The Person Behind the Disease: Managing the Psychosocial Aspects of Multiple Sclerosis

An Honors Thesis

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Special thanks to my Mom who inspired my research in this area because of her own illness. Through studying MS, I have gained an understanding of how this disease affects the individual and family dynamics and how I can apply it in my personal life.
Abstract:

Multiple sclerosis (MS) is an unpredictable and potentially debilitating neurological disease that may result in physical, psychological, and emotional decline. The psychosocial aspects of managing the care of people with multiple sclerosis are as important as managing the actual disease process. Therefore, there is a need to understand how multiple sclerosis affects the people behind the disease. Research reveals that stress may act as a stimulus/response to MS, therefore effective coping skills are necessary. People with MS and their families cope with major changes in lifestyle and roles while moving through the grieving process. Health care providers act as advocates for patients and families facing this disease and developing effective coping strategies. Through understanding the psychosocial impact of MS, I can apply the principles to my nursing practice and help my mother and family cope with MS. I will examine the pathophysiology of multiple sclerosis, stress as a stimulus/response with MS, and how the disease affects and is managed by patients, families, and healthcare providers.
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I. Introduction:

Over 350,000 Americans are currently diagnosed with multiple sclerosis (MS), 70% are women. Another 8,500 to 10,000 new cases are diagnosed each year in the U.S. (International Organization of MS Nurses, 2003). As a result, thousands of people are confronted by the reality of multiple sclerosis daily, whether they have MS or know someone with the disease. The disease affects families across generations from the grandmother diagnosed 30 years ago, to the young boy who helps his father walk, to the newly diagnosed teenager. The psychosocial aspects of managing the care of people with multiple sclerosis are as important as managing the actual disease process. Therefore, there is a need to understand how multiple sclerosis affects the people behind the disease. I will examine the pathophysiology of multiple sclerosis, stress as a stimulus/response with MS, and how the disease affects and is managed by patients, families, and healthcare providers.

II: Multiple Sclerosis: the disease

Before exploring the psychosocial aspects of this disease, it is important to understand normal neuromuscular anatomy and physiology, along with the disease process itself. The nervous system is divided into the central nervous (CNS), consisting of the brain and spinal cord, and the peripheral nervous system (PNS), consisting of nerves and ganglia outside of the CNS (Porth, 1998). The functioning cells of the nervous system are neurons, which carry information throughout the body. Surrounding the neurons in the CNS is myelin, which acts as an electrical insulator by having high electrical resistance and a low capacitance (Porth, 1998). Small uninsulated junctions, known as nodes of Ranvier, are located between the cells of the myelin sheath. Electrical
currents, known as action potentials, are transmitted from node to node, which increase the speed of impulses through the CNS (Porth, 1998).

A person with MS has white blood cells and antibodies that attack the myelin sheath that surrounds the nerves in the CNS. Acute myelin breakdown causes sclerosis, or scarring, which results in areas of lesions, that are called plaques (Cleveland Clinic, 2004). The plaques in the myelin cause disruption in neural conduction, similar to a short-circuit in an electrical line. The lesions may occur in the optic nerves affecting visual fields, the corticospinal tract affecting muscle strength, the corticobulbar tracts affecting swallowing and speech, the cerebellum affecting gait and coordination, spinocerebellar tract affecting balance, and the posterior spinal cord affecting position and vibratory sensation (Porth, 1998). As the damage within the CNS increases, the sclerosis progressively impairs nerve transmission causing increased debilitation.

The interruption of neural conduction in the demyelinated nerves is manifested by an array of symptoms (Porth, 1998). Symptoms may change daily with intermittent exacerbations. Sensory symptoms of MS may include abnormal sensations such as paresthesia, visual disturbances, dizziness, vertigo, and sexual dysfunction. Paresthesia may be manifested as numbness, tingling or burning, gaze paralysis, optic neuritis (visual clouding or partial loss of vision), and diplopia (double vision) (Porth, 1998). Motor symptoms may include weakness, numbness, tremors, difficulty with ambulation, bowel and bladder dysfunction, fatigue, stiffness, spasticity, and constipation. Psychological symptoms may include mood swings, depression, inappropriate euphoria, and inability to control emotions (Beers et al., 2004).
The course of MS is unpredictable. The disease minimally affects some people while others experience rapid progression to total disability. Four types of Multiple Sclerosis have been identified that exemplify this unpredictability (National Multiple Sclerosis Society, 2005). Relapsing-remitting MS is characterized by unpredictable attacks in which new or existing symptoms appear, followed by period of recovery. Secondary progressive MS is identified with progressive disability and reoccurring relapses. Primary progressive MS is characterized by a lack of distinct attacks and has an insidious onset of progressively worse symptoms. Lastly, a person with benign MS may experience one or two attacks followed by complete recovery with no subsequent exacerbations or development of disability (National Multiple Sclerosis Society, 2005).

