed self assessments to state how accurately the contrived interactions mirrored typical day to day interactions. Of the mothers with MS and their daughters, 77% independently reported daily at-home interactions as "very good" (Crist, 1992). This percent average was slightly higher to the responses of daughters without disability.

Deatrick, Brennan, and Cameron's (1998) found the perceptions of mother and child to be similar when the mother's condition was stable but significantly different during exacerbation, at which time the mother perceived that she was offering more affection than the child perceived. Mothers with younger children perceived themselves to be more affectionate than those with older children. Additional results showed that

male children felt they received less affection than their female counterparts. The relationship between fatigue, sensory symptoms, and the ability for mothers to show and perceive physical affection was also examined. Symptomology changes may explain difficulty engaging in the parental occupation of interacting and showing affection to children. Understanding these discrepancies may help mothers experiencing MS acknowledge the impact of their symptoms on the feelings and perceptions of their children. Increased understanding may drive proactive strategies to strengthen family bonds.

The interdependent nature of the family system calls for health care workers to address the needs of not only the ill parent but also those of the entire family system including partners and children (Steck, et al., 2007; Turpin, Leech, & Hackenberg, 2008). Children who live with a parent with MS are considered to be a “high-risk” population with an increased propensity towards more intense unhealthy emotions, concern for the ill parent, and greater feelings of responsibility and obligation toward household management and care of the ill parent (Yahav, Vosburgh, & Miller, 2005). These burdens may place the child at risk for developmental and emotional deficits if their focus is on the domestic role rather than engagement in age appropriate occupations (Yahav, Vosburgh, & Miller, 2005). Children may feel compelled to adopt the homemaking role and also feel as though they need to become the protector of the parent. This perception in a child with chronically ill parents leads to a sense of “false maturity” in which children feel more drawn to form relationships with adults rather than children (De Judicibus, & McCabe, 2004). In return, they have less developed friendships with peers as they often view individuals their own age as immature. This view as well as domestic

responsibility can negatively impact the child's desire and ability to form friendships resulting in a decreased feeling of social connectedness (De Judicibus & McCabe, 2004).

The anger, depression, and anxiety afflicting children of ill parents may necessitate intervention through psychological and social supports. Feelings of anger may be due to the child's inability to engage in the activities of their choosing, but also because the child adopts and internalizes the anger and frustration portrayed by the healthy parent. The stress that is to be expected from experience with chronic illness is compounded with unhealthy coping strategies which then adds an additional friction to the marriage relationship and is often internalized by the child. Children express often hiding negative emotions from parents in fear of burdening the already stressed home life and stifle or ignore the emotional response produced by the parent experiencing MS (Yahav, Vosburgh, & Miller, 2005). With unhealthy coping strategies, children may act out in ways that put additional stress on families that are already dealing with the burden of chronic illness (De Judicibus, & McCabe, 2004). Turpin, Leech, and Hackenberg (2008) discovered that children experience mixed feelings of expressing resentment towards parents and often feel guilty for having these negative feelings about their parents.

However, there are also positive aspects and benefits of growing up in this unique environment as reported through by Blackford (1999). Benefits include personal competence, hopefulness, spirituality, and an increased understanding of the meaning of occupations (Blackford, 1999). Children report pride in their ability to provide care for their ill parents in capacities that peers are unable. The care provided by the children also facilitates a greater sense of relationship between child and parent (Turpin, Leech, &

Hackenberg, 2008). Despite the possible negative influence of parental MS on a child's development, with the right resources to develop appropriate coping skills and roles, children adjust well to the situational complexities (De Judicibus & McCabe, 2004).

The occupational adaptation (OA) model provides a foundation to guide occupational therapy interventions for mothers with multiple sclerosis. This model recognizes that positive changes in one's adaptive processes will enable occupational role performance for mothers with multiple sclerosis. Adaptation is achieved through attention to the concepts of occupational readiness, occupational activity engagement, the influence of context on occupational participation, and the attainment of relative mastery as an outcome of therapeutic intervention.

Following the OA model, the readiness skills of the individual in regard to cognitive, psychosocial, and sensorimotor requirements of each activity are considered. Readiness skills and occupational activity components facilitate or inhibit the individual's ability to achieve occupational mastery during occupational involvement (Schkade & McClung, 2001). The ease in which an individual is able to complete the necessary occupations depends upon their competency in the areas of readiness. For individuals with MS, limitations in readiness skills related to energy use (sensorimotor) and depression (psychosocial readiness) are often evident. Cognitive readiness is also inhibited due to a lack of information and resources regarding mothering with MS. These areas can be addressed through occupational therapy principles that promote positive and natural interactions between children and parents for healthy family relations. Occupational therapists can assist the mother in increasing coping skills, physical ability, and knowledge regarding their medical condition and effect on lifestyle. This increased

knowledge and physical ability can minimize the anxiety producing effects of unpredictable health deterioration caused by MS. Balanced family roles provide the necessary structured, consistent, and dependable home life for children to achieve normal growth and development (Turpin, Leech, & Hackenberg, 2008).

The influence of the occupational performance context is also considered through the guidance of the OA model. Through modifications to the physical, social, or cultural context of the activity, clients are able to accomplish desired activities. Commonly, the physical context can be modified to support participation. Individuals with MS often exhibit increased symptoms when exposed to higher temperatures calling for modification of the physical environment. Occupational therapy's role is to provide energy conservation techniques that include modifications to the individual's environmental and temporal context that will promote success in occupational engagement. Techniques ease the demand of the activity through completion during a period of decreased symptoms or placing commonly used items in an easily accessed area.

An intended outcome of occupational therapy intervention is to enhance occupational engagement that has significant meaning to the individual. Occupations should produce a tangible or intangible product through engagement (Kramer, Hinojosa, & Royeen, 2003). Occupations necessary to fulfilling the role of mother have a place of significant meaning in the life of a mother and would therefore be the focus of client centered occupational therapy treatment.

Following the concepts of the OA model, each individual aspires to perform occupations masterfully and the environment in which the occupation occurs requires

masterful task completion. Clients are encouraged to identify personal and socially meaningful roles and the activities that are inherent to these roles (Kramer, Hinojosa, & Royeen, 2003). When the client takes an active role in choosing occupational areas and goals they are motivated to achieve a greater level of mastery. The responsibility of the OT is to provide specialized knowledge of interventions and best practice techniques, task and environment modifications, and assistive aids to assist in the occupational adaptation process for goal mastery (Schkade & McClung, 2001).

Mothers with MS have often chosen the role of motherhood and search for mastery in the activities required to care for their child. The symptoms and deficits in these roles must be addressed and adaptations pursued to accomplish mastery of the motherhood role. Relative mastery is accomplished as the individual evaluates his or her participation in an occupation in regard to the efficiency and effectiveness of their participation. When the individual is satisfied with his or her performance in all areas, mastery is achieved. To achieve mastery, the individual might modify readiness skills required, components of the occupation, and environmental features as needed to support occupational participation. Through the adaptation process, mothers are able to manage MS symptoms and generalize learned responses or habits of engagement to novel occupational roles. Skills learned will expand and strengthen occupational engagement in all personally meaningful roles, including the mothering role.

The concept of relative mastery is particularly appropriate for individuals with MS as persons with disabilities are often viewed with an emphasis on impairments and limitations rather than attention to strengths or personal characteristics. Treatment can be characterized by attention to the use of energy conservation, energy promotion, and social

supports. Historically, women with MS might have been dissuaded from having a child to minimize the rates of perceived “disabled” women taking on the motherhood role (Harrison & Stuifbergen, 2001). Although the energy required for mothering roles should be framed in a realistic light, the abilities necessary for successful engagement in tasks is often presented as radically insufficient in this population of women. Women with MS may be led to believe that they are unable to complete the tasks required in the motherhood role. With echoes of these concerns from the highly regarded and trusted medical community, women may also generalize this sense of inability to other desired and necessary roles and life activities enforcing learned helplessness as a condition of a general belief of self inability. Because of this reality, occupational therapists and other medical professionals are encouraged to respect the woman’s values and hopes for motherhood while providing realistic information regarding impact of the disease on activity participation.

A treatment approach commonly discussed for optimal functioning is the use of energy conservation strategies during daily activity. Energy conservation techniques are utilized as compensatory strategies in response to a deficit in a particular occupational area. The current literature substantiates the use and effectiveness of these strategies as a therapeutic intervention among the MS population (Sauter, Zebenholzer, Hisakawa, Zeitlhofer, & Vass, 2008; Matuska, Mathiowetz, & Finlayson, 2007; Holberg & Finlayson, 2007; Steultjens, Bouter, Cardol, van den Ende, & van de Nes, 2009). Energy conservation and fatigue management is often the aim of therapy as fatigue is a primary, chronic, and disabling symptom. It is important to note, however, that it is essential to maintain an appropriate balance of the use of compensatory strategies and skill building

to accommodate symptom fluctuations.

Energy conservation strategies commonly taught to individuals with MS include positive and effective communication, proper body mechanics, ergonomic principles, the importance of rest, modifications of environment, use of adaptive equipment, priority setting, activity analysis and modification, and leading a balanced life style (Matuska, Mathiowetz, & Finlayson, 2007; Sauter, et al., 2008). These techniques reduce the amount of energy expended to complete daily activities when fatigue symptoms are exacerbated. Energy conservation usually involves techniques for changing the activity or the context to minimize energy requirements.

Sauter et al. (2008) examined the longitudinal effects of a six week energy conservation course and found no significant decreases in level of fatigue. However, there were significant improvements in sleep quality, decreased depression symptoms, along with improvements in the readiness skills of cognition, and physical ability along with the learned coping skills from involvement in this fatigue management course. Through the data gathered by this study, it suggests that treatment should not focus solely on decreasing fatigue, as it is chronic. Rather complete treatment involves providing the coping strategies that increase function through the management of the effects of fatigue. Techniques can be learned to assist those experiencing MS to manage symptoms and increase functional independence. Completion of an energy conservation course was found to be helpful, not only initially following course completion, but over a lengthy seven to nine month post course time frame. An effective outpatient treatment option that has good carryover into the home setting may also decrease future hospitalizations and need for in-patient treatment.

