

Running head: LIVING WITH MS

Living With Multiple Sclerosis:
Effects on Activities of Daily Living

Raquel Jones

Carroll College

Abstract

Multiple Sclerosis (MS) is a chronic and incurable autoimmune disease that affects the central nervous system. It is one of the leading causes of neurodegenerative disability in persons 20 to 40 years of age. The purpose of this thesis is to explore the difficulties that an individual living with Multiple Sclerosis experiences in his or her everyday life and to give nurses and other healthcare workers a better understanding of how debilitating this disease can be. Phenomenology was the research method selected for this thesis in an effort to understand the meaning of the lived experience of Multiple Sclerosis and its effects on individuals' activities of daily living. Participants for this study included two women who have been diagnosed with MS, one having been diagnosed in her twenties and the other in her fifties. The lived experience of MS was described with the following themes: (a) living with a diagnosis of MS, (b) accessing treatment, (c) coping with the diagnosis and its effects in the family, (d) having supportive relationships, (e) living with a positive attitude. The results of this study concluded that even though MS can affect everyone differently, there are many common themes between the effects that this disease has on the activities of daily living.

Acknowledgements

I would like to acknowledge my grandmother, who was my inspiration for this thesis. I would also like to thank Dr. Joni Walton for helping me to write this thesis and for spending many hours reading and editing it. Finally I would like to thank my readers Kim Garrison and Joan Stottlemyer for also reading and editing my paper many times.

Table of Contents

Signature Page.....2

Abstract.....3

Acknowledgement.....4

Chapter 1

LIVING WITH MULTIPLE SCLEROSIS.....7

Risk Factors.....7

Social Implications.....8

Ethical Dilemmas.....9

Financial Implications.....9

Chapter 2

REVIEW OF LITERATURE.....11

Etiology and Pathophysiology.....11

Types of MS.....12

Goals of Treatment.....13

Early treatment.....13

Treatment of symptoms.....14

Pharmacological treatments.....14

Immunizations.....18

Financial concerns of treatment.....18

Non- Pharmacological Treatments.....19

Exercise therapy.....20

Alternative diets.....21

Multidisciplinary rehabilitation.....22

MS educational resources.....22

Impact on Individual and Family.....23

MS and marriage.....24

Sexuality and MS.....24

Pregnancy.....25

Quality of Life.....26

Chapter 3

METHODOLOGY.....28

Phenomenology.....28

Bracketing.....28

Participants.....29
Confidentiality.....29
Data Collection.....30
Data Analysis.....30

Chapter 4

RESULTS.....31
Living with the diagnosis of MS.....31
 Initial diagnosis.....31
 Reacting to the diagnosis.....33
 Family's reaction.....34
 Researching the diagnosis.....36
Accessing treatment.....37
 Alternative therapies.....40
Coping with the diagnosis and its effects on their family.....43
 Losing independence.....43
 Limiting activities.....45
 Extracurricular activities.....46
Having supportive relationships.....47
Living with a positive attitude.....50
Conclusion.....52

Chapter 5

DISCUSSION.....53
 Living with the diagnosis of MS.....53
 Accessing Treatment.....54
 Coping with the diagnosis and its effects on their family.....55
 Having supportive relationships.....56
 Living with a positive attitude.....57
 Nursing Implications.....58
REFERENCES.....59

Chapter I

Living with Multiple Sclerosis

Multiple Sclerosis (MS) is a chronic and incurable autoimmune disease that affects the central nervous system. It is one of the leading causes of neurodegenerative disability in persons 20 to 40 years of age (Ignatavicius & Workman, 2006). A cure for this debilitating disease has not yet been discovered; therefore individuals with MS must solely rely on treatments which decrease the progression of the disease and ease the common symptoms (National Multiple Sclerosis Society [NMSS], 2007d). Individuals with MS experience a wide variety of debilitating symptoms including the following: bladder and bowel dysfunction, decrease of cognitive functioning including difficulties with memory, attention, and problem solving skills, dizziness, depression, fatigue, difficulty walking, numbness, pain, sexual dysfunction, involuntary muscle spasms, and vision problems (NMSS, 2007f). The purpose of this thesis is to explore the difficulties that an individual living with Multiple Sclerosis experiences in his or her everyday life and to give nurses and other healthcare workers a better understanding of how debilitating this disease can be.

Risk Factors

There are approximately 400,000 Americans living with MS, and 200 more individuals are diagnosed every week. Most individuals with MS are diagnosed between the ages of 16 and 40. It is very rare for the diagnosis to occur before the age of 16 or after the age of 60, although it is possible (Wood, 2007). More than half of all MS diagnoses occur in women, causing a ratio of 1:2 between the men and women who are diagnosed. However, this ratio between men and women becomes more balanced when

people are diagnosed later in life (NMSS, 2007h). MS is primarily seen as an adult disease; however the number of children and adolescents being diagnosed is slowly increasing due to new technology that enables us to view the brain (NMSS, 2007e). MS occurs mostly in the Caucasians. It affects twice as many Caucasians as it does African Americans, and it rarely occurs in the Asian population (Wood, 2007).

Another risk factor for the development of MS relates to temperature and climate. Statistics have shown that individuals who grow up in colder climates, as opposed to more tropical, warmer climates, have an increased risk for developing MS. Studies have proven that individuals who move from warmer climates to colder climates before the age of 15 have a higher risks for developing MS, whereas the opposite is true if a person moves from a colder climate to a tropical climate prior to the age of 15. Exactly why colder climates put people at a higher risk for developing MS is still unknown (Wood, 2007).

Social Implications

Multiple Sclerosis affects not only the individual who has the disease, but also everyone who surrounds and cares for the individual. Caring for someone with MS can be physically and emotionally exhausting (NMSS, 2007b). Not only does the caregiver care for the individual's physical needs, but also his or her emotional and social needs as well. According to a recent study, "women with MS may be at more risk for loneliness due to social network changes that occur in the course of chronic illness" (Beal & Stuijbergen, 2007 p. 2). This can potentially put more stress on the caregiver, making caring for a woman with MS more emotionally draining. However, research has also shown that individuals with MS who have a supportive person involved in their care are

more likely to accept the disease (Harrison, Stuijbergen, Adachi, & Becker, 2004).

Therefore, these individuals are more likely to accept having MS and continue on with life as much as possible.

Ethical Dilemmas

Many ethical implications revolve around individuals with MS. One of the biggest issues surrounding persons with MS is health insurance. Because many individuals with MS eventually become unable to work, health insurance often becomes unavailable; Medicaid or Medicare will not cover all forms of treatment. Another major ethical implication has to do with women diagnosed with MS and pregnancy. Many of the MS treatments can harm the developing fetus which means that the mother would not be able to take them during pregnancy and breastfeeding. This could make for a very difficult pregnancy as well as a difficult decision on whether or not to get pregnant (NMSS, 2006). If the woman is not sure that she wants to carry a child and her spouse would really like to have a family, this can put a tremendous amount of stress on the relationship between a woman with MS and her spouse.

Another major ethical issue that many individuals with MS face centers around anxiety related to treatment. Many of the medications that are available for the treatment of MS have potentially dangerous side effects. An individual with MS faces the choice to take the medications along with the potential side effects that can occur or look for other alternative treatments that may not be as beneficial (NMSS, 2006).

Financial Implications

The financial implications for an individual with MS can be very shocking. The cost of treatment and therapies alone can range from 30,000 to 50,000 dollars per year

depending on the severity and type of MS that an individual has (NMSS, 2007d). On top of this, the cost of assistive devices such as walkers, canes, and wheelchairs can add to the expense when a person becomes dependent on such devices due to debilitation from the disease. If the disease becomes severe enough, the individual may no longer be able to work and provide for his or her family, which causes more of a financial struggle.

Despite the fact that a cure for MS has yet to be discovered, researchers are still working on finding a cure with the millions of dollars that are donated by foundations every year. In 2006, the National MS Society alone was able to raise “over \$46 million to drive research in 380 Society –funded research projects” (NMSS, 2007a). Although this may sound like a lot of money, the cost of research still needed to be conducted greatly exceeds this amount.

Chapter II

Review of Literature

An individual with MS and his or her family have to adapt to many emotional and physical challenges which begin at the moment of diagnosis and continue for the rest of the individual's life. Currently there is research being conducted with the ultimate goal of finding a cure for this disease, as well as identifying treatments to manage symptoms. Researchers are also exploring the experiences of patients with MS and the impact that it has on individuals as well as their families (NMSS, 2007c). The goal of this research is to not only manage symptoms and slow progression of the disease, but also to improve the quality of life for individuals with MS. This review of literature will summarize treatment, medications, activities, diet, stress, and education.

Etiology and Pathophysiology

Multiple Sclerosis is a demyelinating disease which affects the brain and the spinal cord, also known as the central nervous system (Ignatavicius & Workman, 2006). Myelin is a fatty tissue that surrounds and protects nerve fibers. MS results when the body's immune system attacks myelin producing cells. When myelin has degenerated in multiple areas, scar tissue or sclerosis develops (NMSS, 2007c). As sclerosis develops around the nerve fibers, the electrochemical transmission of nerve impulses between the brain and spinal cord and the rest of the body decreases in effectiveness. In time nerve transmission can become completely blocked (Ignatavicius & Workman, 2006). This sclerosis of the nerve fibers is the primary cause of the loss of sensation that many MS patients experience.