Currently, there is no definitive test to diagnosis MS nor is there one symptom that specifically indicates MS. A diagnosis of MS is made after extensive review of a person's medical history and neurological testing, including MRI, spinal tap, and evoked potentials (Cleveland Clinic, 2004). The MRI uses magnetic fields and radio wave energy to provide pictures of internal structures. The MRI may show evidence of scar tissue, or plaques within the brain and spinal cord. A spinal tap is a procedure to remove spinal fluid from the spinal canal. Results may reveal presence of antibodies and specific proteins that break down myelin, supporting a diagnosis of MS. The evoked potential test measures the time it takes for nerves to respond to stimulation. Electrodes attached to the head record brain wave activity before, during, and after stimulation (Cleveland Clinic, 2004). The test helps determine what parts of the nervous system have been affected by MS including vision, auditory and sensory pathways (Beers, Fletcher, Jones, Porter, Berkwits, & Kaplan, 2004). Criteria for diagnosis include experiencing either two or
more episodes of symptoms that last twenty-four hours and occur at least one month apart or a progression of symptoms over six months (Cleveland Clinic, 2004). Also, a biopsy with evidence of plaques in two more areas in the CNS with no other reasonable explanation is necessary for definitive diagnosis.

There is no known cure for MS; however interventions are available to manage symptoms, reduce severity and frequency of exacerbations, and to modify progression. Disease-modifying medications, such as Avonex©, Betaseron© and Copaxone© reduce the severity and frequency of attacks and prevent early destruction of myelin (Beers et al., 2004). Chemotherapeutic agents, such as Novantrone©, decrease the number of white blood cells that cause myelin sheath destruction, therefore slowing the autoimmune process that occurs with MS (International Organization of MS Nurses, 2005). Corticosteroids, such as Solu-Medrol©, used to control exacerbations of MS, may reduce inflammation and improve nerve conduction (Multiple Sclerosis, 2005).

Specific sign/symptom management involves cognitive retraining, medications, adaptive devices, and self-management education. Cognitive retraining consists of stimulating the mind through techniques such as puzzles, memory games, notebooks, and filing systems. This therapy is used to minimize memory and cognition decline that occurs from demyelination interrupting the flow of messages to and from the brain (National Multiple Sclerosis Society, 2005). Bowel and bladder dysfunction can be treated with medications, dietary changes, retraining, and aids. Medications such as Detrol© and Ditropan© help with urge incontinence. Dietary changes for urinary control include reduced total fluid intake and reduced intake of caffeine and alcohol. Bladder training is used with urge incontinence to increase the time intervals between voiding.
Timed and prompted voiding are used for functional incontinence. Aids include absorbent pads, catheters, urethral insert, and external urethral barrier (Multiple Sclerosis, 2005). If on the other hand, bowel control is a concern, total fluid intake and dietary fiber must be increased. Stool softeners such as Colace© may also be used for constipation. Emotional symptoms are managed with medications, therapy, and adequate rest. Medications may include antidepressants, such as Zoloft© and anti-anxiety drugs such as Xanax (Multiple Sclerosis Society, 2005). Psychotherapy may involve one-on-one counseling or group sessions. It is important to note that rest can help alleviate emotional symptoms of MS. Sensory alterations such as visual alterations are treated with adaptive devices, including glasses and contacts (Multiple Sclerosis Society, 2005). Mobility aids include canes, wheelchairs, or walkers. There are different types of pain reported with MS. Chronic pain is treated with anti-inflammatories such as Tylenol©. Acute pain treatment may include anticonvulsants, such as Neurontin©. Although, the mechanism for pain control of these drugs is unclear, doctors prescribe anticonvulsants for pain more often than for seizures (Multiple, Sclerosis, 2005). Alternative/complementary modalities for pain may include yoga, tai chi, and music/art therapy (Multiple Sclerosis International Federation, 2005).