Matuska, Mathiowetz, and Finlayson (2007) examined the frequency of energy conservation use and the perceived effectiveness of those experiencing MS after participation in an energy conservation course. By modifying energy conservation techniques to meet the client where they are at in terms of physical and cognitive abilities, their motivation level to comply with treatment was enhanced. Of the 123 participants who completed the study's six week energy conservation course, more than 70% of individuals reported using strategies learned through course participation upon discharge, with the most effective strategies being delegating tasks to others, planning the day to include a balance of rest and work, and rest during longer activities (Matuska, Mathiowetz, & Finlayson, 2007). The techniques used the least by participants included changing the time of day of an activity or using new adaptive equipment (AE) or devices. Some study participants reported that they did not implement the AE strategy as they were unsure of proper equipment and use of the equipment. Other cited reasons for not employing the strategies were related to environmental or personal (i.e. work schedules, equipment location) limitations. The need for personalized plans for adaptation, a hallmark of the occupation adaptation model, is supported by the study's results.

A similar research study by Holberg & Finlayson (2007) sought to examine the various factors that influence the initial and continued use of selected energy conservation strategies amongst participants with MS. Four themes were uncovered through semi-structured qualitative interviews: experience with the disease, sense of self, environmental factors, and value of education. Several reasons were found as to why energy conservation strategies were not used. Cognitive deficits hindered conceptualizing and problem solving to recognize a need for and appropriately

implement the use of the strategies. For example, study respondents identified inability to simplify a task due to poor problem solving skills. Variability of fatigue symptoms also hindered utilization of the technique of structuring one's day and balancing work and rest due the unknown and episodic nature of the disease, specifically the symptom of fatigue. Participants also found taking breaks to be difficult when symptoms were not as prevalent, citing "not wanting to lose train of thought" and "wanting to keep going when feeling good, as they might not be able to finish tasks later" as reasons (Holberg & Finlayson, 2007). However, scheduling breaks into long activities were used by all eight participants and states as most beneficial fatigue management technique by three of the eight participants. This article supports the need for attention to the client's status in readiness skills to support occupational participation, particularly cognitive readiness required for problem solving skills.

The demanding role of mother often does not often allow the individual to use certain energy conservation strategies such as taking breaks when fatigued or changing the time of day an activity is to be completed. This may call for a greater use of communication and delegation of responsibilities between the mother and other care providers. Psychosocial factors may influence the mother's readiness to admit a need for help or change in routine. Some may realize the need for change but may be reluctant to give up a sense of independence in caring for themselves and their child. Expectations of self along with life goals have been established by adulthood, which also may be difficult to relinquish or modify. This highlights the importance of education to external supports such as family and employers for assistance with understanding the need for delegation of tasks.

Therapeutic treatment thus far has focused on modification and adaptation of lifestyle to prevent overuse and relapse rather than regaining function for engagement in occupation. As medical professionals emphasize a threat of overuse, overexertion, and relapse, patients may be frightened into learned non-use similar to the affected limb of a CVA. To illustrate this concept, Smith, Adeney-Steel, Fulcher, & Longley (2006) found that participants' perceptions of energy required for an exercise session was significantly higher than the amount of fatigue actually experienced post exercising. Likewise, those with MS may have the perception that their motor ability fluctuates and dependent on the amount of time they spend in physical activity. These beliefs result from a misunderstanding of the different types of fatigue experienced as motor ability is often not strained to the point of fatigue through physical activity. Levels of aerobic energy and endurance were found to be constant over a three week time period suggesting that the perceived daily fluctuations do not match actual motor and occupational ability (Dettmers, Sulzmann, Ruchay-Plossl, Gutler, & Vieten, 2009). These misperceptions of decreased ability may promote unhealthy withdrawal of daily activity, specifically those that are perceived to require higher amounts of energy.

Often exercise routines are perceived to require high amounts of energy which deters mothers from engaging in such activities. This concept might be extended to all physical activity, creating a negative thought cycle that promotes one's inability to engage in occupation (Esdaile & Olson, 2003). Motherhood activities mimic those of a formal exercise program. As suggested by the occupational adaption model, mothers may be more likely to engage in activities that are enjoyable and necessary to the motherhood role than physical exercises requiring the same amount of energy for completion.

Because of the attention given to energy conservation strategies, individuals with MS may not appreciate the important role physical activity can play in restoring endurance. Consequently, the appropriate balance between energy conservation and use of physical activity in treatment is not emphasized. A 1996 study from the University of Utah was the first to clearly state the benefits of exercise for improving MS symptoms (NMSS, 2010). While this research shows that motor fatigue can be reduced through regular cardiovascular exercise it is important to note that motor fatigue is separate from the subjective feeling of overall fatigue. Therapists can encourage patients to do as much as they can without dependence on caregivers. Attention to a balanced lifestyle takes the emphasis off of “disability”, placing attention on “ability” instead.

There are significant therapeutic disadvantages that arise from providing intervention that solely emphasizes energy conservation to avoid overexertion. Motl, Snook, McAuley, & Gliottoni (2006) found that individuals with MS were involved in significantly less physical activity than the general population. As most of the general population engages in physical activity at lower levels than recommended by the general health guidelines, individuals with MS are placed at risk for cardiovascular disease further complicating the fatigue experienced as a result of MS. Actual inability is reinforced through decreased physical readiness skills such as poor body conditioning and physical stamina. Limited exercise or activity level results in poor cardiovascular abilities, limited physical capacity, along with increasing propensity toward coronary heart disease, muscle weakness, decreased bone density with an increased risk of fracture, and shallow, inefficient breathing (NMMS, 2010). These risk factors compound the fatigue that is already experienced due to the illness.

There is evidence that regular physical activity is associated with lower fatigue, lower depression, and higher quality of life. Depression has been shown to be a component of fatigue; exercise has been shown to reduce depression in the general population. Stroud and Minahan (2009) examined the variables of fatigue, depression, and quality of life in individuals with multiple sclerosis who do and do not regularly exercise. Exercisers demonstrated lower disability status while also reporting higher satisfaction in all areas of the quality of life assessment with lower fatigue and depression scores than did their counterparts who did not exercise. Correlations between the disease severity, physical readiness, and quality of life suggest that participation in regular physical activity appears to be beneficial for those in early stages of the disease. Young mothers are ideal candidates for this physical intervention regime as they demonstrate less disability, and have a greater exercise capacity than individuals who have had MS for a longer period of time. For example, when searching for healthy individuals with MS for a research study, Dettmers, Sulzmann, Ruchay-Plossl, Gutler, and Vieten (2009) had significant difficulty recruiting study participants as 70% of patients admitted to the hospital were unable to complete the required interventions and exercise training. Some identified physical limitations such as paresis, spasticity, ataxia, and decreased mobility causing wheelchair dependence and walking stick use while others experienced cognitive limitations and psychosocial issues, such as depression, with decreased motivation. Younger parents with a new diagnosis are more likely to value and are better able to work towards maintaining level of functioning and independence through engaging in physical activity than those with more developed forms of the disease (Motl & McAuley, 2009). This points to the value of early intervention in developing and maintaining readiness

skills needed for to achieve relative mastery in their motherhood role.

Parents' desires to pursue an active lifestyle are advantageous for continued quality of life. There is a correlation between physical activity and aspects of illness such as depression, fatigue, pain, social support, and self-efficacy that ultimately leads to improved quality of life (Motl & McAuley, 2009; Motl, Snook, & Schapiro, 2008). Motl and McAuley (2009) suggest that physical activity is inversely correlated to pain and fatigue as well as having a direct relationship to social support and self-efficacy. Increases in self-efficacy can lead to increases in physical activity which in turn reduces symptoms. The ability to change a range of variables affected by one's experience of MS can occur through physical or occupational activity. Although a central focus of MS research is fatigue's effect and correlation to other illness variables, there are other symptoms and aspects of illness to address for holistic treatment. Because of the pathways and correlations between the variables, addressing one aspect of the illness, such as involvement in daily activity, can help to alleviate other negative symptoms and enhance positive behavioral abilities including self efficacy and use of social support. Motl, Snook, and Schapiro (2008) established a correlation between physical activity and overall symptoms of MS which differed from the inaccurate hypothesis that one specific symptom of fatigue, depression, and pain would singularly influence the engagement in activity. This again emphasizes the need for holistic treatment in MS intervention programs.

Fatigue can be managed by engagement in balanced physical activity with the focus of expending energy to gain energy. Recent evidence has supported the idea that symptoms of depression, sleep, self-efficacy, and task tolerance resulting from multiple

sclerosis can be improved through exercise and engagement in regular daily activities that require energy. Although there is a perception that exercise can lead to exacerbations of symptoms in the MS population, there is little evidence of lasting pernicious effects from exercise. With continued exercise and strength training, positive functional outcomes would be expected or at least may provide increased endurance and functional ability for a longer period of time throughout the course of the disease (Smith, Adeney-Steel, Fulcher, & Longley, 2006).

