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The Lived Experience of Multiple Sclerosis: A Family Perspective

Joanne L. Nelson

THE LIVED EXPERIENCE OF MULTIPLE SCLEROSIS:

A FAMILY PERSPECTIVE

DISSERTATION

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the Degree of Doctor of Philosophy in
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Barry University

by

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Area of Specialization: Marriage and Family Therapy

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ABSTRACT

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A FAMILY PERSPECTIVE

Barry University, 2007

Dissertation Chairperson: Catharina M. Eeltink, Ph.D.

Purpose

The goal of this study was to increase understanding of how parents and children cope with parental Multiple sclerosis (MS).

Background: Multiple sclerosis

MS is a common neurological illness affecting individuals in the most productive time of their lives. It can be diagnosed at any age; however it is usually diagnosed during the early adult years when parenting is most important. Individuals are not only affected by physical symptoms, such as vision problems and debilitating fatigue, they also face emotional problems such as depression and anxiety. The ability to cope effectively with the physical and emotional symptoms of MS directly affects the person's ability to maintain a high quality of life. The inability to adjust will, not only negatively influence the individual with the illness, but their entire family including their children. Consequently, it is important that family therapy interventions are developed to assist the families that are facing chronic illness, specifically MS.

Method

A qualitative approach, specifically the phenomenological method, was utilized for this study because it allowed the researcher to understand the essence of living with, or having a parent with MS. Participants included four female parents and one male parent ages 38 – 48, and two male and three female children ages 11 - 14 who volunteered after being recruited through self help groups. The participants responded to short questionnaires concerning their level of disability, symptoms, ability to cope and family relationships. They participated in separate open ended interviews answering ten (10) questions about the experience of having MS, or a parent with MS

Findings

Four major themes were uncovered in the data. They are: Support, priorities, family relationships and emotions .Twenty-five sub themes were identified. All of the parents and children identified the importance of peer-support groups, and family support as the most important thing to help them cope with the disease. This information will assist family therapists who provide intervention to families living with MS to achieve a deeper understanding of how MS affects families.

ACKNOWLEDGEMENTS

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DEDICATION

I dedicate this dissertation and its research findings to individuals living with MS and their families who bravely face the new challenges the disease brings everyday. Finally, I am especially grateful for the peer support leaders that give their time and energy to assisting others, and making their lives better.

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CHAPTER I

THE PROBLEM

Introduction

Multiple sclerosis (MS) is a common neurological illness affecting individuals in the most productive time of their lives. It can be diagnosed at any age; however, it is usually diagnosed during the early adult years when career and parenting are most important. Individuals are not only affected by the physical symptoms, such as vision problems and debilitating fatigue, they also face emotional problems such as depression and anxiety. The illness also causes problems with employment. People living with MS may be forced to reduce their work hours, and therefore economic difficulties may arise. The ability to cope effectively with the physical and emotional symptoms of MS directly affects the ability a person has to maintain a high quality of life. The inability to adjust will not only negatively influence the individual with the illness, but their entire family, including their children. Consequently, it is important that family therapists who assist families that are facing a chronic illness such as MS have information as to how the disease impacts family functioning.

There are a number of qualitative studies available on the lived experiences of individuals with MS. Finlay (2003) described the life of one individual during her first year of living with the diagnosis of MS. Russell, White, and White (2006) completed a study on how individuals with MS make meaning of the experience of living with MS. Reynolds and Prior (2003) explored women’s strategies for achieving quality of life with MS. A phenomenological study completed by Flensner, EK, and Soderhamn (2003) described MS related fatigue as lived by individuals. This is not an exhaustive list of the available qualitative studies. This researcher, however, did not discover any studies that explored the lived experiences of children and parents with MS. This study will begin to fill the gap by focusing on the lived experiences of parents with MS and their children.

Overview of Multiple Sclerosis

MS is a serious neurological disorder that has a major impact on people living with it and their family, specifically the children. MS is thought to be an autoimmune disease that causes the body's immune system to attack itself. In MS, the immune system attacks myelin, the protective coating that surrounds the nerve cells in the central nervous system. Demyelination results in plaques, or lesions that interfere with nerve conduction. The resulting symptoms of MS are a direct result of the damage to the myelin sheath, or the axons themselves. These symptoms can include vision loss, stiffness, weakness, problems with balance, numbness, pain, problems with the bladder or bowels, sexual changes, speech and swallowing difficulties, emotional changes and cognitive impairment. The symptoms vary from one person to the next, depending on what area of the central nervous system has sustained damage (Kalb, 2000).