Types of MS

There are four major types of MS: relapsing-remitting, progressive-relapsing, primary-progressive and secondary-progressive (Ignatavicius & Workman, 2006). Relapsing-remitting occurs in 85% of MS cases at initial diagnosis, making it the most common type of MS (NMSS, 2007c). People with this type of MS will experience acute periods of relapse in neurological function. This is followed by recovery periods that are free from disease progression. Progressive-relapsing MS is a rare form of the disease, occurring in only 5% of all cases. People with this type of MS will experience a continual decrease in condition from onset of disease. They also have clear acute relapses that may or may not be followed by a recovery period. Unlike relapsing-remitting MS, progressive-relapsing has periods of progression that occur during the periods between relapses. Primary-progressive MS is also a rare form of the disease, occurring in approximately 10% of MS cases. This type is characterized by a slow, continuous worsening of the condition from initial diagnosis, with no distinct periods of relapse. Primary-progressive MS is also characterized by varied progression rates over time in which plateaus and minor improvements may occur. Secondary-progressive MS is developed by 50% of relapsing-remitting MS individuals within 10 years of their time of diagnosis, before the introduction of treatment medications. This type is characterized by an initial diagnosis of relapsing-remitting MS with progressive worsening of the disease that may or may not occur with relapses, and minor recoveries or plateaus (NMSS, 2007c).

Goals of Treatment

Current available treatments for MS focus on management of symptoms, treatment of exacerbations, and decreasing the progression of the disease. Though many of these treatments can be very beneficial to the individual with MS, the actual treatment of choice may depend on the person's level of severity of the disease. Because each case of MS can be very different, it is important for nurses and other healthcare providers to monitor for adverse effects of these treatments. It is also crucial that the nurse monitors for adverse effects related to combination therapies because more often than not, people with MS are taking more than one disease-modifying medication which have the potential to adversely react with each other (NMSS, 2007g). The nurse should also be knowledgeable regarding current alternative treatments so that he or she can aid the individual with MS in seeking other treatment options in order to help improve quality of life.

Early treatment. For a long period of time it has been unknown whether or not early treatment can actually slow the disease progression of MS. However, new developments have shown that early treatment can in fact slow the progression of MS. Early treatment in individuals who have had a first event suggestive of MS, but who have not yet been diagnosed, can slow the rate at which the debilitating effects of the disease progress. In one study, there were 418 participants who had suggestive signs of MS; 216 of these participants received early treatment and the other 157 did not receive any treatment at all. The treatment was the drug Betaseron, which is clinically proven to slow the progression of MS in individuals who have already been diagnosed. After a one year follow-up, only 37% of the individuals receiving treatment developed MS, whereas 51%

of the individuals not receiving early treatment developed MS. This showed a 41% reduction in the risk of developing definite MS, if early treatment was received. This study is planning to follow up with the individuals involved in another year (NMSS, 2007g).

Treatment of symptoms. There are currently many drugs that prevent the progression of MS; however these drugs do not treat the various symptoms that come along with MS. Therefore, various other medications are designed to treat specific symptoms of MS, such as the following: fatigue (Amantadine), tremors (Isoniazid), erectile dysfunction (Vardenafil), bladder dysfunction (Oxybutynin), and constipation (Mineral Oil) (NMSS, 2007f). These are just a few of the common symptoms and drugs routinely used to treat them. In giving other drugs to treat common symptoms along with disease modifying medications, proper care must be taken in order to prevent potential combination drug reactions (NMSS, 2007f).

Pharmacological Treatments

There are many prescriptive medications currently being used for treatment of MS-related symptoms, although there are some that are used more than others. A commonly used medication is interferon beta-1a. Interferon beta 1-a is used for the treatment of relapsing-remitting MS in order to decrease the frequencies of exacerbations and slow the progression of the disease (Micromedex, 2008, p. 1). This drug is approved by the FDA and is only recommended for individuals over the age of 18. Currently there are two different interferon beta-1a medications that are approved by the FDA for the treatment of MS, Avonex and Ribef. Avonex is an intramuscular (IM) drug that is given once weekly. It is prescribed for individuals with relapsing forms of MS to decrease the

frequency of exacerbations and slow the progression of the disease and its disabling symptoms (NMSS, 2007g).

In a controlled clinical study with over a hundred individuals with relapsing MS, Avonex was found to slow the progression of disability, decrease exacerbations, and reduce the number and size of active lesions on the brain as shown by an MRI. These results were compared to a group receiving placebo treatments (NMSS, 2007g). The progression of the disease was measured via the Expanded Disability Status Scale (EDSS). The EDSS “is a method of quantifying disability in MS and monitoring changes in the level of disability over time” (Multiple Sclerosis Trust, 2008, p. 1). It is widely used in clinical trials and in the assessment of people with MS. The EDSS scale is scored from 0 to 10 in 0.5 increments, with 0 being no disability at all. The reliability and validity of the EDSS is .92. Although this scale is widely used, it is often criticized for using walking as the main measure of disability (Multiple Sclerosis Trust, 2008). Therefore in this study, individuals’ baseline EDSS scores were compared to their EDSS score after taking Avonex (NMSS, 2007g).

Ribef is the second FDA-approved interferon beta-1a drug for relapsing MS. It is to be taken subcutaneously three times per week. In a randomized three-year study on 557 people taking the interferon beta-1a Ribef versus people taking placebo medication, the people who were taking Ribef had significantly lower relapse and exacerbation rates within the three-year period. Therefore, the interferon beta-1a was proven to be more effective than the placebo in this study (Micromedex, 2008). It also decreased the number of lesions on the brain and also decreased the progression of disability. In comparing the outcome of Ribef and Avonex, the FDA found that individual who take 44 micrograms

(mcg) of Ribef three times per week were more likely to be relapse free at 24 and 42 weeks, as compared to individuals taking 30mcg of Avonex once per week (NMSS, 2007g).

Betaseron is another form of the interferon; however this is a beta-1b drug rather than a beta-1a. It is proven to have similar results as Ribef. This medication is also used for individuals with relapsing MS, and it is recommended that this medication be given subcutaneously every other day in order to be effective, and therefore strict adherence is required for expected effectiveness. In a clinical study of 372 individuals with relapsing-remitting MS, those who took the current recommended dose of Betaseron not only had fewer and less severe exacerbations, but they also had longer periods of time between exacerbations. These results were compared with individuals receiving placebo medication and individuals taking lower doses of Betaseron. Additionally, all of the individuals who received Betaseron experienced no growth in brain lesions, viewed on MRI, whereas brain lesions in the placebo group showed a significant increase (NMSS, 2007g).

Tysabri, or Natalizumab, is used by individuals with MS who are unable to take other commonly used medications such as Interferon Beta blockers. It is a monoclonal antibody that is given by intravenous (IV) infusion once monthly in a clinical care setting. It is made to impede movement of damaging immune cells from the bloodstream into the brain and the spinal cord. According to a two-year clinical study in which individuals with relapsing MS taking Tysabri were compared to individuals who took a placebo medication, Tysabri was proven to be an effective medication for the treatment of relapsing MS. Individuals who took Tysabri had a reduced risk for disability

progression and fewer exacerbations as compared to the placebo group. However, Tysabri was also proven to increase the individual's risk for progressive multifocal leukoencephalopathy (PML), a viral infection that occurs in the brain and can potentially lead to severe disability or death. Though PML occurred only in patients who were taking other immunomodulating or immunosuppressing drugs along with Tysabri, there is not currently enough evidence to prove that this cannot occur while just taking Tysabri alone. Because of this, Tysabri is only recommended to individuals who cannot tolerate other disease modifying medications that are available for the treatment of MS (NMSS, 2007g).

Scientists are studying many different medications and their effects when taken with other disease-modifying drugs. Currently, researchers have discovered that one dose of the IV drug Rituximab can reduce disease activity and relapses for 48 weeks in people with relapsing MS. This medication is known to “deplete immune B cells, which may play a role in the immune attack on the brain and spinal cord tissues in MS” (Hauser et al, 2008, p. 2). In this study, two IV infusions of Rituximab were given two weeks apart to 69 individuals with relapsing MS. Thirty-five other individuals were given placebo infusions. The main goal of this study was to determine this drug's effect on inflammation of the brain which may elicit an attack. After 24 weeks, the number of active lesions was reduced by 91% in the group receiving Rituximab, compared to those in the placebo group. The individuals receiving Rituximab also experienced a decrease in relapses. This suggests potential for a new therapeutic approach for treating MS (Hauser et al., 2008).

Immunizations. There are many questions regarding whether or not individuals with MS should receive certain immunizations. According to the National Guidelines Clearinghouse (NGC) (2008), individuals who have MS should follow the Centers for Disease Control (CDC) indications for the proper immunizations (Rutschmann, McCrory, & Matchar, 2002). NGC also recommends that people with MS should delay vaccinations during relapses until they have begun to improve or they are stabilized. However if they need a tetanus vaccination due to a wound, they should not delay it, even if they are in the midst of a relapse. As with the influenza vaccination, it is recommended that the vaccine should be given on an individual basis, dependent upon their physician's expert opinion. The pneumococcal vaccine is only recommended for individuals with MS who have compromised pulmonary function, such as bed-bound or wheel-chair dependent people (Rutschmann, McCrory, & Matchar, 2002).