A 30 day period of inactivity is the accepted guideline following remission of a relapse of MS symptoms (NMMS, 2010). When experiencing more intense symptoms, the chance of engagement in physical activity significantly declines (Motl, Snook, McAuley, & Gliottoni, 2006). The differences between the various causes of increased symptoms should be established, whether these increases are due to daily symptom fluctuations or a disease exacerbation. This distinction should influence one's persistence in completing and participating in daily occupations. An exacerbation calls for following the 30 day guideline of rest and decreased activity. During this time, patients should focus on recovering rather than participating in exercise programs or strenuous occupational tasks. After the recovery period, patients should not fear further exacerbations from involvement in physical activity as this belief can lead to learned helplessness and a negative impact on self-efficacy. With a decreased sense of self-efficacy, individuals may become less motivated to prevent deconditioning and further decomposition of skills and independence. Participants who reported increased severity and greater variety of MS symptoms also reported lower levels of self-efficacy and pursuit of engagement in physical activity. During these periods, increased self efficacy

and self control is needed to promote the participation and adherence to physical activity which leads to higher quality of life (Molt, Snook, McAuley, & Gliottoni, 2006). White, Mendoza, White, and Bond (2009) discovered that only 22 % of women with MS utilize physical exercise to reduce pain and indicate that a large percentage of women could benefit from education concerning the activity modifications and physical exercises that can be incorporated into daily occupation to reduce not only pain and fatigue, but also other physical limitations. Monitoring the effects of physical activity engagement on symptoms can assist in knowing when to alter an exercise routine. This self-assessment process will allow the individual to determine the efficiency, effectiveness, and satisfaction in achieving relative mastery. This process, in turn, can increase the likelihood of engaging in physical activity and adherence to therapeutic suggestions for increased involvement in a daily activity routine (Molt, Snook, McAuley, & Gliottoni, 2006). Activities should also be planned for completion during periods of milder temperatures as excessive heat has been linked to exacerbations of fatigue (NMMS, 2010). For optimal functioning and productivity, individuals with MS should plan activity according to time of day as well as season. With reduced pain and fatigue, women may be able to participate in a greater variety of mother-child activities.

White, Mendoza, White, and Bond (2009) identified commonly utilized coping strategies for child rearing by mothers who experience chronic pain. Utilization of coping strategies during times of remission and exacerbation of pain symptoms were compared. Engagement in self cares through the use of exercises, relaxation techniques, and other physical movement to reduce pain was identified by 22% of women. Secondly, 20.3% of mothers utilized quiet or low effort activities to engage the child without expending a

high amount of energy. Nine percent of mothers allow their children to play alone or in another room to self-preserve by remaining inactive. An additional strategy for 4.9% of mothers was to explain their chronic pain condition to their children in hopes of encouraging more mature behaviors. Effective planning, scheduling, and simply saying “no” to excess activity are used by 14.4% of mothers to accommodate pain. A total of 16% of mothers also reported employing help from spouses and other social supports during episodes of pain. Attitude and emotional management strategies were utilized by 8% of mothers in attempts to ignore pain symptoms. Lastly, some mothers did not have clear coping strategies to utilize during pain. Importantly, mothers with MS listed significantly less coping strategies than the well mothers or mothers with rheumatoid arthritis (RA). The low percentages of women who used the listed coping strategies reinforce the need for education regarding the benefits of the use of coping and readiness skills to increase occupational performance. Those mothers with MS who were able to list coping skills were more likely to engage in child activities and encouragement of mature behavior from their child during episodes of pain than women with RA. Women with chronic pain were also found to engage their children in less activity than did women without pain (White, Mendoza, White, & Bond, 2009).

Gulick (2007) investigated the factors affecting functional performance of mothers experiencing multiple sclerosis in the second six months of their postpartum period. The importance of social support for new mothers was supported as involvement with support was found to increase functional performance despite symptoms experienced after the birthing process (Gulick, 2007). Social participation has also been linked to decreasing the affective symptom of depression (Harrison & Stuifbergen, 2001).

Participation in social support groups can increase the amount of social and emotional support being provided to parents with MS. Social supports such as close friends or family may be a source of emotional well being (Harrison & Stuijbergen, 2001). Support groups are also beneficial for family members of those affected with MS. Steck et al. (2007) outlined the benefits of support groups in providing non-affected spouses more information on how to effectively care for their ill spouse which provides the healthy spouse a greater sense of control in addressing both psychological and physical needs of the ill spouse. Social support, when given to each family member, can result in a well balanced family life in which all members have the necessary tools of knowledge and emotional well being to cope with chronic illness.

Despite the wealth of evidence based interventions regarding the management of MS symptoms, many women report that they do not have knowledge to effectively cope with symptoms while attending to a household and providing for a family (Prunty, Sharpe, Butow, and Fulcher, 2008). Mothers expressed a need for more resources and education regarding pregnancy and its effects on MS and child-rearing as information is limited and not easily accessible. Mothers expressed that they would be more confident in their future performance as a parent with increased education. Therefore, there is a need for a product that will address the occupational role of a mother with young children. An educational resource is needed to balance remedial and compensatory strategies along with the development of physical, psychosocial, and cognitive readiness skills that can be utilized during mothering occupations.

CHAPTER III

METHODOLOGY

The literature revealed that there is a need for an activity workbook resource for mothers diagnosed with multiple sclerosis (MS) to promote optimal success and independence in the motherhood role. Mothers have expressed a need for more resources and education regarding pregnancy and its effects on MS and child-rearing as this information was limited and not easily accessible (Prunty, Sharpe, Butow, & Fulcher, 2008). An extensive literature review was completed and informed the creation of this product.

The literature review focused on three main areas that were then utilized in the design of the product. These areas included influence of MS symptomology on motherhood activity engagement, best current practice to address MS symptoms, along with the correlation between the mother's symptom level and her ability to provide care and nurturing to her child. The resulting workbook targets the mothering activities of individuals who have been newly diagnosed with MS and are raising young, pre-school aged children. Mothers are provided education and guidance to optimize performance in three parental areas of occupation: self-care, household management, and childcare.

According to the literature, the relationships between MS course progression, type of symptoms experienced, and perceived severity of symptoms are influential factors in determining not only one's physical wellbeing but mental and social health as well. Poor

role performance is a consequence of the presence of MS symptoms as compounded by the various environmental and behavioral factors experienced by the individual. Fatigue was identified as the most prominent and debilitating symptom of MS with 96% of the population experiencing this symptom (Hemmet, Holmes, Barnes, & Russel, 2004). Thus, combating fatigue was a central focus of the created guidebook as doing so directly benefits the overall ability of mothers to complete required daily tasks.

A common underuse of energy promotion during the treatment of MS and an overemphasis on energy conservation strategies was evident in the literature. A balanced approach to fatigue management is indicated.

The literature review demonstrated that mothers with MS are more likely to be perceived by their children as showing a decreased amount of affection during a period of increased symptomology (Deatrick, Brennan, & Cameron, 1998). It is for this reason that the childcare section addressed alternate forms of nurturing and affection that mothers may use to compensate for increased symptomology. The literature expressed mothers' worries about the future need for their children to become their caregivers which may deprive them of childhood experiences (Prunty, Sharpe, Butow, & Fulcher, 2008). These feelings were substantiated by literature that outlines the negative impact of parental childhood (Yahav, Vosburgh, & Miller, 2005). Expected childhood occupations and peer socialization are essential for the acquisition of skills and abilities at the appropriate age and stage of development (Case-smith, 2004). Therefore, concerns were addressed through educating mothers as to developmentally appropriate roles and responsibilities of children, allowing for personal growth of the child while decreasing the mother's workload.

Balanced family roles provide for a structured, consistent, and dependable home life (Turpin, Leech, & Hackenberg, 2008). However, the unpredictable and fluctuating nature of MS can make structure and dependency in everyday activities difficult to achieve. To promote positive interactions between children and parents for healthy family relations, this product focuses on increasing coping skills and physical ability. Increased knowledge and physical ability then minimizes the anxiety producing effects of unpredictable health deterioration caused by MS.

Bandura's theory of reciprocal determinism assisted in the development of the product. This theory is significant in encouraging self efficacy among ill individuals. A sense of not being able to control one's symptoms has been shown to lead to ineffective management of both physiological and affect symptoms as lower levels of self efficacy decrease likelihood of the individual to seek out and utilize coping strategies (Snook & Motl, 2008). The bi-directional relationship outlined by this theory demonstrates that the separate factors of behavior, the individual, and the environment can be manipulated to elicit change in the desired areas in order to produce an overall change in behavior. Self monitoring of daily symptoms along with physical activity and its effects on these symptoms can lead to a higher sense of control of disease process, and therefore a higher sense of self efficacy. With the perception of increased ability to perform necessary tasks, an individual is more likely to engage in interventions that allow engagement in the everyday occupations that are required to fulfill life roles such as parenting.

The occupation adaptation (OA) model was used to as the foundation of the workbook structure and outcome goals. The OA model places a strong emphasis on the importance of appropriate and effective adaptation changes in role requirements and

ability. This fundamental construct of the model is applied to mothers as they change and adapt their role of motherhood in response to MS symptomology.

The OA model assisted the organization of the information presented through the workbook. The mother is encouraged to examine her individual perceptions of effectiveness, efficiency, and satisfaction while completing meaningful motherhood tasks. Mothers are encouraged to recognize activity priorities and self perceptions of efficiency in task performance. With this knowledge, the individual is empowered to make decisions on her own and generalize knowledge to other important and desired motherhood tasks.

Mothers were given the opportunity to gain insight into the effectiveness of strategies used to carry out self-care, household management, and childcare activities. Guided by the OA Model, the workbook promotes occupational mastery and skill generalization and is intended to be used as a supplement to occupational therapy (OT) services.

Throughout this workbook, mothers acquire many concepts and knowledge that allow them to manage daily activities and disease symptoms in order to best benefit the motherhood role. To promote self efficacy, the mother is taken through the process of a weekly plan to implement and practice newly learned information and skills. Following the implementation of the weekly plan, mothers are given the opportunity to evaluate their level of success and use of the material provided in each section. The evaluations are set up in order for the mothers to assess their progress according to the occupational adaptation concepts of effectiveness, efficiency, and satisfaction.

Finally, readers are encouraged to continue to evaluate the outcomes of the

strategies as they continue making new plan in order to continue to increase their mastery in mothering occupations. This continued evaluation will allow the mother to properly use the skills that have been learned to generalize the use of the knowledge presented and practiced in a variety of tasks and settings.