III. Stress as a stimulus /response to Multiple Sclerosis

Being diagnosed with MS causes stress and a rush of emotions. While some people experience feelings of relief that their symptoms finally have a diagnosis others feel stress and remorse. Changes in self-esteem and body image occur accompanied by feelings of isolation and depression (Johnson, 2003). Emotional changes are associated
with both the pathologic changes incurred by MS and with the grieving process that can occur with chronic illness.

The stages of grieving, as defined by Kubler-Ross, include denial, anger, bargaining, depression, and acceptance (1969). Denial occurs after diagnosis in an attempt to deny the reality and to rationalize emotions. Denial buffers the shock and carries the person through the initial pain. Anger occurs as denial subsides and the reality of illness is acknowledged. Anger may be directed at inanimate objects, other people, or oneself when expressing emotion. Bargaining occurs as anger leads to helplessness and vulnerability. Bargaining is an attempt to regain control and involves questions of “what if.” Depression marks the breakdown of defense. The reality of loss surrounds, consumes, and crushes us. Symptoms of depression include sadness, hopelessness, poor appetite, and insomnia. Eventually, acceptance creeps through, and the good days begin to outnumber the bad. Life is moving forward again and happiness is possible, but the grief associated with chronic illness is not forgotten. The grieving process is acted out as people face lost health and redefine their life in the face of MS (Multiple Sclerosis International Federation, 2005).

The emotional responses are also associated with high levels of stress as the person copes with the new diagnosis. In Rice (2000), stress is defined by Hans Seyle as “a state manifested by a specific syndrome which consists of all the nonspecifically induced changes within a biological system” (p.28). The physiologic changes in the body that occur with stress, particularly with a chronic illness, can be detrimental to one’s health. An acute stress response that occurs with a new diagnosis begins in the hypothalamus which stimulates the release of hormones, such as adrenaline. Responses to
adrenaline include increased muscle tension, increased blood pressure, increased heart rate, increased blood sugar, and enlarged pupils (Buljevac, 2003). Chronic stress associated with chronic illness can cause migraines, chronic fatigue, insomnia, anorexia, diarrhea, constipation, high blood pressure, and acid reflux disease (Buljevac, 2003). Over time, these physical responses to stress can cause strokes, heart attacks, diabetes, and immune system disorders. Stress can make the person less able to suppress MS symptoms and may accelerate progression of the illness. In addition, stress has also been found to increase the development of brain lesions.

Coping is an effective way to short-circuit the stress response and reduce the effects of stress on the body. The three main styles of coping are task-oriented, emotion-oriented, and distraction-oriented (Mohr & Goodkin, 2002). Task-oriented coping involves analysis of the situation and then taking action. Emotion-oriented coping involves dealing with feelings and finding social support. Distraction-oriented coping uses activities or work to divert thoughts from the situation. Each person must find their own style of coping when faced with stress and chronic illness. In fact, coping as a moderating factor may decrease the relationship between stress and brain lesion development in MS (Mohr & Goodkin, 2002). Healthcare providers need to help patients utilize effective coping strategies to manage the complexities of the disease and reduce stress.

Currently, medical studies show no clear, specific evidence that stress causes MS, however, the body’s response to uncontrolled stress can result in exacerbations of illness because it weakens the immune system (Davis, 2003). In a study published in the British Medical Journal, researchers examined the link between stress and symptom
exacerbations of 73 adults with MS. Over 16 months, 70 reported experiencing at least one stressful event, with a total of 457 stressful events. Of those patients, 56 patients had 136 symptom flare-ups. These findings show that stress doubled the risk of MS symptom exacerbations. Buljevac and colleagues (2003) also found in people with MS, the experience of a stressful event within the four weeks of the study doubled their risk of an exacerbation within the next week. Another study found that nearly 85% of MS exacerbations were associated with stressful life events (Ackerman & Heyman, 2002). Current research, therefore, indicates that stress is strongly associated with exacerbations of the disease, but does not indicate it is a stimulus of MS. More research needs to be conducted to explain the relationship between stress and MS.