Financial concerns of treatment. Although there are many pharmacological treatments for MS available, individuals with MS in the United States often face financial barriers when it comes to obtaining prescription medications. Though many individuals with MS do have health insurance, the cost of medications for MS is often so high that insurance does not cover enough for the individual to be able to afford them. This study was conducted in order "to explore how financial and health insurance concerns affect access to services including MS drugs" (Lezzoni, Ngo, & Kinkel, 2008, p.1). There were 983 participants between the ages of 21 and 64 with MS who participated in a thirty-minute telephone survey regarding their insurance (if they had it) and access to medications. Ninety-six point three percent of the participants had some sort of insurance. However, "22.3% reported having not filled prescriptions, skipping doses or splitting

pills because of cost concerns,” while “22.4% worried ‘a lot’ about getting MS medications when they needed them” (Lezzoni, Ngo, & Kinkel, 2008, p.1). Therefore this study concluded that even when an individual with MS has health insurance, it does not mean that he or she has access to various prescriptive medications and other alternative treatments. Nurses need to be aware of the financial barriers that many individuals with MS face when it comes to their access to treatment. Nurses should be prepared to search for other treatment options that may be more affordable for the person.

In caring for individuals with MS, there are many effective interventions that nurses and members of the healthcare team must consider. It is critical that nurses understand the drugs that their client with MS is taking so that they know the correct dosages, the potential side effects, and whether or not they have the potential for a drug-related reaction.

Non- Pharmacological Treatments

There are several alternative or complementary therapies available to individuals with MS. If an individual would prefer to combine various non-pharmacological therapies with medications, then the other therapies are referred to as “complementary.” However, if an individual would prefer to just have non-pharmacological therapies and no medications, then the therapies are referred to as “alternatives” (NMSS, 2007g). According to the National MS society, approximately 75% of individuals diagnosed with MS in the U.S. are currently using some form of complementary or alternative treatment (NMSS, 2007d). Some of the common therapies used are exercise, altered diet, and various methods of rehabilitation. When working with a patient with MS, the nurse

should be encouraging and helpful while the patient is considering complementary and alternative options for treatment.

Exercise therapy. At this time, there have not been any interventions found to be effective in modifying the long-term disease process that accompanies MS. However, many individuals with MS find exercise therapy to be a beneficial form of treatment for management of symptoms (Rietberg, Brooks, Uitdehaag, & Kwakkel, 2005). Therefore, in an attempt to prove whether or not exercise therapy aids in the outcome of MS, the Cochrane database analyzed several studies that were previously conducted. These analysts wanted to know whether or not exercise therapy was effective for patients with MS in terms of health-related quality of life and activities of daily living (Rietberg, Brooks, Uitdehaag, & Kwakkel, 2005). After analyzing several studies, they concluded that exercise therapy is in fact beneficial for MS patients. However, exercise is not helpful for an MS individual who is experiencing an exacerbation. These analysts also concluded that there is not one particular exercise therapy that is proven to be more beneficial than others.

Though the Cochrane database identified that there is not one particular type of exercise that is more beneficial than others, researchers identified that progressive resistance exercise can be very beneficial for MS. This study was conducted to determine whether or not “participation in a progressive resistance exercise program can: (1) increase the ability to generate maximal muscle force, (2) increase muscle endurance, (3) increase functional activity, and (4) improve overall psychological function of people with multiple sclerosis” (Taylor, Doodd, Prasad, & Denisenko, 2006, p. 1). This study included nine participants with a mean age of 45.6 years old. These participants went to

the gym three times a week for the first four weeks in order to obtain a baseline and become familiarized with a routine. The routine included two sets of ten to twelve repetitions for each weight-bearing exercise. Following this, the participants then completed an individual ten-week progressive resistance exercise program, during which they went to the gym twice per week. When the ten weeks were up, significant improvements were found in comparison with the participants' baselines. Improvements were in arm strength, leg endurance, walking speed, and distance, with a decrease in the adverse effects of MS. Therefore, this study concluded that adults with MS benefited from progressive resistance exercise "by improving muscle performance and physical activities" (Taylor, Doodd, Prasad, & Denisenko, 2006, p.1).

Alternative diets. Many individuals with MS choose to make alterations in their diets because "clinical and experimental data suggests that certain dietary regimens, particularly those including polyunsaturated fatty acids (PUFAs) and vitamins might improve outcomes in people with multiple sclerosis (MS)" (Farinotti et al. 2007, ¶ 1). Therefore special diets and supplements are used frequently by people with MS in hopes that they might help slow their disease process. In an effort to prove whether or not PUFAs would actually improve outcomes in people with MS, the Cochrane database analyzed the results of several studies that were previously conducted. In doing so the Cochrane database found that "PUFAs did not have a significant effect on disease progression, measured as worsening of Disability Status Scale" (Farinotti, 2007, ¶ 7). Therefore it is concluded that there is currently an insufficient amount of data regarding the effects of PUFAs on persons with MS.

There are numerous diets that many individuals with MS feel are very beneficial

for management of their symptoms. However, due to a lack of evidence proving the effectiveness of alternative diets related to MS, it is still uncertain whether modifying the diet can actually affect the management of MS symptoms.

Multidisciplinary rehabilitation. Several individuals with MS have turned to multidisciplinary rehabilitation as an alternative or complementary therapy for treatment of their MS. Multidisciplinary rehabilitation can include anything from physical therapy, occupational therapy, therapy for speech and swallowing problems, cognitive rehabilitation, and vocational rehabilitation (NMSS, 2007g). According to researchers, “multidisciplinary rehabilitation (MD) is an important component of symptomatic and supportive treatment for Multiple Sclerosis” (Khan, Turner-Stokes, Ng, & Kilpatrick, 2005, p. 1). In order to prove whether or not MD rehabilitation therapy is effective or not, the Cochrane database analyzed previously conducted studies. They wanted to “explore rehabilitation approaches that are effective in different settings and the outcomes that are affected” (Khan, Turner-Stokes, Ng, & Kilpatrick, 2005, p. 1). In the end they concluded that though MD rehabilitation does not affect an individual’s level of impairment, it can improve the individual’s quality of life in terms of participation in activities and social life.

MS educational resources. In an effort to decrease the common stress and anxiety that most individuals with MS experience, many people with MS look for educational resources for information about the disease. When looking for educational material regarding MS, there are many resources to turn to. Today the most common source for individuals to find health related information is the internet; however there are many websites that are not scholarly sources and therefore may not provide accurate

information. A good educational source for individuals to find information is the National Multiple Sclerosis Society. This is an accredited resource where patients can find information about anything that they are interested in regarding MS. Another online source that can be very helpful when looking for the validity of current research is the Cochrane database. This online database analyzes many similar research studies and compares them to see if their results coincide with each other. This is an excellent resource for individuals who are seeking validity and reliability of certain therapeutic regimens and their effectiveness related to the treatment of MS.

When caring for individuals with MS, it is important for nurses to be able to aid patients in seeking other alternative and complementary therapies. The nurse should be knowledgeable about these possible alternative treatments and should give the patient information as necessary. It is important that the nurse has a good understanding of the benefits of these therapies so that he or she can be informative and encouraging for the MS patient who is showing interest in them.

Impact on Individual and Family

Not only does MS affect the individual who is diagnosed, it also affects the family members of that individual. MS can have a profound effect on the stress of individuals and family members. The disease can be stressful for a marriage when the spouse becomes the caregiver (Courts, Newton, & McNeal, 2005). MS can also have a big effect on the diagnosed individual's sexuality and his or her desire for intimacy (Barrett, 1999). Another issue for women that MS can have a major effect on is pregnancy, or the desire to start a family. A woman with MS has to decide whether or not she wants to risk her MS becoming more severe with pregnancy. These issues as well as

many others that can come with the MS disease process can make for a poorer quality of life for an individual diagnosed with MS.

MS and marriage. Coping with the challenges that come along with MS is not only challenging for the person who is diagnosed, but also for his or her spouse. This is because the spouse without MS often takes on the role of the caregiver (Courts, Newton, & McNeal, 2005). According to researchers, “spousal caregivers of people with MS face unique challenges and demands. With its physical, social, and psychosocial effects, the disease permeates all aspects of family life” (Courts, Newton, & McNeal, 2005, p. 20). A tremendous amount of stress can occur when the spouse without the diagnosis attempts to continue his or her roles as a husband or wife and possibly a mom or a dad, while being an active caregiver at the same time.

In a recent qualitative interview consisting of twelve individuals (8 male and 4 females) with a diagnosis of MS and their marital spouses, researchers attempted to figure out the roles that men and women generally take on in an MS marriage. In listening and observing the open discussion, researchers found that within the MS marriage, men and women tend to take on different roles depending on whether the husband or wife has the diagnosis. In a marriage where the wife had the diagnosis, the husband often tried to protect and nurture his wife, in an attempt to conserve her energy. On the other hand, if the husband is the spouse who had the diagnosis, his wife often encouraged independence in her husband (Courts, Newton, & McNeal, 2005). Although this was a qualitative study, it had several limitations including a small group, only one encounter with the group, and all heterosexual couples.

Sexuality and MS. A common occurrence for individuals diagnosed with MS is to

experience a decrease in sexuality. While trying to adjust to the uncertainties that accompany MS, many individuals may “experience a decline in their sexual interest, frequency, and enjoyment” (Barrett, 1999, p. 4). These effects can occur due to direct, indirect, or interactive causes. Direct causes include a decrease in the bodily functions of sensation or movement. Indirect cause can include a loss in sexual interest due to distractions caused by a major life change, anxiety related to the disease process, and psychological and social stressors. When a combination of both direct and indirect causes leads to a decrease in sexual interest, it is referred to as “interactive causes.” Many individuals with MS experience a decreased sexual interest due to interactive causes (Barrett, 1999).