Medical historian can trace MS back as far as the fourteenth century. However, documented history of the disease began in the nineteenth century when damage to the spinal cord was discovered during autopsies. In 1824, patients started to be diagnosed with symptoms that today would be classified as MS. AugusteD'Este documented his personal account with the disease, which included what would be diagnosed today as optic neuritis and relapsing remitting MS. Jean-Martin Chargot, a nineteenth century French neurologist, was the first to document a comprehensive description of the symptoms of MS in 1868 (Rao, Huber & Bornstein, 1992; Rumrill & Hennessey 2001).

There is no cure for the impairments that MS causes, but there are disease modifying treatments that slow the progression of disability and medications available to manage the symptoms to help the person with MS have a higher quality of life (Kalb, 2000).

MS brings about changes in the lives of the people diagnosed with the disease. Many of the changes are physical; however there are emotional and psychosocial consequences as well. MS has some unique characteristics that can make an individual's adjustment to the illness difficult. These include the following: (a) the variability in the course of the disease caused by the unpredictable rate that the patient may experience an exacerbation, or worsening of the symptoms; (b) the range of MS symptoms which can cause impairment to virtually any area of the body; (c) while individuals with MS can expect to live up the 75%-90% of normal life expectancy, they are more susceptible to infections pulmonary embolism, and pneumonia; and (d) cognitive problems may develop in short term memory, verbalization, executive functioning and social judgment. MS generally has a negative impact on the career advancement. Due to the erratic unpredictable course of the disease, and increased impairment as the disease progresses, individuals have difficulty with long term career planning. It can also force individuals into leaving employment early, particularly if employers are unwilling to provide reasonable accommodations (Rumrill & Hennessey, 2001).

While each person's emotional response to the changes that MS causes to their life is different, there are some common reactions. When people are initially diagnosed with MS, they experience shock, denial, anxiety, anger, and relief. The longer-range emotional reactions include grief, anxiety, resentment, and guilt. Individuals with MS may experience emotional changes such as depression, bipolar disorder, mood swings, suicidal ideations, affective release, euphoria, disinhibition, poor impulse control, and antisocial behavior (Kalb, 2003). Some researchers suggest that the high level of emotional problems observed in individuals with MS is related to the demyelinated lesions, while others argue that emotional problems are related to the challenges that the individual and their family face living with an unpredictable chronic illness (Rao et al., 1992).

The Functioning of Families affected by Multiple Sclerosis

When a member of the family develops MS, the lives of all of the family members are affected. As the disease progresses, they face unpredictable and sometimes difficult transitions. The family members are sometimes forced to adjust their schedules, duties, or plans for the future. The roles of the family members may also change. All of the family members face grief and loss issues. There is the need for additional research on the effects that MS has on the family, specifically the children when a parent is living with MS. This could be helpful to clinicians in developing interventions for the family to maintain a better quality of life.

Parenting with MS

MS can affect parenting in different ways. The individual with MS may not be physically capable of caring for an infant. A parent may be concerned about keeping an active toddler out of harms way. Parents may feel guilty because they can not play active games with their children. The parents may feel like they are not supporting their adolescent because they are too tired to attend sporting and/or arts events. According to Crawford (2001), parents may also worry that their use of assistive devises will embarrass their children. However, it is believed that the children would rather have their parent’s presence, even if they are using assistive equipment. Many children report that they are proud of their parent’s ability to overcome their disability and share information about MS with their friends and classmates.

How Parental MS Affects Children

Chronic illness not only affects the individual with the illness, but also the children. When a parent has MS, the children are considered to be at risk for developing emotional problems (Yahav, Vosburg & Miller, 2005). The children of the parents who have MS are asked to cope with the changes that this illness brings to the family and to them individually. They may experience a change in lifestyle due to the financial restraints that this illness often brings on, and they may not become involved in after school activities because of additional household responsibilities. They may have to assist with the care of younger siblings or their ill parent. Research shows that the children’s responses to these changes are anger, anxiety, and difficulties with interpersonal relationships.

The Researchers Interest in Family Multiple Sclerosis

The family’s ability to implement healthy coping strategies can influence the long term emotional health of the children. I am interested in exploring this topic because I have a long family association with this illness. My aunt was diagnosed with the illness in the 1950’s. My oldest brother was diagnosed about 15 years ago, and I was diagnosed in 2002. Recently a cousin was informed that she has MS. Each of our families have coped with, and adjusted to, the illness in different and unique ways. There were some devastating consequences such as marriage breakups, teen pregnancy, and extreme financial problems. Some accepted their diagnosis as something that happens, while others became depressed. Others used their diagnosis as a growth opportunity. However, all of my family members who were parents were concerned about how the illness would affect their children emotionally.