IV. MS and caregivers

A. The grief process

MS affects not only the person with the illness, but also family members. People expect to care for babies, children, and elderly parents, but they are not prepared to care for a chronically ill spouse or parent. Family members may experience guilt with the diagnosis. Guilt may occur because the family is exhausted from hearing about symptom complaints with no definitive diagnosis, and then finding out that the family member has MS (Sullivan, Wilken, Rabin, Demorest, & Bever, 2004). When no physical symptoms are obvious, it is normal to identify other symptoms as “in the head” or stress related, unless proven otherwise. Guilt can be resolved by recognizing that MS is often difficult to diagnose and their feelings are normal.

When the person is diagnosed with MS, family members may experience emotions similar to the grieving process. An initial reaction of caregivers is denial, which
protects them from experiencing emotional pain with the diagnosis (Johnson, 2005).

Denial is a normal response with chronic illness. It is manifested in refusing to learn about the disease, minimizing its impact, or denying disability or need for medical treatment (Johnson, 2005). Each family member copes with feelings of denial at their own pace, however if denial persists for a prolonged period of time, referral to counselors or spiritual leaders may be recommended.

Family members also may experience anger when the diagnosis is made. This anger may be expressed at the physician, the person diagnosed, or each other. Anger may result from changes in family dynamics, including change in role, responsibilities, or income (Johnson, 2003). Tension between family members builds when emotions are not expressed. As a result, feelings of anger, loneliness, and frustration are more damaging than open expression of feelings. By realizing that they are angry at the disease, not the person, they can cope more effectively with the diagnosis.

When anger subsides, bargaining may occur as family members try to rationalize the diagnosis (Kubler-Ross, 1969). Thoughts may include, “if only we had believed her symptoms,” or “if only we had seen a doctor sooner.” Although, these “what if” questions do not change the outcome, family members seek resolution in considering alternative outcomes. Bargaining is often used in an attempt to regain control of the situation.

At some point, family members stop feeling angry or trying to bargain and start feeling sad. The many losses of MS cause grief and sadness that must be faced. Losses may include physical health, mobility, autonomy, work, caregiver role, marital role, and income. Sadness may become depression that can last for weeks to months. Research has
shown that caregivers who provided care to a spouse with a chronic illness were six times more likely than noncaregivers to experience depression or anxiety (Cannuscio, Jones, Kawachi, Colditz, Berkman, & Rimm, 2002).

With time, family members begin to gain acceptance of the diagnosis. Family members and the person diagnosed with MS must grieve and cope with the diagnosis in their own way and time. Adequate social support and resources are necessary to help the family adjust to the changing lifestyle.

**B. MS and spouses**

MS has an immense impact on the person with MS and his/her partner. Family role changes, sexual difficulties, and modification in life plans may put a heavy burden on marital relationships. People with MS often fear abandonment by their spouse related to the chronic and complex nature of the disease (Courts et al., 2005). MS adds new challenges and increased demands on the family. Caregiving partners may experience social disruption, fear of an uncertain future, financial strain, and isolation (Courts, Newton, & McNeal, 2005). Courts, Newton, and McNeal’s research (2005) found differences in perceptions across genders as caregiver and relationship changes occur. Men expressed more difficulty than women with stepping into a caregiver role for a spouse with MS. Reported negative relationship changes included increased arguing and miscommunication, and strain of role reversal of breadwinner and homemaker. Results also revealed positive relationship changes including improved communication with each other, personal growth and increased strength of relationship. The caregiving spouse is forced to change their lifestyle, which can result in their decline in quality of life. If this burden becomes too great, spouses may look for alternatives. Resources are needed for
couples facing MS to help them transition into the new lifestyle and avoid major difficulties within the marital relationship.

C. MS and children

Parental multiple sclerosis can be difficult for children to comprehend and the experiences of children vary greatly. There is not one explanation for how children will react and cope with the debilitating diagnosis of MS in a parent. Research has shown that the responses of children of parents with MS may follow the social learning model (Judicibus & McCabe, 2004). This theory explains that children and adults acquire attitudes, emotional responses, and new styles of conduct through modeling behavior. When a parent has a chronic illness, as the model predicts, the child may manifest physical complaints, such as headaches or stomachaches. Children of parent’s experiencing depression with MS may exhibit a more negative outlook on life (Judicibus & McCabe, 2004). This model does not explain why parents act the way they do toward the child. For example, a chronically ill parent may inadvertently pay less attention to the child resulting in negative behaviors or emotions.