CHAPTER IV

PRODUCT INTRODUCTION

The Activity Strategy Workbook targets the mothering activities of individuals who have been newly diagnosed with MS and are raising young, pre-school aged children. The workbook is guided by the occupational adaptation model and aims to guide mothers toward achievement of relative mastery of desired and necessary occupational tasks. Mothers are provided education and guidance to optimize performance in three parental areas of occupation: self-care, household management, and childcare.

The focus of the workbook resource is to enable mothers to live a fulfilled and healthy lifestyle by leading a balance lifestyle through both task adaptations to conserve energy and also engagement in physical conditioning to increase muscle strength and endurance. The mother is also empowered to learn about and recognize individual symptoms and disease process, which will assist the mother in understanding more about how the disease influences her ability to complete self and family care. With this individualized information, the mother is encouraged to begin to plan for life decisions on both a daily and long term basis through appropriate responses to the symptoms experience.

The workbook provides mothers with an opportunity to reflect on abilities and feelings towards self care, household tasks, and childcare activities which can then be

prioritized in response to importance of activity and symptoms experienced. This self-reflection follows concepts from the occupational adaptation model to determine the efficiency, effectiveness, and satisfaction of engagement in daily activities in order to increase the ability to complete the motherhood role. By considering all of the strategies presented in the workbook, the mother will be more empowered to complete meaningful and necessary motherhood roles. Please refer to project Appendix to view complete Activity Strategy Workbook product.

CHAPTER V

SUMMARY

The purpose of this scholarly project was to create an educational and interactive resource for mothers who have young children and a recent diagnosis of MS. A workbook was created to promote early intervention and education allowing mothers to fulfill their full mothering potential while managing their experience of MS. The focus on daily occupations enabled mothers to learn and practice skills needed to maximize their functional and occupational performance. The use of the occupational adaptation model provided a balanced emphasis on use of readiness skills, activity modifications, and environmental adaptations that allowed for continued engagement in occupations. The resource developed provides information on possible adaptations to the activity and home environment that will promote increased involvement in meaningful and valued motherhood roles. Mothers have the opportunity to practice learned skills, self monitor, and make changes to future occupational and mothering endeavors.

The activity workbook is intended to provide guidance for mothers experiencing symptoms of excessive fatigue and muscle weakness. Mothers are encouraged to reach their full role potential through attention to the effects of MS symptoms and learned habits of ineffective interaction. In order to provide a well balanced resource for mothers experiencing MS, it is necessary to provide opportunity to explore both energy conservation and energy promotion techniques and modifications. The varied

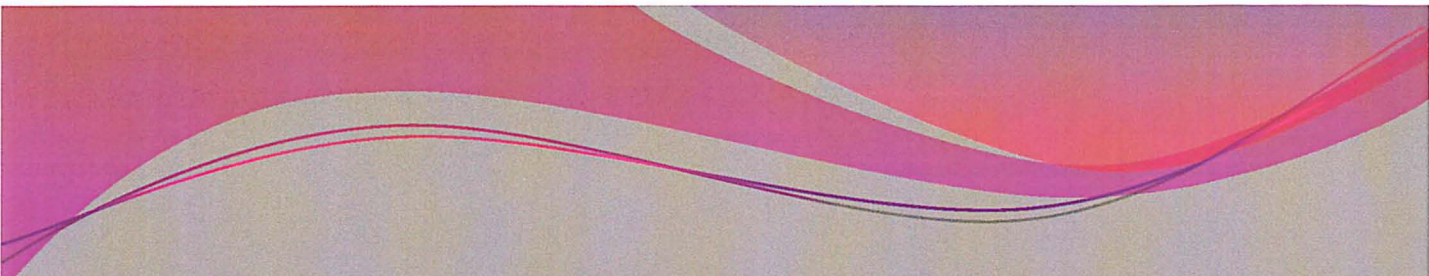
interventions provided increase functional performance while maintaining the quality of occupational engagement during symptom exacerbation.

This workbook is not only beneficial for those experiencing multiple sclerosis, but may be used for individuals with a variety of fatigue limiting diagnoses. Mothers experiencing any types of extreme fatigue or muscles weakness and/ or other debilitating neurological disorders may benefit. This workbook can be implemented in a variety of settings. It is intended to be used as a supplement to outpatient occupational therapy services. It may also be used by occupational therapists during inpatient and outpatient treatment sessions.

In order to effectively distribute the workbook, multiple copies will be made and dispersed to local hospitals namely the inpatient and outpatient rehabilitation centers, doctor's offices and fatigue management centers as a resource for appropriate patients. The workbook would also be dispensed to MS local support groups.

Finally, it is recommended that research be conducted to obtain feedback from mothers and medical professional who have used the workbook. Discrepancies in the findings will inform potential modifications needed to enhance the quality and applicability of the product.

APPENDIX



UND University of North Dakota
Occupational Therapy Department

Activity Strategy Workbook:

For mothers experiencing multiple sclerosis

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2010

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Overview of MS

With your new diagnosis of Multiple Sclerosis you may be concerned as to how your disease will influence your family life and your ability to parent. MS is a neurological disorder that affects 400,000 Americans, with 200 new diagnoses each year. Of those diagnosed, women are effected 2-3 times more than men. This has resulted in a large amount of mothers with MS who are raising children. Symptoms can vary with each individual and their disease process as there are several different forms and courses that this disease may take. Although symptoms are not always experienced the same from person to person, the most common symptoms are fatigue, pain, numbness, difficulties walking or moving, bladder and bowel dysfunction, visual problems, vertigo or dizziness, sexual dysfunction, spasticity, cognitive deficits, and psychological issues such as depression and emotional changes (National Multiple Sclerosis Society, 2010).

Type and severity of symptoms depend upon the course of illness that someone experiences. There are four disease courses that have different course progressions: relapsing-remitting, secondary-progressive, primary-progressive, and progressive-relapsing.

Relapsing-remitting: This is the most common course of MS and is experienced by 85% of individuals with MS. It is characterized by periods of relapses, flare-ups, and periods of normalcy at which point symptoms return to normal.

Secondary-progressive: Ten percent of those who are diagnosed with relapsing-remitting MS will progress to secondary-progressive MS, in which symptoms become more pronounced and are experienced at a steadier rate.

Primary-progressive: This type of MS is experienced by approximately 10% of individuals with MS. The symptoms present at a slow and steady pace with no severe exacerbations or flare-ups of symptoms.

Progressive-relapsing: This is the rarest form of MS and is experienced by only 5% of individuals with MS. Chronic symptoms and exacerbations are present throughout this disease progression without periods of plateau or remission of symptoms.

(National Multiple Sclerosis Society, 2009)

What Does This Mean For Mothers?

You may be asking yourself “What does all of this information mean for me as a mother?” A new diagnosis of MS may be at first overwhelming, but there are many resources and personal characteristics that you can use in response to your illness that allow you to be a capable and nurturing parent. As a mother, you most likely have many expectations of yourself and dreams for your family. Many mothers desire to be independent in fulfilling the parenting role. They are able to do so with the help and direction from healthcare professionals, social and family supports, along with the use of the tools presented in this workbook.

You can live a fulfilled and healthy lifestyle through balancing task adaptations to conserve energy and engagement in physical conditioning to increase muscle strength and endurance. By learning about and recognizing your individual symptoms and your own disease process, you will understand more about how your disease influences you and your ability to complete self and family care. With this individualized information, you can begin to plan for life decisions on both a daily and long term basis through appropriate responses to the symptoms you experience. This workbook will provide you with the opportunity to reflect on your abilities in self care, household tasks, and childcare activities and design your schedule through consideration of the importance of each activity and symptom exacerbation. By considering all of the strategies presented in the workbook, you will be empowered to complete meaningful and necessary motherhood roles.

This workbook provides education and follow-up applications for self care, household management, and childcare activities. You can use the information you have learned to make positive and practical changes to your daily life. After making the necessary changes, you will have the opportunity to reflect on the efficiency, effectiveness, and satisfaction of your engagement in your daily activities to further assess and strategically plan for the motherhood role

Self Care

Performing self cares is an important role for mothers as a mother who is able to care for herself is better equipped to manage other family needs. Self care activities can be described as the completion of daily care requirements that are necessary for healthy and independent engagement in daily activities. Some of these activities include bathing, dressing, engagement in physical exercise program, or following and implementing a medication routine.

Your ability to perform these activities might be difficult due to your illness and symptoms. Organizing, pre-planning, and preparing your daily routines will be helpful in providing a sense of structure and organization to ease daily care completion. The development and management of these routines is very important to establish a strong foundation for your own health and wellness. This section of the workbook will help you to identify the self care activities that you find to be important for yourself and how these activities can be made easier through balancing your schedule, daily activities, and environment.

In the “Self Care” section you will provide personal information regarding your daily activities and symptom fluctuations through completing two charts. This information will be used as a foundation to allow you to discover the best approach for managing daily activities in order for your motherhood role.

Mark which self care activities are part of your daily routine.

- Bathing
- Dressing
- Hygiene (brushing teeth, using deodorant)
- Grooming (putting on makeup, shaving, brushing hair)
- Medical Appointments
- Medication Routines
- Physical Exercise
- Relaxation Activities
- Alone Leisure Time
- Social Engagement
- Healthy Sleep Routine
- Other _____

In your schedule that you have created [Table 1], use a highlighter to mark the self care activities you feel are most important to your health and wellness. List each activity and identify its significance to your motherhood role.

Activity	Significance
1. _____	
2. _____	
3. _____	
4. _____	
5. _____	

As you prepare for self care activities, there are several points to consider while planning for your day. Some of these activities require more effort than other activities and/or require more focus and attention to complete.

Reflect back upon your daily schedule [table 1] and identify those self care activities that require a large amount of effort or are difficult to complete. Now, underline these activities on your schedule and write these activities below for your personal reference.