Pregnancy. For a woman with MS, the decision of whether or not to get pregnant and start a family can be a major issue. This is because during and after the pregnancy the woman will be unable to take her MS medications. This makes being pregnant a lot harder for women with MS. With MS and pregnancy, the woman is at increased risk of harming her body not only during the pregnancy but also during the postpartum period (Gulick, 2007).

For every new mother, the postpartum period brings increased family demands. However, for a postpartum mother who has MS, the ability to cope with the increased symptoms and decreased everyday functioning in the first year postpartum may suggest the need for additional support. This study investigates the effects of additional support for postpartum mothers with MS. It was conducted after a previous study that concluded that 60% of postpartum women with MS had not fully regained their usual level of household activities by six months postpartum, suggesting a continuing need for support

during the second six months postpartum. There were 172 participants included in this study. These participants were questioned during the second six months of their first postpartum year. This study concluded that postpartum mothers with MS who had received social support, especially emotional support, reported higher levels of everyday functioning. Social support limited the effects of MS symptoms on functional performances, and therefore made an easier postpartum experience for mothers with MS (Gulick, 2007).

It is very important for nurses to have an understanding of the different pregnancy and postpartum period that a mother with MS experiences. The nurse needs to be sure that a new mother with MS has an adequate support system so that she can make it through these difficult periods.

Quality of Life. There are not many scales that have the ability to accurately measure a person's perception of his or her own quality of live (QOL). In patients with MS, a quality of life instrument called The Functional Assessment of Multiple Sclerosis (FAMS) is often used to measure individuals' QOL. The FAMS consists of 44 questions that include questions regarding mobility, symptoms, emotional wellbeing, general contentment, family and social wellbeing, and general thinking and fatigue. The score can range from 0-176, with 0 representing a poor QOL. The test-retest reliability and validity of the FAMS is .90 (Tripoliti, Campbell, Pring, & Taylor-Goh, 2007).

In one particular study, the FAMS was used to compare the QOL scores given by people with MS versus proxy scores given by close relatives. Forty individuals with MS completed the FAMS as well as a proxy (close relative or friend) who was chosen by each of them. These people were interviewed in their homes, separate from their chosen

proxies. The results showed a .62 correlation between the individuals with MS and their proxies. This was comparable to other studies in which the proxies underestimated the scores of the individuals with MS who have high QOLs and overestimated the scores of individuals with low QOLs (Tripoliti, Campbell, Pring, & Taylor-Goh, 2007).

Chapter III

Methodology

Phenomenology

Phenomenology is “a philosophy and research method that explores and describes everyday experiences as it appears to human consciousness in order to generate and enhance the understanding of what it means to be human. Phenomenology limits philosophical inquiry to act of consciousness” (Russell, 2004, p. 220). It is a research method that looks at the views of the human’s conscious experiences through a first person point of view. According to Russell “In phenomenological terms, these experiences are called the lived experience” (Russell, 2004, p. 220). Therefore, this method was selected in an effort to understand the meaning of the lived experience of Multiple Sclerosis and its effects on individuals’ activities of daily living.

Data collected from this study used a qualitative perspective to explore the experience of MS. “Research emerging from this perspective could center on understanding from the patients view point, discovery of social processes, and descriptions of happenings” (Russell, 2004, p. 221). The purpose of this study was to gain an understanding of the meaning of living with MS and its effects of activities of daily living.

Bracketing

When a researcher is using bracketing, it “requires the researcher to identify any previous knowledge, ideas, or beliefs about the phenomenon under investigation” (Russell, 2004, p. 221). While researching and analyzing data concerning MS and its effects on activities of daily living, the researcher was fully aware of any bias or

misconceptions about MS that she already had. This “allows the researcher to remain impartial to beliefs or disbeliefs” that she may have regarding MS prior to her research (Russell, 2004, p. 221).

The researcher’s interest in the lived experience of MS and its effects on activities of daily living come from her observation of the profound affects that MS has had on a close family member. The researcher has viewed the detrimental effects that this disease process has had on her family member for the last 20 years. Because of her personal tie with MS, the researcher acknowledges that she does have some partiality concerning living with MS and its effects. The researcher personally believes that the diagnosis of MS is a life-changing event for not only the individual, but also his or her family.

Participants

Participants for this study included two women who have been diagnosed with MS, one having been diagnosed in her twenties and the other in her fifties. Currently they both range in age from 50 to 73. The participants have experienced what it means to live with MS and its debilitating effects on activities of daily living. Participants were both able to communicate in English and exemplify that they were a reliable source in regards to living with MS and its effects. These participants were recruited by word of mouth and then given the researcher’s contact information so that they were able to contact the researcher at their own convenience.

Confidentiality

An informed consent form was given to the participants and signed by them before the interviews were conducted. One of the participants met with the interviewer in a mutually agreed upon, private location, while the other opted to do the interview by

phone. Any identifiable information regarding the participants such as names or addresses was locked in a personal computer file and was not disclosed.

Data Collection

Information collected during the interviewing process was recorded via audio tape. The interviewer also took field notes during the interview. Participants were asked questions regarding their age of diagnosis, their current and past symptoms, treatments used, and the effects of the disease on their family members and their activities of daily living.

Data Analysis

This study followed Giorgi's Method, which required an interview and written descriptions of 2-10 participants who have lived the experience under study (Russell, 2004). Once the interviews were completed, the researcher read through the entire description of the lived experience so that she was able to obtain a sense of the participant's perspective. The descriptions were then reread to explore the meaning or ideas behind the lived experience. These meanings or ideas were transcribed into themes which are to be observed for redundancies, elaboration, and clarification. The meanings of these themes all relate to each other in order to make sense of the whole experience (Russell, 2004). The researcher was sure that the themes within each interview correlated with one another in order to portray an accurate sense of the lived experience as a whole.

Chapter IV

Results

The purpose of this qualitative study was to gain an understanding of what it means to live with MS and its effects on activities of daily living. The findings of this study revealed that MS can affect everyone differently; there are many common correlations between the effects that this disease has on the activities of daily living among the participants. These common findings were grouped into the themes, according to Giorgi's phenomenological analysis. The themes are as follows: (a) living with a diagnosis of MS, (b) accessing treatment, (c) coping with the diagnosis and its effects on the family, (d) having supportive relationships, and (e) living with a positive attitude.

For this study the sample population consisted of two women, one from a suburb of Seattle, WA and the other from a small, rural town in Montana. One of the women was diagnosed in her fifties and is currently in her seventies while the other woman is currently in her forties and was diagnosed in her twenties. Therefore both of these women were diagnosed around the same time twenty years ago. Both of these women were elementary school teachers at the time of diagnosis and they both currently have grown children.

Theme 1: Living With the diagnosis of MS

Initial diagnosis. The devastating effects that the presenting symptoms of MS can have on an individual are absolutely profound, causing an immense amount of stress and worry that can only make their symptoms worse. This was clearly evident for the individuals in this particular study. Both participants were diagnosed in the late 1980s when access to treatment was limited. Participants expressed that they were fearful of the

diagnosis and symptoms of MS. Symptoms such as tingling, numbness, extreme fatigue, blurry vision, and difficulty waking were some of the common symptoms that both of the participants shared. The first participant interviewed, whom we will call “Kim” to protect her confidentiality, discussed her initial presenting symptoms:

I was diagnosed in 1988; however I have been symptomatic since the age of 18. I didn't really know what was going on. . . I used to go running all the time but I noticed sometimes I would get really tired and I would just be totally wiped out but I wasn't sure why. . . The first symptoms I had were tingling and numbness which feels like pins and needles in my hands and on my inner chest wall for probably about 3 or 4 months and I kept thinking this will go away.

The second participant, “Sarah” had similar symptoms; however hers seemed to be far more severe by the time she was diagnosed because the healthcare system simply did not have the technologies available at the time her symptoms began. Sarah expressed the following concerns:

I had difficulty walking. . . I would trip all the time. . . I was very fatigued all the time; I had a great difficulty with swallowing anything. . . I had blurry vision and for a while my vision was split. . . I was diagnosed in 1987 because that's when they had the first MRIs. When looking at the MRI I had only a slight amount of lesions and damage. . . The biggest area of damage is actually in my spine. This damage in my spine is what affects my lower body, which has been the biggest problem for me. . . I had symptoms since 1961 but the doctors didn't know what was wrong with me because they couldn't see the nerves within my body and my

symptoms were relatively mild compared to the severe symptoms that other people had that were being diagnosed with MS at the time.

Kim was also diagnosed via an MRI; however she went through a very rough time before this actually occurred and shared the following experience:

I lost my eyesight one night, and I kept running into the walls because my balance was off. I could not walk straight or turn around corners without hitting the wall. So we went to the emergency room thinking that I had possibly had a stroke because my speech was also slurred. . . They did an MRI and they thought that I might have a brain tumor which having two small children at home and being a young mom was not anything that I wanted to hear. So they sent me to a neurologist in Billings. . . I actually saw two different neurologists. . . They sent my MRIs with me that they had taken at my home hospital and on that MRI you could just see what looked like a light bulb right in the center of my brain. . . Then later on they ended up diagnosing me with MS because it is in my family; my aunt does have it so they do think that there is a greater family history of MS in my family.

Reacting to the diagnosis. Being diagnosed with a lifelong disease was devastating for participants. Participants were diagnosed with a chronic debilitating disease and expressed that this was a disease that they knew little about. Kim had a family member with the disease, and after seeing what she had gone through, she was very frightened and shared the following:

I knew that my aunt had it and I knew that I had watched her go from being able to walk and be a fully functioning individual with her own business to being

bound to a wheelchair and having to have other people do almost everything for her. . . . And knowing what had happened to her, I knew that this was not a good disease and that it was definitely not something that I would want to have. It was really scary for me because I knew that I had two kids to raise and that I had to be able to care for myself so that I could take care of them.