Difficulties in marital relationships related to a partner with MS place children at risk for emotional, developmental, and behavioral problems. Evidence supports that increasing tension between couples living with MS has a negative effect on their children (Courts et al., 2005). Marital distress appears to have an especially harmful effect on older girls. Daughters of parents with MS are more likely than their peers to be in tune to the needs of adults. Daughters also may take more responsibility for helping others. This can result in false maturity, which may cause difficulty interacting with their peer group. These children experience their peers as less mature and relate better to adults than to
other children. Alternatively, they may manifest behaviors, such as anger or aggression, that are detrimental to establishing good peer relationships (Judicibus & McCabe, 2004). Current research findings show that children of parents with MS are at greater risk for adjustment difficulties and the quality of parent-child interaction may be more negative when the parent with MS is experiencing exacerbations (Judicibus & McCabe, 2004).

The unpredictability of MS is frustrating for the whole family. People with MS do not know day to day how they will feel physically and if they will be able to participate in daily activities. This can lead to family conflict and misunderstandings. Children need to have an explanation for changes in family dynamics and parenting (Kikuchi, 1987). This explanation is geared toward the individual child, and they need to know it is not their fault. By developing alternative plans for activities, family members will feel less disappointment and resentment when changes in activities are needed. Keeping communication open between family members helps facilitate transition into a new unpredictable lifestyle (Kikuchi, 1987).

V. MS and the patient

Emotional changes experienced by a person with MS result from various causes including a lack of knowledge, unpredictable and variable pattern of remission and exacerbation, and decrease in functional ability. Adjusting to a disease that is unpredictable, variable in course, and potentially debilitating across an unknown time frame can produce stress and anxiety. Stress can result from lack of knowledge in a newly diagnosed person. Medications and the pathophysiological changes within the CNS also may alter emotions (Johnson, 2003). The most frequently occurring emotional alterations with MS are grief, anger, clinical depression, emotional lability, mood swings,
stress, pseudobulbar affect (uncontrollable crying/laughing), and inappropriate behaviors such as laughing or crying at inappropriate times, shouting, and cursing (National Multiple Sclerosis Society, 2002).

A person diagnosed with MS will go through a grieving process, which may manifest similarly to that of their family (National Multiple Sclerosis Society, 2004). Loss of work, autonomy, primary caregiver role, and physical mobility can cause feelings of grief. The grieving process may involve denial, anger, depression, ambivalence and acceptance. The person with MS needs to know they can move through the grieving process (National Multiple Sclerosis Society, 2004). Grief is different from major depressive disorder because depression is persistent and potentially chronic (Hample, 2000). The grief process seems to resolve on its own, even without professional treatment; with time, adequate coping skills, and support groups, the person can develop a new positive definition of self.

Anger is a normal adaptive human emotion, but can be debilitating with MS. Existential and instrumental anger are two forms of anger that occur (Cohen, 2003). Existential anger occurs when the person feels great injustice about their disease and that life is unfair. Instrumental anger is experienced with the daily frustrations related to the manifestations of MS, such as difficulty opening a bottle, tying shoelaces, or dealing with expensive medical bills related to treatment. The two types of anger are linked in that each person must deal with the injustices of the diagnosis and face the daily challenges of the disease (Cohen, 2003) to truly live life. The first step of facing anger is accepting that it is normal. Men express anger through increased assertiveness, whereas women tend to become passive-aggressive. It is important to identify personal triggers, such as new
symptoms, dependence on others for transportation, feeling isolation in social events, handicap inaccessible venues, and uncooperative persons (Cohen, 2003). By understanding how anger affects each individual, it is easier to develop a plan to manage it. Management of the triggers may include physical exercise, music therapy, reading, prayer or meditation, and participating in a favorite hobby. Referral to a counselor might be necessary to help identify altered thought patterns and promote change.