Theoretical Framework: Coping with MS.

Family Systems Illness Model (Rolland, 1994, 1999) and coping theory Folkman and Lazarus, 1988) will provide the theoretical frameworks for this study. It is important to consider the individual living with MS in the context of the family system. Family members, including children, provide essential social support to the person with MS. The coping strategies that individuals and families use when MS is diagnosed will have an impact on their adjustment to the illness.

The Family Systems-Illness model provides a useful model for the evaluation, formulation and intervention with families dealing with MS. The model is strength based and views family relationships as a resource and stresses the potential for resilience and growth instead of just their liabilities and risks The model focuses on three dimensions. (1) psychosocial types of illness; (2) developmental phases; and family systems variables. (Rolland, 1999)

Folkman and Lazarus (1988) describe coping as learned behaviors that contribute to survival in response to life threatening dangers. The model identifies repression, denial, intellectualization, and problem-solving behaviors as techniques individuals employ to reduce anxiety and other upsetting emotions. Adapting to or normalizing the illness are methods that may be used to cope with MS. Coping strategies vary among individuals, and are related to their background and personal factors such as gender, age, socioeconomic status, cognitive, ego strength, religious beliefs and prior illness and coping experiences. Illness factors may also impact on coping such as the symptoms being experienced, and the level of impairment caused by the specific symptoms; for example, memory problems may be difficult to cope with by a high level executive. Lastly, physical and social support improves the chances of coping successfully with the challenges that MS invites (Royer, 1998).

Statement of the Problem

People with a chronic illness such as MS cannot be separated into having only biological or psychological problems. MS patients and families come with bodies, minds, feelings, relationships, and belief systems. Family therapists address psychological problems, while physicians treat the biological symptoms. It would be more effective to integrate the medical and psychological services that are provided to the patients and their families (McDaniel, Hepworth & Doherty, 1992). There is extensive research on the physical and psychosocial response of individuals who are living with MS, however a literature review suggests that there is a need for additional research on families' emotional response to the illness. This study hopes to find information that will improve the family's ability to cope with MS and psychologically adjust when a member of the family has MS.

Purpose, Rationale and Design of the Study

The purpose of this study is to understand the lived meaning of parents and their children in families where a parent has MS. A qualitative approach, specifically the phenomenological method, will be utilized because it will allow the researcher to understand the essence of living with, or having a parent with MS. Semi-structured interviews with the parents and their children will be conducted to understand how the parent is coping with the disease, how they feel it is affecting their parenting abilities, and how the children emotionally react to having a parent with MS.

Research Questions

The research questions for this study are: (a) What are the emotional responses of parents and children in a family where a parent has MS? and (b) How do parents and children cope in a family where a parent has MS?

Definitions

Epoche - suspending one's own prejudgment's, biases, and preconceived about the reality of the world to study the essential structures of the world (Creswell, 1998; Van Manen, 1990).

Essence - makes a thing what it is, rather than being or becoming something else (Van Manen, 1990).

Lived experience - involves our immediate, pre-reflective consciousness of life: a reflexive awareness which is, as awareness, unaware of itself. Lived experience gain significance as we gather and give memory to them. Through interpretive acts we give meaning to the phenomena of lived life (van Manen, 1990).

Organization of the Study

In conclusion, this chapter provided an overview of MS, psychosocial aspects of the disease, coping issues, and how the illness affects the children and adolescents of parents living with MS. Chapter II provides a review of the relevant literature. Chapter III describes the methods that will be used to conduct this study, a description of phenomenology, characteristics of the participants, procedures of data collection, and analysis techniques. Chapter IV will discuss the results of the analysis. Chapter V will provide an in-depth discussion of the results of the study and will present recommendations for family therapists' working with people with MS and their families.

CHAPTER II

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REVIEW OF THE RELATED LITERATURE

Introduction

When a parent is affected by MS, their entire family may be emotionally impacted in both negative and positive ways. The central purpose of this research is to explore the lived experiences of MS for parents with MS, and their ~~children and adolescents~~children. A secondary goal of this research is to explore the parent's ability to cope with the uncertainty of MS, and how they believe their coping affects their ability to parent. This chapter provides a review of the literature related to the following topics: (a) an overview of MS; (b) psychosocial issues of MS; (c) theoretical framework; and (d) multiple sclerosis treatments, including postmodern and narrative therapy models.

What is Multiple Sclerosis?