Although Sarah's children were grown and able to care for themselves by the time she was diagnosed, she also had a lot of fear regarding the unknown of the diagnosis and stated:

I didn't know much about it at all. . . . I was completely shocked. . . . I had a very hard time accepting the diagnosis. I am a big believer in positive talk, and I figured that if I told myself that everything was going to be all right then it was going to be ok. But suddenly it wasn't going to do any good to tell myself that everything was going to be ok because everything was not ok.

Family's reaction. When an individual is diagnosed with a chronic disease that not a lot of people know much about, it not only affects the individual but also his or her families. The fear of the unknown regarding how this disease will affect the family member is very scary for everyone involved. On top of this, the individual fears what will happen to his or her family if this disease progresses to a very severe point. When Kim was diagnosed, she had a family that she was still raising and taking care of. She was very fearful of what might happen to them and shared this story:

My kids were very young so they didn't really understand what was going on; however they did know that they had to help out a little more. My family of course was devastated because they didn't think that any of us were ever going to

get it. . . My parents were a good support system during that time, not so much physically because they lived in a different city but they helped out a lot emotionally to talk to. . . My husband of course had to do more things around the house.

Because Kim's children were very young at the time of her diagnosis, they were unable to really understand what was going on with their mom. However Sarah had the exact opposite issue at the time of her diagnosis and said:

When I was diagnosed my children were already grown and out of the home. But they never really understood why I was always so tired all the time or how I could just get in the car and fall right to sleep. They didn't understand that I was always very fatigued. . . My family also noticed that I tripped very easily and that I was always falling but they took it "matter of factly" because that's the way that I took it. As far as my husband goes, it always bothered him that I was constantly falling; he was very concerned. . . At the time of my diagnosis my family was very confused. I didn't know much about the diagnosis so I couldn't really tell them much so they were very alarmed. There wasn't a whole lot of information available to us, and so I was trying to find out what was going on and so were they, which made for a very confusing time for everybody. None of us really knew what was going on and what the prognosis would be and that was scary for all of us.

Sarah's children were grown and had watched their mother have these symptoms throughout their childhood; this made it very difficult for them when their mother was diagnosed with a lifelong disease that they knew nothing about.

Researching the diagnosis. Like many others who are diagnosed with MS, these women did not know a whole lot about the diagnosis of MS, other than what their doctors had told them. Because of this, they educated themselves and found research on the disease. While conducting this research, both participants found that the Multiple Sclerosis Society was the best source of information. While Sarah was conducting her research, she found that the library was the least helpful to her and stated:

I got a lot of information from the MS Society. We didn't have the Internet at that time so information was less accessible. . . I found that the worst place to go was the library because their books were so outdated. . . And I have found that information on MS can practically be thrown out every ten years because of all of the new information that they are continually finding. So my main source of information was from the MS Society because it was the latest information. . . The MS Society would also let me know whenever new MS books came out and then I would go buy them and read them.

Kim conducted very similar research and found the resources from the MS society were very informative as well. Kim described the process:

Being an avid reader and a teacher, I went straight to the library the internet. . . I also had the MS Society sending books to learn about the disease because I think that it is important to educate yourself. I learned a lot about the symptoms of MS and especially how stress relates to the disease and how it can exacerbate the symptoms. I educated myself as much as I possibly could.

After having researched the diagnosis, both the women reported feeling more at ease about it. Sarah reported that she and her husband try and keep up with all of the latest research on MS:

Because I live in the Seattle area, every year they do seminars on managing MS and the latest research. . . My husband and I make ourselves go to a seminar at least once a year so that we know what the current research is and what the recommendations are. There are so many different research studies on MS that are going on that it is impossible to keep track of them all. But we like to have somewhat of an idea of what's going on. I feel that it is very important to keep myself educated.

After being diagnosed with MS, both of these participants found it very helpful and comforting for themselves and their families to research and learn about the diagnosis. This was especially helpful when it came to making decisions about how to treat the disease because of the vast number of treatments that were available.

Theme 2: Accessing Treatment

In the late 1980s when both of these participants were diagnosed, the treatment available for individuals with MS was almost nonexistent. Their doctors recommended that they make many lifestyle changes in order to decrease the chances of an exacerbation occurring. Kim stated that her doctor's initial recommendations were:

That I take it easy, that I eliminate as much stress in my life as possible, get more sleep than what you are used to getting, continue the prednisone therapy.

Sarah's doctor gave her very similar advice:

He told me that I needed to learn to pace myself and to not go to the point where I get really fatigued and keep going. . . He told me to safety check my home so that I didn't have things that were obviously barriers that would make me trip. We had to be sure that we had non-slip rugs and things like that so that I had a lesser chance of falling. He also told me to be sure that I always got a flu and pneumonia vaccine and basically just to take good care of myself and to stay active.

Accessing medications has been a very difficult issue for many people dealing with MS because of many different factors. The first one being that because each individual with MS may have different symptoms, finding the right medication for each individual can be very difficult. Both the participants in this study had a particular problem with steroid treatment in relation to their MS and its side effects. Sarah had a difficult time with the side effects that the steroids had on her and said:

They put me on ACTH injections that I took for a few years. However the problem with this medication was that it would make me feel like I was on a high and be very awake day and night for a few days and then I would hit a very low point where I would feel very tired and then the medication would level off and then it would be time to get the next injection. It was just too big of a "roller coaster" for me so I finally just told the doctor that I'm not going to take this anymore.

Kim had a similar experience with another steroid that her neurologist was having her take and said:

I have been on prednisone several times to try and stop the onset of symptoms and probably for five years I took it on and off all the time. But the problem with

being on prednisone for an extended period of time is that it tends to make your bones brittle so you have to be very careful with taking it for a long period. It also made me antsy and unable to sleep which also made it harder for me to be able to get the things done that I needed to.

Because of this Kim also discontinued taking the steroid treatment and has since then not been taking anything else for treatment. Sarah, on the other hand, is currently taking one of the newer more expensive medications that are available for MS treatment, and despite the minor side effect of this medication, she feels that overall the benefits of the treatment are worth it. Sarah said:

Currently I'm taking Avenox, which is an interferon that I inject once per week. I just had a long discussion with my neurologist about it because the thing that I really don't like about Avenox is that when I get ill it takes me a very long time to get well. . . When I get an illness such as the Noro virus it takes me about 2- 3 weeks of relapses until I can get rid of it whereas something like that would take a healthy person 1-2 days to get over. My neurologist says that this is very typical of interferons and that if I get off of these meds at my age and have a bad flare-up, I probably won't recover from that flare-up. I would just stay in the condition caused by the flare-up. So I've been convinced that I should stay on them.

Another major issue that many individuals with MS face is the cost of medications. Most of the medications are so expensive that many individuals are unable to afford the medications because of a lack of financial resources. Sarah is very privileged in that she has good coverage on her costly medications that she takes and said:

I am very fortunate to have very good insurance that I have had since before my diagnosis. The interferons that I'm currently taking cost approximately 17,000 dollars per year without insurance. But with my insurance I only pay about twenty dollars a month. So I have very good insurance and I know that there are a lot of people who are unable to take these medications because of their costly prices.

Kim is unfortunately one of the many who does not have access to the many medications because of their costly prices and a lack of financial resources. Because of this she is very thankful that she is able to function without the use of medications by just doing other alternative therapies. Kim said:

I have looked into medications and other treatments and they are just too expensive and my medical insurance will not cover them. . . It would have cost me well over 1000 dollars a month to be on injections and I just could not afford that. . . So I am not currently taking anything for treatment. . . Now I don't take anything and I really don't need to because overall the last 20 years have been pretty good.

Alternative therapies. Since access to medication is not possible for every individual with MS, many of these people look to other alternatives for treatment. These can range from surgeries, changes in the diet, various forms of exercises, and even just getting more rest. Both Kim and Sarah have used all of these forms of alternative therapies, and they have all been effective for them in treating various symptoms of MS. Sarah stated that she made rest and exercising a big part of her life per her doctor's request:

I try to stay as active as I can. I like to exercise several times per week, and the neurologist feels that is very good for me and that I do a lot better than other people with MS because I do exercise. I also have to take naps every day for about an hour and that really seems to help me with my fatigue.

Kim stated that she also incorporates getting lots of exercise and rest into her daily life:

I opted to do alternative therapies like yoga therapy where I was able to calm my mind and I also took some "down time" every day where I would take naps and that seemed to be my saving grace at that time.

Many of the studies conducted on special diets in relation to treatment of MS have been inconclusive. However in this study both the individuals have found that special diets have proven to benefit them by relieving some of their symptoms of MS. Sarah is not only following a diabetic diet for her diabetes but she has also eliminated foods from her diet per her doctor's recommendation, and it has really helped her. She said:

I follow a diabetic diet for my diabetes. . . I have a real problem with urinary frequency related to my MS. The doctors say that I have a very spastic bladder. . . An alternative therapy that seemed to help my bladder a lot is when the doctors told me that I had to give up caffeine, which they said was a real irritant for my bladder and that has helped a lot.