People with MS have a greater incidence of depression and more difficulty with psychosocial adjustment. The incidence of depression among persons with MS is three times greater than the national average (Cohen, 2003). Currently, it is estimated that 14% of the MS population is suffering from depression and more than 42% will experience major depressive disorder (Hample, 2000). Research has revealed that depression may be both a complication and symptom of MS. Depression may be the consequence of altered lifestyle, disease exacerbations, medication use, or changes in the central nervous system (Hample, 2000). There is some difficulty in identifying depression because symptoms, such as fatigue and loss of energy are common to both MS and clinical depression. As a result, research has shown that as many as 40% of MS patients do not receive care for psychiatric problems (Butt & Demaree, 2004). To make matters worse, research indicates that depression and emotional fluctuations increase frequency and severity of disease exacerbations (Butt & Demaree, 2004). In a longitudinal study by Mohr and colleagues (2000), evidence showed that self-report of stressful life events coincided with lesion development. Treating depression, therefore, may serve as a disease modifying method (Mohr et al., 2000). Studies also have found that persons experiencing exacerbations of MS have more difficulty with psychosocial adjustment as compared with persons that are
in remission (Sullivan et al., 2004). It is evident that disease exacerbations increase the likelihood of experiencing stress, anger, depression, and other emotions.

People tend to see emotions as separate from the body. However, an inability to control emotions termed emotional incontinence, may result from lesions in the brain, abnormalities in neurotransmitters, as well as normal physiologic responses to situational crises or emotional pressure (Arnold, 2000). Emotions are strongly linked to our body because the way we think affects the release of neurotransmitters in the brain.

Psychosocial effects of MS are attributed to various causes and the person faces many challenges in coping with the disease. Evidence shows that emotional responses can affect the course of MS. The person needs psychosocial support from caregivers and healthcare providers in managing the effects of disease. Learning to cope with potentially destructive thoughts and behaviors can help control emotions, including depression and anger (Arnold, 2000) and modify the interaction of mind and body.

VI. Nurses role in managing MS

Nurses face an interesting challenge in caring for patients with MS because the disease is unpredictable, exacerbations are random, and patients face various prognoses and levels of disability. A nurse plays many roles in caring for MS patients, which include advocate, care provider, educator, counselor, case manager, and researcher (International Organization of MS Nurses, 2003). In providing care to MS patients, a nurse must be patient, creative, caring, empathetic, energetic, and hopeful. An MS nurse is an expert that works with MS patients through sharing knowledge, strength, and hope. Nurses empower people while managing symptoms, modifying or reducing relapses, delaying progression of disability, and facilitating an acceptable quality of life (National
Multiple Sclerosis Society, 2005). The variable effects of MS can be startling and frustrating for the nurse. Some people appear physically well, while others may experience great debilitation. The nurse must increase understanding about the effects of the disease on the individual (Arnold 2000).

One of the most important roles of the nurse is helping people with MS improve their quality of life by coping with changes. Nurses can help individuals and families cope with emotional effects, caregiver role changes, cognitive deficits, physical decline, and need for disease management. Nurses promote client coping and readiness for change. A person must develop a sense of readiness to cope with their feelings of stress about their chronic condition. People with MS and their families may not be ready for change because of anxiety, stress, fear, or shock from a recent diagnosis. Allowing time to absorb the new diagnosis may promote better coping and readiness to change (Dalton & Gottlieb, 2003). Research has revealed that a number of factors trigger readiness, including a health condition taking on a new significance, perceiving that a health condition is not going to change, feeling able to manage stress, and the person feeling that they have support to make changes to cope with stress (Dalton & Gottlieb, 2003). Once a person feels a high degree of readiness, he/she reports less anger and depression and is able to view the condition in a positive light. Nurses play an important role in promoting and supporting change (Multiple Sclerosis International Federation, 2005). Through assessment of readiness for change and the factors that enable it, the nurse mediates ways that facilitate change. In facilitating readiness, nurses evaluate the patient's current coping strategies. Communication strategies, decision making, self esteem, spiritual beliefs, and stress management are components of coping strategies.
(National Multiple Sclerosis Society, 2002). Once the evaluation is completed, the nurse can help the individual build effective coping strategies based on the individual’s strengths and improve likelihood of successful coping.