MS is a common degenerative neurological disorder, involving axonal demyelization and plaque formation in the central nervous system. It is estimated that it affects 150,000 to 400,000 people in the United States, and 2.5 million worldwide (Aikens, Fischer, Namey & Rudick, 1997; Eeltink & Duffy, 2004; Steck, Amsler, Kappos, & Burgin, 2001). MS typically commences between the ages of 20 and 40, which is a time in life when parenting is important. There are many theories of the underlying cause of MS, which include environmental and genetic factors. The physical and emotional impairment experienced by individuals causes occupational disruptions and changes in family roles (DeJudicibus & McCabe, 2004). Women are affected more than men by a ratio of about 2 – 3:1 (Eeltink & Duffy, 2004). MS produces a wide range of symptoms, and they vary considerably among patients. The most common physical symptoms include numbness, visual disturbances, bladder and bowel disturbances, coordination problems, spasticity, paresthesia, sexual dysfunction, and pain (Rao et al. 1992). Disabling fatigue and cognitive changes that affect some people living with MS are often invisible, which makes it a difficult disease for people to understand, both for medical personnel and the children of the person living with MS. (Deatrick, Brennan & Cameron, 1998).

The symptoms of the disease vary with each individual, and change over the course of the illness (Cross & Rintell, 1999). There are several courses that MS may follow: benign, relapsing remitting, secondary progressive, primary progressive and malignant. Approximately 10%-15% of people with MS are diagnosed with the benign type. This type is characterized by minimal activity. The most common forms of MS are relapsing remitting and secondary progressive, which account for 65% to 70% of people with the disorder. With ~~this types~~these types there are periodic exacerbations, causing worsening symptoms. The symptoms may stabilize partially, fully, or completely remit during the course of hours, days, ~~weeks~~weeks, or months~~.~~. The primary progressive type has a steady worsening of symptoms.

Multiple sclerosis means multiple scars. The illness is chacterized by lesions in the brains white matter due to demyelization of nerve fibers (Eeltink & Duffy, 2004). As the disease progresses, neurotransmission within the affected regions of the brain and the central nervous system become significantly impaired, leading to disruption of the sensory and motor functions (Mullins, Cote, Fuemmeler, Jean, Beatty & Paul, 2001).

Disruption in the ability to parent is likely to occur as disability increases. (DeJudicibus et al, 2004).

Psychosocial Issues in Multiple Sclerosis

The burden of living with a chronic illness is a major stressor for the individual with the disease and their family members. Chronic illness has been found to relate to higher levels of psychological distress in adults, and to some extent their children (Kotchick,forehand, Armstead, Klein & Wierson, 1996)~~.~~. The heterogeneous nature of the disease with its unpredictable exacerbations, lack of a cure, and eventual functional impairment often leaves patients perceiving their illness as highly unpredictable and uncertain (Mullins et al., 2001).

Initial Diagnosis Issues

The intrusion of MS is an extremely stressful life event, with the potential of posing major challenges and obstacles to everyday functioning. Adapting to MS requires not only an initial adjustment following the diagnosis of the disease, but also continuous efforts of readjustment due to the erratic nature of the symptoms. Uncertainty is more than likely the first stressor that is placed on individuals with MS (Halper & Holland, 2002). Unpredictable and uncertain symptoms such as numbness and vision problems may be the fist sign of MS. It may take months, or even years, to make a definite diagnosis of MS. While waiting for a diagnosis the symptoms may be attributed to stress, depression, psychosomatic issues, or a multitude of other cause. Once the diagnosis is made, it is important that the patient receive ongoing support and reassurance. (Thorn, Con, McPherson, & Harris, 2004). Communication with their medical team wields a powerful influence for people who are newly diagnosed and will assist them as they adjust to living with MS.

In their research, Koopman and Schweitzer (1999) recounted the story Kelly shared with them, concerning her MS diagnosis. She reported that in an instant, her life had been shattered. Her future was dark; the first few months were filled with fear and desperation. Visions of wheel chairs, incontinence, and other negative thoughts played in her head. She often thought of suicide, and even had a plan in place.

Chalfant, Bryant & Fulcher (2004) did a study to investigate if people with MS experience post traumatic stress disorder (PTSD) type reactions secondary to their diagnosis of MS. There are two main reasons to question whether PTSD is a correct diagnosis to describe the emotional distress people with MS face. First, the stress of MS is internally caused, rather an externally induced event that is usually associated with PTSD. Second, PTSD usually involves a discrete past traumatic event that leads to anxiety about the event; the stressor in MS is often on-going and future-orientated because of fears about the prognosis. The study suggested that MS is a significant stressor, and it can bring on the same symptoms observed in the traditional PTSD populations. The authors believe that changes in the diagnostic criteria, allowing for perceived trauma, make a PTSD diagnosis viable for MS patients.