Now list your self care activities that require a low amount of effort and are easily completed. Write these activities below for your personal reference.

It is important to be aware of your energy level and symptom experiences when participating in activities so that you can make adjustments in your schedule as needed. The next section will guide you in identifying the reasons for the difficulty you may experience while completing activities. Once you have identified the cause for difficulty, you are better equipped at choosing strategies that will ease your task performance. You will learn more about these strategies in the next section “Energy Conservation.”

Self Care: Energy Conservation

Now that you have completed the charts provided in the previous section, you can begin to learn how energy conservation techniques may make your self care tasks easier to complete. Energy conservation is a group of techniques that allows you to minimize the amount of effort or energy expended to complete an activity. There may be several reasons that make activity completion difficult. The presence and severity of symptoms will greatly influence the level of energy you will have to complete self care activities. Symptoms and energy levels change throughout the day, so planning in order to complete daily tasks will be necessary to expend your energy in the most efficient way possible. Some activities will require high amounts of energy for you to be able to complete them. To best be able to engage in these activities, it is wise to plan these activities to be completed during times of day that you experience the least amount of symptoms or are most able to engage in physically demanding tasks. Other energy conservation strategies can be used when a difficult yet necessary task cannot be completed at another time of day. You may find that other activities are not as essential to your everyday functioning which allows you to either delegate the task to another individual or put off the completion these tasks until you feel more capable.

This section will introduce four aspects of energy conservation: changing time of day, adapting the activity, changing your environment, and the use of assistive devices. Additionally, this section will discuss the benefits of a strong social support system. These strategies can be used in coordination with each other and separately, according to your need and physical ability.

Activity Changes: Time of Day

Examining your daily activities and symptom fluctuations will guide you in choosing the best time of day to complete activities. It is less efficient to complete physically demanding tasks during times of days that you have increased symptoms. Completing the task during a period of decreased symptoms will be a more optimal use of your energy reserves.

Place Table one and Table two side by side. Circle those activities that require high energy use and also coincide with an increase in your symptoms.

Are you able to change the time of day that you regularly complete activities that coincide with increased symptoms? Identify which activities that would best be completed at another time of day and when you would like to complete these activities.

Activity	Alternative Time of Day	Why is this a better time of day?
1.	_____	_____
2.	_____	_____
3.	_____	_____
4.	_____	_____
5.	_____	_____

* Note: MS symptoms are very sensitive to high temperatures and heat. Time of year and daily seasonal temperatures will influence the time at which activities are most easily completed. Keeping these factors in mind, you can begin to plan for activity adjustments.

Activity Changes: Adapting Activity

Sometimes you are not directly able to change your daily schedule to fit in all of your essential daily activities. You may need to decrease the amount of energy required to complete an activity rather than changing your schedule. These changes will allow your continued engagement and independence despite the presence of symptoms. Through regular practice, you will learn to recognize the amount of energy required for completion of each activity and make adjustments with minimal effort.

This list provides overall energy conservation techniques that can be generalized to ease the physical requirements of a variety of daily tasks.

- Try to do the major part of the task while seated in a chair, preferably one with arm.
- A long-handled reacher will eliminate the need to bend over while retrieving items.
- Where possible, sit rather than stand. Bar stool height is a compromise between standing and sitting.
- Have work in front of you rather than at the side.
- Reduce effort when moving by moving slower and not lifting as much as before.
- Slide rather than lift objects.
- Try to maintain good posture when standing, bending, or sitting.
- Alternate work and rest periods.
- Plan a basic itinerary each day in order to reduce unnecessary motions and steps.
- Prioritize and pace your work schedule. Don't feel the need to try and complete all tasks in one day. Have a weekly plan for scheduling major tasks such as washing, ironing, shopping and cleaning, so that one task can be done each day.

Identify “adapting activity” strategies that you can use to reduce your energy use throughout the day.

Activity	Activity Adaptation
1.	
2.	
3.	
4.	

Activity Changes: Changing Your Environment

Energy conservation might also involve changing your environment to encourage easy access and completion of your daily activities. Modifications to the environment may include changing the way your home and household items are set up or organized.

- For example, you might utilize containers or put everything needed for a task in a basket or box, such as storing all items for morning care together in order to decrease the amount of effort searching for needed items.
- If you have a young child who you find gets messy often and requires frequent clothing changes, you could keep several changes of clothes in a downstairs cupboard that is easily accessible rather than expending energy to walk up stairs every time a new change of clothes is needed.
- You might also organize and store frequently used items, such as essential kitchen supplies, in a close and convenient location that is easy to reach so you don't have to use up your energy searching for needed items.

These are just a couple of ways that you can set up your home that will allow you to save energy and make the most of the energy you have. Specific modifications will depend on the needs of the individuals living in each home.

Consider your previous list of activities requiring high energy use. Can you modify your environment to reduce the amount of energy you use to complete that activity throughout the day?

Activity	Change in Environment
1.	_____
2.	_____
3.	_____
4.	_____
5.	_____

Activity Changes: Assistive Devices

In addition to energy conservation strategies, the use of assistive devices can simplify the tasks further while also ensuring the safety of others. Some examples of these devices include the use of a button hook if fastening clothes becomes challenging or a bath bench which allows you to stay safely seated while taking a shower if experiencing fatigue. An occupational therapist can provide guidance on appropriate devices for each situation and may have knowledge of the contacts for local supply companies in your area. You can also explore and obtain devices from medical and surgical supply stores, online websites, yellow pages telephone directory listing, or catalogues for assistive device and self-help companies.

Devices you may find helpful include:

- Dressing sticks
- Reachers
- Long-handled shoe horns
- Button hooks
- Elastic shoe laces
- Sock aids
- Grab Bars
- Long Handled Shower Sponge

Are there activities that you complete which might be modified through the use of an assistive device?

Activity

Assistive Device

1.

2.

3.

4.

Activity Changes: Social Supports

As a mother, you may feel the desire to be directly involved in completing every aspect of your daily activities. At times, you may need to seek out and rely on social supports to accommodate you and your family's needs. You are doing a service to yourself and your family by seeking out help when you need it. Realizing that you will be better able to care for yourself and your family when you use all of the resources available to you, there are many people and programs accessible to you that will provide you the necessary assistance you may require. The use of these resources can help you to make certain that you are focusing on the right type of help rather than counting on your children or other family members who may not be able to assist with the parenting role.

You are encouraged to consider your beliefs and views regarding assistance from others by answering the questions.

How do I view assistance, in a negative or positive light?

In what areas would I find assistance to be beneficial?

Activity: _____

Type of Assistance:

Activity: _____

Type of Assistance:

For each activity above, identify drawbacks to using social supports to complete your daily tasks.

For each activity above, identify positive aspects for using social supports to complete your daily tasks.

Seeking assistance from others can preserve your health and energy and allow you to perform and engage in activities for a longer period of time. Seeking out appropriate assistance promotes your mothering competency and your authority in the decision making process of your daily life structure. There are many resources available with your community that may be able to provide assistance that close family and friends are unable to provide. These can include support groups, family and individual counseling, child care services, home cleaning services, among others. In this section, you are encouraged to look at the resources available at local, family, and social levels for assistance in completing daily activities during a period of increased symptoms.

Using your local phone book and an internet search complete community resources search. You may also find additional information by contacting the occupational therapist at your local healthcare facility.

TABLE 3:

List the name and phone number of each local resource and identify how the social support would be of assistance.

Name of Resource:

Phone Number/Contact Information:

Benefit:

Name of Resource:

Phone Number/Contact Information:

Benefit:

Name of Resource:

Phone Number/Contact Information:

Benefit:

Self Care: Weekly Plan

In this section you will develop a weekly plan to practice the knowledge that you have gained about your symptoms, abilities, and energy conservation techniques. You may find the use of these skills to be difficult at first. However, the more you use these skills, the easier they will become as you form a habit and greater awareness of how to appropriately use each strategy. Practice makes perfect, so make sure to focus on even small successes! For this week, start by modifying one activity that you would like to make easier.

This week you will use your newly acquired knowledge regarding energy conservation to increase your ability to perform one self care task. Choose one highlighted self care activity from your daily schedule [Table 1]. The activity that you choose should be one that is difficult to complete but is of significant importance to your daily routine.

Chosen Self Care Activity:

Identify what makes this activity challenging to complete.

Which strategies will you try to make this activity easier?

- **Time of Day**
- **Adapting Activity**
- **Changing Your Environment**
- **Use of Assistive Devices**
- **Social Supports**

List the specific strategies that will assist you to best complete this activity.

Evaluation of Your Plan

After completing the Self Care Weekly Plan, use this evaluation to assess your performance in completing your weekly plan.

The changes you have made this week to your schedule should be examined for their ability to ease your daily tasks. In doing so, you can also evaluate whether these changes match your expectations of yourself as a mother. You should continue to evaluate your ability to complete your activities in a satisfying way. You can then use your knowledge and resources to problem solve strategies to increase your satisfaction and effectiveness in you motherhood role.

Examine the energy you spent on the one activity you chose to work on this past week. List the chosen activity and modification you used to make this task easier.

Activity

Modification

Do you believe that the changes that you made allowed you to be more effective in completing your chosen activity? For example, how did the changes directly result in your ability to more easily complete your chosen activity?

Rate your effectiveness on a scale of one to ten (ten being the most effective)

1 2 3 4 5 6 7 8 9 10

In what way did the modification help or hinder your effectiveness?

Do you believe that the changes that you made allowed you to be more efficient in completing your chosen activity? For example, how did the changes directly result in your ability to best use your time needed in order to complete your chosen activity?

Rate your efficiency on a scale of one to ten (ten being the most efficient)

1 2 3 4 5 6 7 8 9 10

In what way did the modification help or hinder your efficiency?

Do you believe that the changes that you made allowed you to be more satisfied in completing your chosen activity?