Kim is following a very different diet that she started when she realized that she had allergies to a major food group. However it was a real struggle for her to start this new diet because it consisted of eliminating a particular food from her diet that she consumed very frequently. Kim shared the following:

I went in and got food allergy testing because I was talking to some people in my MS support group and found out that some of the other people in my group had certain foods that they were allergic to that could trigger MS symptoms. So I decided that I would go in and see if I was allergic to any particular foods. And come to find out, I was allergic to beef. And that was really hard for me because I grew up on a cattle ranch and farm, and beef was definitely one of our main food sources. So I eliminated that from my diet and over the years I have begun to not miss it because I know that I feel better when I don't eat it. And so I don't even attempt to cook with it. My family has learned things like ground turkey chili and turkey burgers. I still cook steak and things for them sometimes but I don't fix it for myself; I just don't want to take the risk.

Another alternative yet major therapy that has proven to be effective for the individuals in this study is surgery. Although these two individuals had completely different operations, they both improved their MS symptoms greatly by doing so. Sarah states that her lower body is affected most by the MS. She has had many problems with walking and falling in relation to her MS, and therefore she opted to have surgery to help fix this problem.

For several years I was having problems with really bad knee joints and that made my problem a lot worse because the walking was impaired not only by my MS but also my bad knee joints. Because of this I ended up getting two total knee replacements, the first one being in 2001 and the second one in 2005. And that has helped tremendously; I have fallen a lot less.

Kim was having major issues surrounding her monthly menstrual cycle. She noticed that her MS symptoms would be severely worsened during this time every month to the point where it was affecting her daily life every month during this time.

I noticed that when it is getting close to menstrual cycle time and my hormones were changing, my MS symptoms were the worst and it was very hard for me. I would get the worst headaches and I would get the tingling, numbness and the pain. So eventually I just got used to having these symptoms every month; I gained a high tolerance for the pain. . . . When I had a hysterectomy about three and a half years ago, which made it so I didn't have the fluctuations of the female hormones anymore, it helped tremendously with my MS symptoms.

There are many alternative options that can be used for the treatment of MS other than medications. In this study this is proven by the many alternative forms of treatments that were used with great benefits by these participants.

Theme 3: Coping With the Diagnosis and Its Effects on Their Family

Losing independence. One of the major things that individuals lose when they are diagnosed with MS is their inability to do most tasks by themselves. Many people struggle with the fact that they now need help with many of the things that they originally may have been able to do by themselves very easily before the diagnosis. Doing something as simple as the household chores can become very difficult for these individuals, and finally coming to the decision that they need help can be very traumatic and hard for them. It took Kim several difficult incidences before she finally came to the realization that she needed to get someone to help her.

There were times when I would be stirring food on the stove and all of a sudden things would start going wrong and I would end up with the food all over the stove and the counters and that really made me realize that I do need to get someone to help me.

It was after this and many other frustrating situations that Kim finally enlisted the help of her family and a housekeeper:

I had a housekeeper that would come in and help me do things in the house because there were lots of things that I wasn't able to do. It was really hard for me to make a bed with just one hand; I couldn't get the fitted sheets on the bed. It was really hard to carry a mop bucket and a mop with one hand. It was very hard to get up and down the stairs. Lots of times I felt like my knee was going to give out and so I had to re-teach myself to do things that I used to be able to do very quickly, like throwing things from the washer into the dryer. My son would have to carry the laundry basket from one room to the next so we could put stuff away. My daughter would have to help with folding laundry and unloading the dishwasher and putting them away. So the MS didn't just affect me; it affected the whole family.

Prior to her diagnosis, Sarah had a real issue with getting fatigued with many of her simple household chores, and therefore she also hired a housekeeper to help her.

I always had a problem with fatigue, and I had been working, and as long as I worked, I always had a housekeeper that would come to my home and help me with the cleaning and I still do. She comes in once every two weeks and does the

heavy duty cleaning for me, and she has been coming into my home since before my diagnosis because I would just get too fatigued.

Limiting activities. The loss of the ability to carry out many leisurely activities can be very upsetting for many with an MS diagnosis. MS can also inhibit individuals from doing things that they have never done before or even limit the people that they can go out with. This can pose a big issue for some individuals with MS as Sarah states:

I don't go for walks anymore; it's just not an option. When I go out to do various activities such as shopping, I have to use an electric cart, so that I can get around. Some people are comfortable with going out with me while I use my cart and some people do not feel comfortable, and therefore I am limited to who I can participate in various activities with. I feel that my MS has limited where I can go and what I can do. For instance I could never go to Europe because it isn't handicap accessible enough for me. And that's something that a lot of people do at my age and really enjoy it. I won't be doing things like that.

When Kim originally had her first exacerbation of MS, she lost a lot of her independence, and this was really problematic for her. She always wanted to be the one taking care of other people not the other way around.

I couldn't run any more, I couldn't drive anymore, and I just couldn't do the things that I wanted to. In fact there were times that it was so hard for me to just get out of bed. I had to have help getting dressed; I had to have help making dinner and cut my food up. . . I really just did not want people to do these things because I was always the one who was taking care of other people.

Kim, like many other individuals with MS, also has a major issue withstanding heat. This was a real issue for her because she had two young children who often had sporting events outdoors, and she liked to go watch them:

I couldn't stand anything above 75 degrees. I had to be in the house or indoors, and I had to have air conditioning. When I wanted to go watch my kids play baseball and softball in the summertime, I had to have a cool wrap around my neck Just to keep myself cool and prevent myself from overheating. If I got too hot then I would be in trouble and this scared me. I would get the tingling and the numbness back if my body was to overheat.

Extracurricular activities. In losing the ability to do many physical activities, it is important that individuals with MS find other activities that they are not only able to do with their MS but also that they enjoy doing. Picking up new, enjoyable leisure activities is very important for the quality of life in a person with MS. Both the participants in this study were involved in many leisure activities on a regular basis, and that really helped to improve their outlooks on their own quality of life with MS. Kim tries to stay very active in her daily life, stating that she likes to always be busy:

I am still unable to run but my husband and I do go on leisurely walks. I am unable to run anymore, but I do still go out with the kids in the summertime and enjoys water activities and bike riding and other outdoor activities. I love to garden; however I have to be sure and do it when it is cool outside. Air conditioning is a must. . . I usually try not to slow down; I like to see how much I can accomplish in one day; I like to see how much I can get done from the time I

get up in the morning to the time I go to bed and then when I am sleeping I think about what I will need to get done tomorrow. I never stop!

Sarah is also very adamant about staying busy in her daily life. She participates in many weekly activities on a very regular basis even though some of them have become more difficult for her to do over the years:

I really enjoy playing my violin. However it has gotten a lot more difficult for me to play through the years. When I told my neurologist this, she said that I really set the bar high; I really don't know how you can play at all. I like to go play cards with my friends as long as I am rested, and for this reason we play in the mornings because in the afternoons I fatigue and have difficulties paying attention. So I have some nice friends who I get together with once a week at ten o'clock in the morning and play bridge. I also attended a reading discussion group at my church that I go to once a week.

Individuals in this study both had to adjust to many changes in life after being diagnosed. However they both discussed the importance of having supportive relationships in their lives during this life changing situation.

Theme 4: Having Supportive Relationships.

Research has proven that the outcome for an individual with any disease is always increased when the individual has supportive relationships involved. When an individual with MS has someone to stick by his or her side and help through the tough times that MS can bring, he or she generally has a better outlook on life and therefore a decrease in the symptoms of the disease. When the participants in this study were asked about who their biggest support system throughout the tough times has been, they both answered

their family. Sarah stated, "They have been there for me at all times when I needed anything and they have been very supportive of me with my diagnosis". Kim also stated, "I am thankful for the family support. They are the reason that I have the positive attitude that I have." Having a supportive family when times with MS can be very difficult can have a very positive impact on the individual.

After the diagnosis of MS, many people find comfort in talking to other individuals who have been diagnosed with MS. It is very helpful for people to learn that they are not alone and that there are other people out there going through the same things that they are and having very similar symptoms. After being diagnosed, Sarah found a lot of comfort in talking to a co-worker who had been diagnosed with MS long before she had:

After I was diagnosed, I did find that there were a lot of people that had MS and were going through the same thing that I was. I was a teacher at the time, and after I was diagnosed, I learned that the nurse at the school that I worked at had MS. When I was diagnosed, she spent a long time talking to me about it because she had already had the disease for quite a few years. This was very helpful for me to see that there was someone that had already gone through the same thing that I was going through.

Kim also found it very helpful to talk to other individuals who had already been diagnosed with MS. Kim found this comfort while attending an MS support group when she was first diagnosed. Although she no longer attends anymore she did find comfort in attending after her diagnosis:

I don't attend a support group anymore, but I do know other people in town that do have MS, and we occasionally visit when we see each other in public and stuff. However it was really important for me to go to the support group when I was first diagnosed because I didn't know a single other person in town who had it. And listening to other people with MS talk about the symptom that they had was very comforting to me to know that I wasn't alone. And it helped to hear how they dealt with the disease. And it helped to know that if someone else can deal with it then so can I.

Sarah had a similar answer when asked if she attends a support group:

I don't currently attend a support group, but I did when I was originally diagnosed, and it was very beneficial to me; I got a lot out of it. I attended the meetings once per month for several years, and it was very helpful for me to talk with people who were going through the same thing that I was.