Nurses caring for patients with MS witness a variety of emotions as a result of the disease. In dealing with feelings of depression, anxiety, and anger, the nurse strives to instill hope in the patient to facilitate coping. Feelings of hopelessness, which include a desire to give up and an inability to see beyond the current situation, impede a patient’s ability to cope. Promoting a positive self esteem, competence about the disease and autonomy in care promote hope in patients (Foote, Piazza, & Holcombe, 1990). Nurses must assess a patient’s emotional state and readiness, and then determine what resources are available to support hope. Resources include the National MS Society, Multiple Sclerosis Foundation, and the National Institute of Neurological Disorders and Stroke. These organizations offer patients and professionals information about MS, treatments, current research, and local support groups. Creating hope for the future helps MS patients cope more effectively with their fears (Foote et al., 1990).

A common fear of MS patients is becoming a burden to others. While educating the patient, nurses should include the caregiver and children, as appropriate, to promote coping and understanding (National Multiple Sclerosis Society, 2002). A nurse can help confront this fear by encouraging strong relationships that promote emotional well-being (National Multiple Sclerosis Society, 2002).

The nurse must advocate caregivers to maintain their own health. When caregivers become involved in new roles, they may inadvertently compromise their own health. Sleep deprivation, forgetting medications or doctors appointments, and poor diet
can all result in health decline. The nurse reminds caregivers to make their health a priority so they can be healthy enough to act as a caregiver and live a high quality life.

Nursing care of the MS patient is on a continuum. The path of MS can change, and the nurse must be prepared to face these changes with the person. Continual reassessment of coping skills and emotional effects is necessary to facilitate care. A nurse must look beyond the diagnosis of MS and provide care for the person’s entire well-being in all aspects of their life.

VII. Personal Application

Understanding the psychosocial aspects of MS is important to me not only because I plan to be a registered nurse but more importantly because my mother has MS. Through my mother’s diagnosis, I have had a first-hand look at this disease and how it affects the people behind the disease. The emotional rollercoaster that I have witnessed in myself, my mother, and my family members has brought us to a greater understanding of MS.

When my mother was diagnosed, there was widespread denial among my siblings and my parents. My mother initially refused to take classes on self-injections, delayed beginning treatment, and refused to learn about the disease because denying it meant it did not exist. My siblings and I felt anger and injustice that our mother had been sentenced to this doom, while my father tried to remain the peacekeeper. My mother’s denial and grief turned into depression that lasted for nearly three months. Her depression affected the entire family as we coped with her diagnosis. She had difficulty completing daily tasks such as running errands, cooking, and even getting dressed. In retrospect, I
see that our responses to her disease were a part of the normal grieving process. We all had to face the disease at our own pace and in our own way.

In the three years since her diagnosis, we have accepted, but not become resigned to, the disease. Fortunately, she has not experienced physical debilitation yet and is still able to work. But there are emotional highs and lows, fatigue, and other subtle symptoms that remind us that the disease is still present. Support groups, monthly journals, and yearly conventions have helped us face up to the disease and educate ourselves. My literature research helps me interpret our emotional responses to the initial diagnosis and allows me to help my family continue to manage this disease and its ramifications. I have learned that support, compassion, and providing resources are essential to coping and chronic disease management.

As a nurse, I will care for people with chronic illness every day, and some illnesses may cause great debilitation. The patients may experience many of the same emotions as my mother and through understanding these responses, I can help them cope and adapt to their diseases. I plan to apply my knowledge of stress, grief, and coping in relation to chronic disease management with the people I care for and their families.

VIII. Closing

It is important to understand the disease and its effects on psychosocial adaptation. MS is a disease that is difficult to diagnosis, with variable symptoms, uncertain progression, and no known cure. These factors can result in overwhelming stress for people coping with the disease. In addition, studies show that stress may accelerate disease progression and can cause exacerbations and, therefore, is of prime importance to consider when planning interventions, although it is not known to be a
cause of MS. In coping with stress, exacerbations, and disease progression, individuals and caregivers face a multitude of emotions, including denial, grief, depression, anger, and sadness. Emotional changes may be caused by a variety of factors including chemical alterations, neurological changes, altered coping skills, role and responsibility changes, and decreased autonomy. Caregivers also face emotional changes as a result of altered family dynamics and coping with chronic disease. Changes can negatively affect the person, caregiver, and family. To help the person and family manage the disease and its ramifications, a nurse acts in many roles from counselor to educator. Although long term prognosis is unknown, understanding its affect on the emotions of individuals help the nurse effectively manage the ramifications of the disease. We must recognize that a person with MS is a person who just happens to have MS and that our interactions must be individually focused.
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