Rate your satisfaction on a scale of one to ten (ten being the most satisfaction)

1 2 3 4 5 6 7 8 9 10

In what way did the modification help or hinder your satisfaction?

Look back to the difficult self care activities that you underlined in Table 1. How can you implement the techniques you used this past week to simplify other difficult self care activities?

Activity _____

Proposed Changes:

Activity _____

Proposed Changes:

Activity _____

Proposed Changes:

How have these changes contributed to your ability to be a mother and fulfill other motherhood roles? Were you more satisfied in your ability to mother through using these techniques? How or Why?

Household Management

In the previous section, you learned about the benefits of adapting your schedule, activity, and environment in order to ease your self care tasks. These strategies can also help to ease your performance of household management tasks that are required for your motherhood role. The focus of this section will be to increase your activity level through a strategy known as energy promotion. You will learn how to use the energy conservation strategies addressed in the previous section in balance with increasing your activity level through energy promotion while completing household tasks.

There is new research showing that the fatigue you experience can be reduced through regular cardiovascular exercise. This might seem contrary to the way you typically plan or carry out activities while experiencing fatigue. However, there are significant physical disadvantages to only relying on energy conservation techniques to avoid overexertion. You may make yourself weaker over time by avoiding physical exertion. You should feel comfortable in pushing yourself to engage in daily activities without bringing about an exacerbation of symptoms. This takes the emphasis off of “disability” but rather places it on “ability” through your capability in leading a balanced lifestyle which will provide sufficient energy levels for performance of your desired motherhood roles. Household management tasks are great activities to practice energy promotion techniques as most require high levels of energy but can often be postponed when you are having high levels of symptoms.

Mark household management activities you are responsible for completing as part of your daily routine.

- Cooking Meals
- Vacuuming
- Dusting
- Sweeping/Mopping Floor
- Washing Dishes
- Laundry
- Cleaning Bathroom
- Organization of Household
- Driving Children
- Running Errands
- Grocery Shopping
- Other _____

In your schedule that you have created [table 1], use a highlighter to mark the household management tasks that you feel are most important to your ability to feel in control of your surroundings and provide a comfortable household for your family? Why are these activities significant to your motherhood role?

Activity	Significance
1.	_____
2.	_____
3.	_____
4.	_____
5.	_____

Reflect back upon your daily schedule [Table 1] and underline household activities that require a large amount of effort or are difficult to complete? Identify below your highlighted activities.

Activity	Reason for Difficulty
1.	
2.	
3.	
4.	
5.	

Now list your household activities that require a low amount of effort and are easily completed.

- 1.
- 2.
- 3.
- 4.
- 5.

Energy Promotion

In response to your fatigue, you may have found reducing your daily activity level to be helpful in the past. Just as energy conservation is important for wellbeing, so are energy promotion activities. Energy promotion techniques allow you to push yourself through physical boundaries in order to increase cardiovascular ability, muscle strength, and endurance. These physical benefits are important factors in living an active and independent lifestyle and should be engaged in as often as possible. Although energy conservation provides many benefits when your symptoms are severe, you should be careful to not overuse these strategies or use them when physical activity is possible.

You can use both energy conservation and promotion techniques in an appropriate balance for optimal use of both strategies. The use of these techniques will often not remain the same because of the fluctuating nature of your symptoms. Through symptom tracking, you will have a better sense of when to use energy conservation techniques and when to use energy promotion strategies.

Only you will be able to know when either technique is appropriate. It is helpful to examine your intention for completing a certain activity. Ask yourself “Do I stay away from activities that I would like to do or could do because I am overly afraid of causing my symptoms to worsen?” or “Do I push myself too much to complete activities that others may view as unnecessary even though I know these activities are too much for me to handle at the time?” and “Are my choices in activities helpful to my personal goal of being an effective mother?”

Again, place Table one and Table two side by side. Do you notice times that you were not able to complete your necessary or desired activities due to increased symptoms? Circle these activities on your daily schedule chart [Table 2].

Move the circled activities to the corresponding day on the following chart [Table 4]. Looking back to your symptom tracking chart [Table 2], do you notice a better time of day to complete physically tiring activities?

TABLE 4:

Activity	Old Time	Better Time
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

Limited exercise or activity level results in poor cardiovascular abilities, limited physical endurance, and increased likelihood of developing coronary heart disease, muscle weakness, decreased bone density with an increased risk of fracture, and shallow, inefficient breathing. These health factors worsen fatigue symptoms that you may already experience due to your illness. To increase your activity level in a way that is beneficial to your role as a mother, you can utilize daily activities that will increase your overall energy and decrease your experience of fatigue.

The following chart provides examples of household and childcare activities typically completed on a daily basis. Each activity listed is categorized into the amount of energy, or metabolic equivalent of task (MET) required for the task to be completed. The higher the number of METs being used, the higher amount of energy needed to complete the task. The chart should be used with a goal to complete at least 30 total minutes of moderate to high intensity activities throughout the day.

It is important to note that each activity can be broken up throughout the day for a combined total of thirty minutes.

TABLE 5:

METs = Energy Used	Level of Intensity
1-2	Low Energy
3-5	Moderate Energy
6-8	High Energy

Activity	METs	Moderate Intensity	High Intensity
Making beds	3.0	X	
Picking fruit	3.0	X	
Preparing meals	3.0	X	
Loading/unloading car	3.0	X	
Food Preparation	3.0	X	
Taking a warm shower	3.5	X	
Ironing (standing)	3.5	X	
Vacuuming	3.5	X	
Bathing dog (standing)	3.5	X	
Making the bed	3.9	X	
Walking downstairs	4.0	X	
Raking the lawn	4.0	X	
Playing at park with child	4.0	X	
Sacking leaves	4.0	X	
Golfing	4.5	X	
Moving furniture	6.0		X
Shoveling snow	6.0		X
Carrying groceries upstairs	7.5		X
Basketball	8.0		X
Running	9.0		X

Do you recognize activities on this list that are similar to your daily activities? You can also use this chart to estimate the MET value for activities that are not included on this list but require a similar amount of energy as a listed activity.

The use of the MET chart is beneficial as you can track the energy you are using throughout the day. Tracking your energy use allows you to vary your activity level throughout the day according to how you are feeling while giving you a visual reminder of your energy use towards your ultimate goal of 30 minutes of moderate to high activity.

Refer back to your daily schedule [table 1], identify and list the activities that are not included in the MET chart [table 5]. Find an activity similar to the MET chart and approximate the amount of METs your chosen activity requires.

Activity	MET level
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Balancing Energy Conservation and Promotion

It is important to balance your use of energy conservation and promotion by conserving energy during an activity and also completing as many physically demanding tasks as possible throughout the day. Pacing yourself in this way will help you to maintain energy so as to widen alternatives for activity participation.

On days that energy promotion is not possible, don't push yourself too hard to achieve the desired 30 minutes of activity. It is more efficient to save up your energy by using energy conservation tasks and consistently engage in activity throughout the day. Although the intensity of the activity is decreased with energy conservation use, your continued engagement produces a substantial level of energy which encourages endurance.

Energy conservation techniques for household management may include:

- Use fitted bed sheets to eliminate energy spent on bed making.
- To reduce fatigue, use fitted bedsheets to eliminate energy spent on bed making.
- To decrease the need for bending, use long-handled dustpans and self-wringing mops. .
- Wear a pocketed apron or something similar for carrying small lightweight items to reduce unnecessary trips about the house.
- Use a wheeled cart for moving items from one room to another.
- Plan ahead with meal preparation. Write menus for a week's meals at a time.
- Shop for staples once a week and for fresh produce twice weekly.
- Assemble all ingredients and utensils before beginning to prepare a dish.
- Make larger quantities, and freeze portions for later use.
- Plan for using leftovers when cooking.
- Don't be reluctant to use frozen or convenience foods. You can add your own seasonings.
- A Crock-Pot slow cooker will allow you to cook a one-pot meal with minimum preparation time and effort. Your dinner will cook safely in it throughout the day, allowing you to rest.
- Use small tabletop appliances to eliminate unnecessary standing or bending.
- Use lightweight cookware to conserve energy.
- Use nonstick cookware for ease in cleaning up.
- Use paper plates or plastic cups for snacks or lunches to eliminate dishwashing.

*Note: It is also medically advised that you not complete taxing energy promotion activities in the 30 day period following a symptom exacerbation that requires hospitalization or medical treatment. Energy conservation techniques will allow you to continue your daily tasks during your 30 day recovery period. Please contact your physician or occupational therapist for any further questions you may have concerning your physical ability after an exacerbation.

Home Management: Weekly Plan

This week, use the knowledge that you have gained about balancing energy promotion and energy conservation in regard to completing your household activities.

Energy Promotion

Complete this chart to track your ability to achieve 30 minutes of moderate to high energy tasks on a daily basis for one week. Categorize each activity into either high or moderate energy required. Write in the activity and length of time you have engaged in the activity. Look back to the MET chart [Table 5] for your reference.

	High Energy Activity	Moderate Energy Activity
Monday		
Tuesday		
Wednesday		
Thursday		
Friday		
Saturday		
Sunday		

Energy Conservation

Looking back to the daily schedule that you created in the previous section [Table 1], choose an activity that does not allow you to use energy promotion and that you are unable to change the time of day the activity is completed.

Identify ways in which you can adapt the activity, environment, or find supportive assistance from others.

After completing your weekly plan, go on to the next section to evaluate your success in using your plan.

Evaluation of Your Plan

You have now learned both energy conservation and promotion techniques and have had the opportunity to practice these skills during self care and household management activities. Use this evaluation to assess your performance in completing your Weekly Plan.

Your responses to your symptoms will predict how successful you will be in completing your necessary activities. Each activity requires some level of three personal factors: physical, mental, and emotional. When you complete your daily activities, it is important to examine how much energy you are devoting to these three areas. Ideally, there should be a balance between the three factors and the requirements of the task you are completing. An unbalance of these factors signifies that you may be wasting energy on unnecessary task steps or activities or not using helpful areas on the task.