Although Sarah attended a support group for many years and found it to be very helpful, she had a very strong answer when asked why she no longer attends. She stated:

The reason I don't go anymore is because I found that most of the people in the MS support revolve their whole lives around their MS. The only thing they do is things with other people who have MS, and for a lot of them their only outing the whole month long is going to the MS support group. I personally do not like to have my whole life centered around a disease. I feel that is not in my best interest. However I do get flyers from the MS support group in the mail, and I do attend the meetings when they have guest speakers who are very informative. But I don't go on a regular basis because I prefer to participate in other hobbies that I like to

do. I prefer a variety of activities rather than limiting myself to activities that only include people with MS. I feel that that would make me to emerged in my disease and be counterproductive for me. But the thing about MS support groups is that they all have a different mold and a different atmosphere, and you have to find one that you really fit with, and the one in my area I did not fit with. I have been to a lot of support groups because for a while I was going around and talking to them about government relations. For many years my husband and I were very active in government relations aspect of MS by advocating for the rights of people who are physically challenged. So I would talk to many different support groups about their rights as physically challenged people. With this I was able to see how each support group is very different. Some of them the people are more positive and upbeat, and in some of them the members are more active and involved in their communities. Whereas others are just isolated groups of people that are feeling very sick and telling other people about how sick they are.

Both Sarah and Kim found that having strong support systems during this difficult time has made a remarkable difference on their MS symptoms. However they both feel that overall a positive attitude is really what has helped them get through it all.

Theme 5: Living With a Positive Attitude.

When an individual is living with a lifelong debilitating disease such as MS, his or her attitude regarding the disease becomes very important. An individual has two choices regarding his or her attitude after having been diagnosed with MS. He or she can either have a positive attitude after the diagnosis, knowing that even though life will be different it will still go on and therefore living it to the fullest. Or he or she can have a

negative attitude, feeling as if their life is over because of this diagnosis and perhaps no longer wanting life to go on. Often after individuals are diagnosed with MS, they take on a negative attitude which is then followed by a positive attitude. This is because after having spoken with other individuals who have the disease and getting started on various treatments to make the disease more manageable, they realize that life can go on even after the diagnosis. Kim talked about how hard it was for her to have a positive attitude when she was first diagnosed:

I felt like I was going to end up in a nursing home by the time I was 35. And it was not a good thing. I just felt like it was very unfair for me and especially my family. I felt like they shouldn't have to go through what I was going through and that maybe they would be better off without me. And that was hard because then I said to myself I've got two kids to raise; I can't live this way.

Kim had a very hard time dealing with the diagnosis. All she had known was her aunt who deteriorated very quickly after her MS diagnosis and eventually ended up in a wheelchair with a full-time caregiver. She knew that she didn't want to live like that. She stated that it took her a very long time to develop a positive attitude about life again:

It's tough but at the same time you learn to pace yourself, and you learn to take everything with a grain of salt, and I always try to tell myself that tomorrow will be better just to keep my emotions positive. I always try to think that if I can't do something today, then I can do tomorrow, and I just try to take things one day at a time. . . I just thought, you know, if I don't have a positive attitude about this, nobody else is going to. I knew I had to do it, so I did!

Sarah tries to have a similar positive outlook on life but admits that this can at times be very difficult.

Most of the time I have a very positive attitude but you can't help but sometimes feel discouraged about it at times. I definitely can't say that I enjoy it. I feel that life is ten percent what happens to you and ninety percent attitude. I know that I can't just have a bleak outlook on life because I have a disease. I know that if I were to do that, my life would become pretty bleak. I never let myself get bored; I always have something that I want to do.

Conclusion

The participants in this study shared very similar experiences surrounding their MS. They revealed that although MS can affect everyone differently, there are many common themes between the effects that this disease has on the activities of daily living.

Chapter V

Discussion

The emerging themes from this research evolved around the participants recount of similar experiences prior to their diagnosis to their current situations with MS now. It is evident that although MS physiologically affects every individual differently, it has very similar effects on impairments of activities of daily living. According to a study conducted by the Department of Rehabilitation at Lund University Hospital in Sweden, “individuals *with MS* perceive difficulties *with* occupations related to all aspects of daily life. No significant differences between the occupational areas were found when age, disease severity, and/or *living* arrangements were included in the analysis” (Lexell, Iwarsson, & Lexell, 2006, p.1). This study concluded that the severity of an individual’s MS, the age of the individual, and where he or she lives does not have an impact on the individual’s perception of the difficulties that he or she experiences with activities in everyday life.

Living With the Diagnosis of MS

The participants in this study had very similar situations regarding their diagnosis of MS. Prior to their diagnosis both of these women were having several unexplained severe life altering symptoms that they were seeking an explanation for. Although both of these women found comfort in knowing that there was an explanation for these symptoms, like most individuals they both felt a severe amount of anxiety and sadness regarding the diagnosis. The anxiety revolved around not knowing anything about the disease or what it’s overall outcome would be. The sadness had to do with knowing that they would have to live with the threat of these symptoms for the rest of their lives.

In an effort to relieve these feelings, these participants started to conduct a great amount of research. However because this was in the 1980s the access to credible sources was much more limited then it is today; good information was not easy for these women to find. Furthermore, because the technology used to diagnose MS was just recently advancing, healthcare providers did not have the resources available to make an accurate diagnosis. Koch & Kralik stated, "If health care professionals can understand the process that facilitates people to move toward incorporating chronic illness into their lives, we can make a substantial contribution to enhance their chronic disease self care management" (Koch & Kralik, 2001, p. 23). Therefore individuals diagnosed today may have a much easier transition period after their diagnosis because many more healthcare workers are aware of the effects that MS has on diagnosed individuals.

Accessing Treatment

Research has shown that one of the major barriers to accessing treatment for MS is the cost of the treatments, and for one of the participants in this study, this proved to be true. According to research conducted by physicians at Deakin University, the cost of treatments for MS can cause a great amount of financial stress which can significantly lower an individual's perception of his or her quality of life. According to De Judicibus & McCabe, "Adjusting to actual or threatened loss of income caused financial stress. These financial struggles led to a lower quality of life among respondents" (De Judicibus & McCabe, 2007, p. 3). In this study, the cost of treatment was so great that the individual was unable to get it even though it might have helped her condition immensely; this caused a lot of stress for her. On the other hand, the other participant was fortunate enough to have good insurance before her diagnosis so that she could afford the

treatments that she still uses today. In looking at both of these participants' financial situation in regards to their access to treatment, it is evident that finances have a big impact on an individual's access to the costly MS treatments.

In a similar study conducted regarding access to treatment and an individual's perception of his or her health related quality of life, strong correlations were found. According to this study "therapy resulted in significant improvements in HR-QOL in patients with relapsing MS" (Rudick & Miller, 2008, p. 827). Therefore individuals who are currently using some sort of treatment for their MS are more likely to perceive their quality of life in relation to their health as better or improved. This also held true for the participants in this study. Both of these individuals began to feel a lot better after having started a therapy that they felt worked well for them whether it was starting modern medicines or simply exercising regularly. Therefore an individual's overall perception of his or her quality of life is greatly impacted by access to various forms of treatment.

Coping With the Diagnosis and Its Affects On The Family

When an individual is diagnosed with MS it not only has profound effects on the individual but also on the family. Generally the individual and his or her family do not know much about the disease at the time of diagnosis, as was the case for the participants in this study. These individuals and their families were very scared at the time of diagnosis. They had no idea how to cope with the diagnosis of MS. They were aware that this diagnosis would bring many changes into their lives and that living with MS would mean living life in a very different way. MS would have to be incorporated into their everyday life. Once these individuals were able to incorporate MS into their daily lives, they were able to cope with their new lives in a much more efficient and healthier way.

According to research, "Findings suggest that participants who reported integrating MS into their lives, had confidence in their abilities to cope with stress, and had a positive outlook on life, appeared to employ action-oriented strategies to cope with their disease" (DalMonte, Finlayson & Helfrich, 2003, p. 3). Therefore individuals who are able to cope with MS have a much higher quality of life.

Having Supportive Relationships

One of the most important advantages that an individual can have after being diagnosed with MS is a good support system. Whether this be family and friends or healthcare workers, it is very pertinent that an individual has people to support him or her through this difficult time. Not only can a supportive relationship aid in the emotional impacts that the diagnosis of MS has on an individual but also with the individual's adherences to treatment regimens. A diagnosis of MS can have a severe emotional impact on individuals that can sometimes make it difficult for them to stick with the prescribed treatment regimens. In a recent study, it was found that individuals with MS who have strong supportive relationships are more likely to adhere to the treatments that they are prescribed (Siegel, Turner, & Haselkorn, 2008). For the two participants in this study, this held to be true. Both of these women had a few very strong supportive, relationships in their lives at the time of their diagnosis which made it possible for them to make it through this very hard time. Because of their support systems, they were able to stick to their treatment regimens in order to improve their overall health condition.

Another form of supportive relationships that has proven to be very helpful for individuals recently diagnosed with MS is MS support groups. According to Alexiou, this is particularly true regarding individuals who are diagnosed at younger ages. He stated

that “support groups specifically for younger people with MS could help with the adjustment” (Alexiou, 2008, p. 432). This was a similar finding for the participants in this study. Both of them found it very beneficial to attend support groups. It was very helpful for them to find that there were other people out there going through some of the same things that they were so that they knew that they were not alone. This exemplifies the benefits of having supportive relationships with other individuals who also have MS.

Living With A Positive Attitude

Having a positive attitude can have an impact on the symptoms of MS that an individual experiences. Research has shown that there is a positive correlation between having a positive attitude and improving symptoms of MS. According to recent research, “The relationship between improved depression was significantly mediated by both increased optimism and increased positive affect” (Hart, Vella, & Mohr, 2008, p. 230). Although neither of the participants in this study stated that she was actually depressed, they both exemplified that they had many of the symptoms of depression after their time of diagnosis. They both also stated that it took them a very long time to feel better about their diagnosis and to actually develop a positive attitude about life again. However when they developed a positive attitude, they both exemplified a more optimistic outlook on life which correlated with a higher quality of life and a better ability to perform activities of daily living.