Were you successful in completing 30 minutes of energy promotion activities each day? What factors made you either successful or unsuccessful?

How have these changes contributed to your ability to be a mother and fulfill other motherhood roles? Were you more satisfied in your ability to mother through using these techniques? How or Why?

Now that you have learned about and practiced both energy conservation and promotion techniques, you can continue to evaluate your energy use as you plan for the coming week.

Identify your top three activity priorities for the coming week and identify your strategy for using your energy effectively through either energy promotion or conservation.

***Look back in the previous sections for specific energy conservation strategies.**

Activity _____

Proposed Changes:

Activity _____

Proposed Changes:

Activity _____

Proposed Changes:

Childcare

Because you desire to be a nurturing and effective mother, you will want to engage with your child on a physical, emotional, and cognitive level. Your preschool aged child looks to you for modeling and guidance needed for their development. You do this through engaging your child in activities that are typical for their age and developmental stage.

The nature of your illness does not always make it easy to perform physically demanding tasks, so you will need to recall the energy promotion and conservation techniques that you have learned to use in your self-cares and household management. These techniques prepare you to be physically ready for caring for your child and assist you in overcoming fluctuating symptom levels to engage in the skill building tasks for and with your child or children.

Children develop best in an environment where emotional and physical affection is given freely and consistently. Different forms of affection may best suit your ability at any given time. You may experience sensory symptoms that make physical affection difficult to give and may naturally use other forms of affection when you are not able to give affection though hugs and engagement in physical tasks with your child. Being cognitively aware of your role in your child's development will help you make informed choices for activity participation with your child and role responsibilities appropriate for your child at various ages and stages.

This section will emphasize your relationship with your child. The requirements in each area will change as your child matures, becomes mobile, and becomes more interactive with their environment. This workbook places emphasis on the need for nurturing relationships at all stages of development; however, the type of interactions will become more diverse as your child ages. Children require more complex interaction with their parents as they become more mobile and interactive with their parents. This section will help you provide positive affirmations to your pre-school child while encouraging development in areas of self-cares, work readiness responsibilities, along with play and family leisure skills.

Affection

Providing the nurturing care that you desire may be sometimes difficult due to your MS experience. Your symptom changes such as fatigue, pain, limb numbness, and sensitivity to touch may result in difficulty interacting and showing physical and emotional affection to your children. Children thrive in a consistent, nurturing environment and are not able to foresee changes. Therefore the fluctuating nature of MS may interrupt the sense of consistency in your interactions with your child. Children often do not have a great understanding of the medical effects of your illness. Because of this lack of understanding, children may internalize and misinterpret the cause of your physical distance while experiencing increased symptoms.

In this section, you will learn how to effectively use two forms of affection: physical and emotional, with an emphasis on providing emotional support when your symptoms hinder your ability give physical affection. You will also learn how to utilize four different forms of emotional affection and identify high and low energy activities for interaction with your child.

There are different forms of affection and ways of expressing your love towards your child. Dr. Gary Chapman highlights five ways that people express and receive love. Each person has a primary way that they receive and show their love for others. These forms are termed “Love Languages” and consist of physical touch, words of affirmation, quality time, acts of service, and gifts as ways to show affection. Although affection is able to be expressed through each of the five love languages, most people feel the greatest sense of love through one form of affection. In this section, you will have the opportunity to consider forms of affection desired by your child and adaptations that you might make to promote affection when your symptoms worsen.

Physical touch, words of affirmation, and quality time may take different forms. Here are some examples:

Physical Touch

- Hugs
- Kisses
- Having your child sit on your lap
- Holding Hands
- Snuggling and Cuddling

Words of Affirmation

- Words of praise for a job well done
- Compliments
- Saying “I love you”
- Pointing out child’s positive attributes
- Having pet names

Quality Time

- Alone time with your child
- Completing your child’s choice of activity together
- Bonding experiences through unfamiliar activities
- Eating dinner together as a family and sharing the day’s events

It is important to recognize these different forms of affection so that when you are unable to provide one form of affection due to MS symptoms, you can utilize other equally beneficial ways to show love to your child.

- For a better understanding of how to best identify and fulfill your child’s love language, you can seek out Dr. Chapman’s book “The Five Love Languages.”

At times, it may be important to talk to your child to gain a better understanding of their perceptions of your ability to give affection. This will ensure that you are able to attend to their emotional needs.

Identify how your child prefers to receive love and affection. Is it through physical touch, words of affirmation, or quality time?

Child's Preferred Affection Type: _____

Do sensory symptoms such as numbness, tingling, or pain effect your ability to carry out your child's preferred affection type? Yes or No

If you are experiencing sensory symptoms, it is likely that showing affection through physical touch may become difficult. In this case, the other love languages of "quality time" or "words of affirmation" may be more easily used to show affection to your child.

Provide examples of situations when you are unable to give your child their desired form of affection and then brainstorm other strategies for providing affection to your child using the additional love language areas.

Situation	Strategies to Show Affection
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Does overwhelming fatigue affect your ability to carry out your child's preferred affection type? Yes or No

If you are experiencing increased fatigue, it is likely that showing affection through physically demanding activities may become difficult. In this case, you can use strategies from the three love language areas to reduce the amount of energy required by you to show affection to your child.

Provide examples of situations when increased fatigue impacted your ability to give affection and then brainstorm other strategies and ways to provide affection to your child using the additional love language areas.

Situation	Strategies to Show Affection
_____	_____
_____	_____
_____	_____
_____	_____
_____	_____

Are there any other causes that make showing affection to your child difficult? If so, list in what ways can you use your knowledge of the love language areas to make showing affection less difficult?

Cause

Strategies to Show Affection

Play and Family Leisure

Play activities are essential to your child's skill development. The primary role of a child is to play and it is through these play interactions that children learn about themselves and how to interact within their environment.

The activities that your child or children choose to engage in require energy levels for participation. Your ability to engage in the same activities as your child will vary as your energy level and symptoms vary. You may have to choose more sedentary activities to complete with your child when your symptom level does not allow you to participate in activities that require a high level of energy. Bonding through an activity is important for showing interest and affection to your child as well as providing them with these necessary opportunities for growth. Your participation provides opportunity for parental modeling and bonding with your child.

Identify your child's favorite play and leisure activities that they engage in most often.

- | | |
|--|---|
| <input type="checkbox"/> Playing with Toys (cars, dolls) | <input type="checkbox"/> Bike Riding |
| <input type="checkbox"/> Playing on the Playground | <input type="checkbox"/> Video Games |
| <input type="checkbox"/> Outside Play/Exploration | <input type="checkbox"/> Watching Movies and Television |
| <input type="checkbox"/> Imaginative Play | <input type="checkbox"/> Sports |
| <input type="checkbox"/> Reading Books | <input type="checkbox"/> _____ |
| <input type="checkbox"/> Crafts | <input type="checkbox"/> _____ |
| <input type="checkbox"/> Drawing and Coloring | <input type="checkbox"/> _____ |
| <input type="checkbox"/> Music | <input type="checkbox"/> _____ |

After you have identified your child's preferred activities, categorize the activities according to the amount of energy required.

High Energy

Low Energy

As you learned in the household management section of this workbook, high energy tasks are beneficial to promote your physical wellness. High energy play activities that you engage in with child can be counted toward your goal of reaching 30 minutes of moderate to high energy MET level activities.

It is sometimes difficult to keep up with the activity demands of your child when symptoms are present. However, it is still necessary to engage in play with your child during these difficult times. Just as other tasks require high amounts of energy, so do activities that include your whole family. Through recognition of your symptom level, you can choose activities that match what you are able to do or brainstorm other activities to engage in with your child and family. When you choose an alternative activity for your family to engage in, you can use the opportunity to explain to your child the symptoms that you are experiencing and why you would be better able to complete a different activity. This will give them a better understanding of your illness and your need to modify the activity as you experience a high level of symptoms.

Consider the list of high and low energy activities you completed on page 37. Identify alternative low energy activities that you might engage in with your child when physically demanding play experiences are difficult.

1. _____
2. _____
3. _____
4. _____
5. _____

Engaging in family fun activities may lead to strengthened family bonds which will ultimately help when managing difficult times. Being able to incorporate the family into outings and activities provide a sense of normalcy and family cohesions.

Identify new “family fun” activities that would the entire family can participate in when exacerbations are present.

1. _____
2. _____
3. _____
4. _____
5. _____

Using your knowledge of energy conservation, identify ways to modify some of your favorite family outings so that you can participate in spite of decreased energy levels.

Favorite Activities

Modifications

- 1.
- 2.
- 3.
- 4.

By using energy conservation during activities that involve your child and other family members, you are able to participate in more activities with your child, model behaviors, and teach your child which will lead to increased skill development for the child. More opportunities to play with your child will also lead to more opportunities to enjoy their company and have fun!

The next section will offer you information for skill building in your child through responsibility in self and household care tasks.

Self Cares and Work Readiness

Your children play an essential role in determining which activities need to be completed on a daily basis. It is best to find a balance between involving your child in house care tasks. It is most effective to use your knowledge of your child's developmental capabilities along with his or her personality to engage your child in the appropriate amount of self care and household expectations. These role responsibilities can provide many benefits. As a mother, you can unlock the potential benefits of your distinct situation by providing a home environment that encourages your child's development through character-shaping activities and experiences. One way of promoting positive childhood outcomes is through recognizing your child's ability and potential role for assisting in household chores.

Children of parents with chronic illness often report pride in their ability to provide care for themselves and their families in ways that their peers are unable. These children may experience stronger relationships with their parent through the help they provide to their family. Activities may be essential tasks not only the household but also may provide a teaching and bonding experience through shared activity completion. The potential for negative influences of your illness on your child's development can be significantly decreased by providing the right balance between your child's responsibilities and his or her ability to count on you as a mother.

Since the goal of a parent is to raise children to become independent, healthy adults, household tasks can be considered an opportunity to learn valuable skills in personal and social responsibility. Each child, depending on age, is capable in taking on age-appropriate responsibilities which allow the child to develop necessary skills while also easing your daily routine.

This chart provides you an overview of what a typically developing child is able to do at certain developmental ages. Remember that each child is unique and develops at his or her own pace.

Each child requires a differing amount of supervision and care from the parent. This chart can be used as a guideline. However, only you can assess and know your child's capabilities for increasing personal responsibility. For further information on your child's developmental ability, please refer to the book "Ages and Stages: A Parent's Guide to Normal Childhood Development" by Charles E. Schaefer and Theresa Foy DiGeronimo.

Check the tasks your child can currently complete.

2 years:

- Begin to assist you with simple dressing such as pulling up and down pants and putting arms in a coat or shirt.
- Follow simple one step directions such as “put your toys in the bucket” or “put the washcloths in the drawer.” However they may still need assistance with new or unfamiliar requests.
- Independent feeding with finger foods, child size utensils, Sippy cups or open cups. He or she will most likely need help cutting food.
- Understand simple safety commands such as “hot” “no” or “stop.”

3-4 years:

- Begin to be more independent in dressing self with the exception of fasteners, laces, and zippers.
- Independent in the bathroom, although may need help wiping after bowel movement.
- Can feed him or herself with the exception of cutting food.
- Able to help more with daily tasks such as picking up toys and dirty clothes, and brushing own teeth.
- Can follow two step directions such as “pick up your toys, and bring me your blanket”
- Understands the concept of “if, then.” Your child will understand what you mean when you say “*if* you pick up your toys, *then* we can go outside.”
- Your child will be more able to complete chores with your assistance. This provides you with an opportunity to educate your child while they help you complete self and house care tasks. For example, your child may help you set the table. During this time you can take the opportunity to your on skill building in the areas of counting and colors. “We need five spoons” or “Pick the red apples.”
- Can entertain him or herself for up to 30 minutes with supervision.
- Can independently pick up own toys.
- Is able to retrieve a familiar and accessible item when asked.

5-6 years:

- Independent with bathroom and dressing tasks such as tooth brushing, hand washing and putting on clothes and outerwear.
- Can follow multiple step directions especially when part of daily routine such as “pick up your toys, put your shoes in the closet, and brush your teeth.”
- Able to follow through with established chores such as “feed the dog every day,” as long as the chores are set up for them by the parent and the child is given no more than 2-3 chores per day.
- Able to keep themselves entertained for longer periods of time with supervision.

Table 6:

Take this week to track the self care and household responsibilities that are given to your child. Make note of how often your child completes each activity.

Self Care and Household Responsibilities

Monday
Tuesday
Wednesday
Thursday
Friday
Saturday
Sunday

After one week of tracking your children's responsibilities through completion of this chart, go on to the next section to evaluate your child's task completion.

Childcare: Weekly Plan

This week, you will apply your knowledge of finding alternate forms of affection when an increase in symptoms occur, modifying play and family tasks to increase your ability to engage, and identifying age appropriate role responsibilities in self care and household chores.

Affection

During a period of exacerbation this week, use an alternate form of affection, such as physical touch, words of affirmation, or quality time.

Make notes to evaluate your child's response to this form of affection. Also note how you felt about giving affection during periods of symptom exacerbation.

Notes: _____

Play and Family Leisure

This week, engage in modified activities or use your energy conservation techniques when your energy level makes engaging in play tasks with your child more difficult.

Identify which strategies you used and make notes to track the effectiveness of these techniques and your child's response.

Notes: _____

Self Care and Household Tasks

Look back to *Table 6* and determine whether the self care and household tasks your child is completing are appropriate for the age of your child.

List any activities that you notice your child is completing that are not age appropriate.

List self care and household activities that your child could take on to promote responsibility and skill building.

This week, do you need to make any changes to the tasks that your child is responsible for, according to the needs that you have identified through the chart examination?

Change in Responsibility:

If changes were made, make notes to track your child's response to the increase or decrease in responsibility for self care or household tasks.

Notes: _____

After completing one week of the plan, move on to the next section and evaluate the effectiveness of the changes you have made.

Evaluation of Your Plan

Affection

How did your child respond to the different form of affection? Look back to the notes you made during the Weekly Plan.

How did you feel about your ability to provide affection during symptoms exacerbation?

In what ways can you make giving affection easier?

Play and Family Leisure

How did you modify or use energy conservation or promotion techniques during play activities?

How did your child respond to the chosen modification?

How did this provide an opportunity to teach your child about your experience with MS?

Self Care or Household Tasks

What responsibilities did you change? Did you increase or decrease responsibilities, or decide keep them the same?

What was your child's response to the change in responsibility?

Was this change beneficial to your child's role in the family? How or why not?

Was this change beneficial to your role as a mother? How or why not?

Summary

Through this workbook, you have acquired many new concepts and knowledge that will allow you to manage your daily activities and your disease symptoms in order to best benefit your motherhood role. Through the daily tracking of your symptoms and daily activities requirements, you are likely more familiar with how your MS symptoms influence your ability to complete your daily activities. Awareness of your symptoms and their effects on your ability to fulfill motherhood activities helps you determine a plan of action to make activity more effective, efficient, and satisfying through use of energy conservation and promotion. You have skills to carry out a plan of action and turn these skills into daily habits.

You are encouraged to continue to evaluate the outcomes of the strategies you implement in order to continue to nurture your mothering ability. You can continue to assess your motherhood goals through paying attention to how the changes to your daily schedule and activities increase your efficiency, effectiveness, and satisfaction in carrying out your role as a mother. If one of these three areas of efficiency, effectiveness, and satisfaction, has not been positively impacted through your changes and through the use of a particular strategy, you can use your knowledge to revise your plan through choosing more appropriate techniques for your desired outcome.

Your continued evaluation will help you to properly use the skills you have learned to help ease the difficulty you experience across a variety of tasks. You can generalize the information you have learned about adapting self care, household management, and childcare techniques to other areas of daily activity.

You have learned valuable information about balancing your daily activities to make your motherhood role more efficient, effective, and satisfying. Continue to use the beneficial strategies that you have learned as they will become easier through continued use which will form a habit and greater awareness of how to appropriately use each strategy. Practice makes perfect, so make sure to focus on even small successes! Your efforts will directly benefit and enable you better provide care and nurturing to your child or children.

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Month Date, Year

Month, Date, Year

Name
Title
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Address
Address

Dear Occupational Therapist,

We are enclosing an activity workbook as a supplemental therapy resource that you may provide to your patients who are mothers of young children, ages 2-6, and have a recent diagnosis of Multiple Sclerosis. An extensive literature review was completed and informed the creation of this product while the Occupation Adaptation theory was used as the foundation of the workbook structure and outcome goals.

Mothers with MS who are utilizing this workbook may be at different stages of their treatment or may have a variety of treatment regimens. Due to this inconsistency, we have created a workbook which mothers will be able to use as a resource either at times in which they are or are not receiving OT services. When the mother is utilizing both the workbook and OT services, the workbook may act as a facilitator of conversation and client-identified goals that address the motherhood role.

Through the use of this workbook, readers will acquire many new concepts and knowledge that will allow them to manage daily activities and disease symptoms in order to support the motherhood role. Through daily tracking of MS symptoms along with their daily activities requirements, the reader becomes familiar with how MS symptoms influence ability to complete daily motherhood activities. Mothers are also provided with information regarding balancing of energy conservation and promotion techniques in the occupational areas of self care, household management, and childcare. Energy conservation is emphasized in the self care section with strategies involving adjustment of temporal, environmental, and activity components. The use of adaptive equipment is also addressed in this section and the readers are advised to seek out occupational therapy services according to interest in AE and acquisition and training needs.

Energy promotion strategies are emphasized in the household management section as readers learn to recognize the various demands of physical activities. A MET level chart outlines frequent mothering and childcare occupations with the ultimate wellness goal of completing 30 minutes of physically demanding activity per day.

Exacerbation of symptoms is addressed through the balance of energy conservation and promotion strategies. Readers learn to choose the strategy which best compliments their role requirements.

The specific occupation of childcare was addressed in the final section. The literature suggests that mothers with MS are more likely to be perceived by their children as providing less affection during periods of increased symptomology. For this reason, the childcare section provides information on alternate forms of nurturing and affection that mothers may use to compensate for increased symptomology. Mothers are encouraged to use their knowledge of energy conservation and promotion to identify and implement realistic child play tasks and family leisure activities. Finally, the childcare section provides information regarding child participation in household tasks. Such participation is nurturing to the child and has the potential to decrease the mother's workload.

At the end of each section, the reader develops a weekly plan to practice newly learned information and skills. Following the implementation of the weekly plan, mothers are given the opportunity to evaluate their level of success and use of the material provided in each section. Developed according to the occupational adaptation model, the concepts of effectiveness, efficiency, and satisfaction are considered.

Finally, readers are encouraged to continue to evaluate the outcomes of the strategies as they increase their mastery in mothering occupations. Continued evaluation allows the mother to properly use the skills that have been learned, to generalize the use of the knowledge presented, and practice in a variety of tasks and settings.

This workbook is designed to be a valuable supplemental tool for mothers who are experiencing MS. It is the goal of the workbook to provide valuable information about balancing daily activities to make the motherhood role more efficient, effective, and satisfying. Your added assistance as an occupational therapist will directly benefit and enable your patient to have increased confidence in the motherhood role.

Thank you for your time and consideration. If you have any questions regarding the use of this workbook with your patients, please contact the authors at sdavis@medicine.nodak.edu or emeyer@medicine.nodak.edu.

Sincerely,

Skylar Davis, MOTS and Elizabeth Meyer, MOTS

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