Nursing Implications

Nurses play a very important role in providing care to individuals with MS. Nurses must be very attentive to the MS patient because their condition is continually changing. Nurses also need to be aware that every individual with MS is unique in that

MS can affect every individual differently. Therefore the nurse must be sure to care for the patient in a holistic manner. In doing so, the nurse will be sure to care for not only the individual's physical needs but also his or her emotional, social, and spiritual needs as well.

Nurses are also a main source of education for the newly diagnosed individual, and therefore nurses must be sure to keep up to date on the latest research and resources available. In the role of caregiver and educator for the individual with MS, the nurse can become a main support system for the individual throughout the continually changing effects of this difficult disease process.

References

- Barrett, M. (1999). Sexuality and multiple sclerosis. Retrieved March 27th, 2008 from <http://www.mssociety.ca/en/pdf/sexuality.pdf>
- Beal, C., & Stuijbergen, A. (2007). Loneliness in women with multiple sclerosis. *Rehabilitation Nursing, 32*(4), 165-171.
- Courts, N., Newton, L., & McNeal, L. (2005). Husbands and wives living with MS. Retrieved March 4th, 2008 from <http://www.aann.org/ce/pdf/jnn0205a.pdf>
- DalMonte, J., Finlayson, M., & Helfrich, C. (2003). In their own words: coping processes among women aging with multiple sclerosis. Retrieved on March 24th From <http://web.ebscohost.com/ehost/detail?vid=9&hid=104&sid=aad087a3-eaec-4aa0-8aad-474d833e2c21%40sessionmgr104&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ%3d%3d#db=rzh&AN=2004098709>
- De Judicibus, M. & McCabe, M. (2007). The impact of the financial costs of multiple sclerosis on quality of life. Retrieved on March 24th, 2009 from <http://web.ebscohost.com/ehost/detail?vid=9&hid=104&sid=aad087a3-eaec-4aa0-8aad474d833e2c21%40sessionmgr104&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ%3d%3d#db=rzh&AN=2009572805>
- Farinotti, M., et al. (2007). Dietary interventions for multiple sclerosis. Retrieved March 27th, 2008 from <http://www.cochrane.org/reviews/en/ab004192.html>
- Gulick, E. E. (2007). Postpartum functioning in mothers with multiple sclerosis. *Western Journal of Nursing Research, 29*(5), 589-602.

Harrison, T., Stuijbergen, A., Adachi, E., & Becker, H. (2004). Marriage, impairment, and acceptance in persons with multiple sclerosis. *Western Journal of Nursing Research*, 26(3), 266-292.

Hart, S.L., Vella L., & Mohr, D.C. (2008). Relationships among depressive symptoms, benefit-finding, optimism, and positive affect in multiple sclerosis patients after psychotherapy for depression. Retrieved March 24th, 2009 from <http://web.ebscohost.com/ehost/detail?vid=5&hid=104&sid=aad087a3-eaec-4aa0-8aad-474d833e2c21%40sessionmgr104&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ%3d%3d#db=rzh&AN=2009885339>

Hauser S., Waubant E., Arnold, D., Villmer T., Antel J., & Fox, R., et al. (2008). B-cell depletion with rituximab in relapsing- remitting MS. Retrieved March 27th, 2008 from <http://content.nejm.org/cgi/reprint/358/7/676.pdf>

Iezzoni, L. I., Ngo, L. H., & Kinkel, R. P. (2008). Working-age persons with multiple sclerosis and access to disease-modifying medications. *Multiple Sclerosis*, 14 (1), 112-122.

Ignatavicius, M. & Workman, D. (2006). *Medical- surgical nursing: Critical thinking for collaborative care* (5th ed.). St. Louis, MO: Elsevier Saunders.

Khan, F., Turner-Stokes, L., Ng, L., & Kilpatrick, T. (2005). Multidisciplinary rehabilitation for adults with multiple sclerosis. Retrieved March 24th, 2008 from <http://www.cochrane.org/reviews/en/ab006036.html>

Kirkpatrick, P., Ottens, A., & Fisher, T. (2009). Women coping successfully with multiple sclerosis and the precursors of change. Retrieved on March 24th, 2009 from <http://web.ebscohost.com/ehost/detail?vid=5&hid=104&sid=7a9424fd-5a22-435f-a6b2-c5ac2468652a%40sessionmgr108&bdata=JnNpdGU9ZWhvc3QtbGl2ZQ%3d%3d#db=rzh&AN=2001110876>

National Multiple Sclerosis Society. (2007a). About the society. Retrieved February 1st, 2008 from http://www.nationalmssociety.org/site/PageServer?pagename=HOM_SOCIETY_homepage.

National Multiple Sclerosis Society. (2007b). For caregivers. Retrieved January 24th, 2008 from <http://www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/caregivers/index.aspx>.

National Multiple Sclerosis Society. (2007c). Just the facts: 2006-2007. Retrieved January 24th, 2008 from http://www.nationalmssociety.org/site/PageServer?pagename=HOM_LIB_brochures_just_the.

National Multiple Sclerosis Society. (2007d). Living with MS. Retrieved January 24th, 2008 from <http://www.nationalmssociety.org/living-with-multiple-sclerosis/index.aspx>

National Multiple Sclerosis Society. (2007e). Pediatric MS. Retrieved January 24th, 2008 from http://www.nationalmssociety.org/site/PageServer?pagename=HOM_ABOUT_pediatric_and_childhood.

National Multiple Sclerosis Society. (2006). Pregnancy. Retrieved 2/1/2008 from http://www.nationalmssociety.org/site/PageServer?pagename=HOM_LIB_source_book_pregnancy.

National Multiple Sclerosis Society. (2007f). Symptoms. Retrieved January 24th, 2008 from http://www.nationalmssociety.org/site/PageServer?pagename=HOM_ABOUT_symptoms.

National Multiple Sclerosis Society. (2007g). Treatments. Retrieved January 24th, 2008 from http://www.nationalmssociety.org/site/PageServer?pagename=HOM_LIVE_treatments.

National Multiple Sclerosis Society (2007h). Who gets MS. Retrieved January 24th, 2008 from http://www.nationalmssociety.org/site/PageServer?pagename=HOM_ABOUT_who_gets_ms.

Multiple Sclerosis Trust. (2008). Expanded disability status scale (EDSS). Retrieved March 28th, 2008 from <http://www.mstrust.org.uk/information/a2z/edss.jsp>

Rietberg, M., Brooks, D., Uitdehaag, B., & Kwakkel, G. (2005). Exercise therapy for multiple sclerosis. Retrieved 3/27/2008 from <http://www.cochrane.org/reviews/en/ab003980.html>.

Rudick, R. & Miller, D. (2008). Health-related quality of life in multiple sclerosis: current evidence, measurement and effects of disease severity and treatment. Retrieved on March 24th, 2009 from <http://web.ebscohost.com/ehost/detail?vid=10&hid=104 &sid=aad087a3-eaec-4aa0 8aad474d833e2c21%40sessionmgr104&bdata=JnNpdGU9ZWZWhvc3QtbGl2ZQ%3d%3d#db=rzh&AN=2010063129>

- Rutschmann, O., McCrory, D., & Matchar, D. (2002). Immunization and multiple sclerosis: a summary of published evidence and recommendations. Retrieved March 27th, 2008 from http://www.guidelines.gov/summary/summary.aspx?doc_id=4103&nbr=003148&string=Multiple+AND+Sclerosis.
- Russell, G. E. (2004). *Phenomenological Research*. Philadelphia, PA: F.A. Davis Company.
- Siegel, S., Turner, A., & Haselkorn, J. (2008). Adherence to disease-modifying therapies in multiple sclerosis: does caregiver social support matter. Retrieved March 24th, 2009 from <http://web.ebscohost.com/ehost/detail?vid=7&hid=104&sid=aad087a3-eaec-4aa0-8aad-474d833e2c21%40sessionmgr104&bdata=JnNpdGU9ZW hvc3QtbGl2ZQ%3d%3d#db=rzh&AN=2009902991>
- Taylor, N. F., Dodd, K. J., Prasad, D., & Denisenko, S. (2006). Progressive resistance exercise for people with multiple sclerosis. *Disability & Rehabilitation*, 28(18): 1119-26.
- Thompson Micromedex. (2008). Interferon beta-1a. Retrieved March 27th, 2008 from http://www.thomsonhc.com/hcs/librarian/ND_T/HCS/ND_PR/Main/CS/4B9181/ DUPLICATIONSHIELDSYNC/6F38F2/ND_PG/PRIH/ND_B/HCS/SBK/2/ND_P/Main/PFPUI/KN1ex1D2ohPRKd/PFActionId/hcs.common.RetrieveDocumentCommon/DocId/1739/ContentSetId/31/sectionId/therapeuticUsesSection/SearchTerm/Multiple%20sclerosis%20/SearchOption/BeginWith#ip9

Tripoliti, E., Campbell, C., Pring, T., & Taylor-Goh, S. (2007). Quality of life in multiple sclerosis: Should clinicians trust proxy ratings. *Multiple Sclerosis*, 13(9): 1190-94.

Wood, D. (2007). Risk factors for Multiple Sclerosis (MS). Retrieved January 24th, 2008 from <http://www.swedish.org/13581.cfm>