People that are living with MS can experience grief and depression at any time during their illness. The newly diagnosed grieve the loss of self, the old able-bodied self that no longer exists. The long-held expectations of what their future is going to look like are abandoned. Family members often do not always understand this. They often can not comprehend why the family member living with MS is sad. MS grieving can include a number of reactions: (a) Sadness and crying, (b) anger, (c) irritability, (d) asking “why is this happening to me?” (e) longing for the happier times before the diagnosis, and (f) talking about their life prior to the diagnosis (Halper & Holland, 2002).

People newly diagnosed with MS will benefit from access to a MS library, counseling, physiotherapy, and support services soon after diagnosis. Group information sessions and one-on-one sessions are beneficial to people newly diagnosed. It is important to individualize the treatment plan for each person because some patients would like to know as much information as possible after the initial diagnoses, and others are only able to digest small amounts of information at a time (Wollin, Dale, Spenser, & Walsh, 2000).

Mood disorders

MS can also significantly affect social and psychological health. People with MS are at a higher risk for mood disorders. An estimated 25% - 50% experience major depression at some time following onset (Aikens et al., 1997; Kroencke, Denney, & Lynch, 2001), up to three times the amount found in the general population (Nicholl, Lincoln, Francis, & Stephan, 2001). Depressive symptoms include anger, irritability, worry and discouragement. Bi-polar disorders are is also overrepresented in the population, affecting an estimated 10% - 15%. Individuals with MS also have high levels of anxiety and other psychological problems that do not meet current diagnostic criteria, such as pathological laughing and crying, mood swings, and high levels of distress. Fischer, LaRocca, Miller, Ritvo, Andrews, and Paty, (1999) and Kroenck et al., (2001) have reported that there is consistent evidence that distress is higher during exacerbations. MS associated psychological problems have alternatively been suggested to be a possible cause of MS onset and/or exacerbation rather than a consequence (Aikens, et al., 1997).

Long and Miller (1991) examined the suicidal tendencies of people living with MS. In their study~~y,~~ they found that individuals who are at a high risk for suicidal ideation appear to be those who perceive themselves as being less religious, feel hopeless, and lack family support~~.~~. This study supports the need for family involvement and the importance for the entire family to have healthy coping mechanisms as they adjust to their changing roles and expectations.

Mood and affective disorders can cause significant problems with family, children, work, and social life; however, with the proper treatment, an individual can have a high~~er~~ quality of life (Minden, 2000).

Multiple Sclerosis and the Family

When a parent is diagnosed with MS, the whole family must adjust to the disease. Family members must learn to include the illness into their individual and family time without sacrificing their traditional family life (Halper, 2001). MS is able to interfere with and disrupt all aspects of life within the family, including personal relationships, employment, self-care, social interactions, and recreational activities. Family members may be exposed to the psychological, ~~economic~~economic, and social stressors that are often~~may possibly be~~ part of the disease (Rigby, Domenech, Thornton, Tedman & Young, 2003; Eeltink & Duffy, 2004).

Moos and Tsu (1977~~year~~) identified seven important tasks for individuals and families adapting to the demands of chronic illness. They include: (a~~1~~) adjusting to pain and incapacitation; (b~~2~~) managing the hospital environment and special treatment

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procedures; (c~~3~~) developing positive relationships with the medical staff; (d~~4~~) maintaining an emotional balance; (e~~5~~) preserving a positive self image; (f~~6~~) keeping a relationship with family and friends; and (g~~7~~) getting ready for an uncertain future.

Family systems theory supports the concept that there is a relationship between parental illness and family response. When a parent is facing the devastating consequences as a result of a chronic illness, and is unable to cope with the disruption, the entire family is influenced negatively (Woods, Haberman, & Packard, 1993).

Economic hardship

DeJudicibus and McCabe (2005) found that financial stress due to ~~the~~ unexpected loss of income and ~~the~~ change of socioeconomic status caused a loss of security for individuals with MS. Families with lower incomes faced greater financial stress at the beginning of MS than families with higher incomes. Individuals with MS who were unable to work, or had to reduce their hours, were concerned about being a burden on their families~~.~~. Newly diagnosed individuals and their partners were concerned about the economic adjustment that the illness was causing them to make. ~~(~~Armstead, Klein, & Forehand, (1995) found that financial pressures have an impact on the wellbeing and adjustment of families affected by MS. Families that include children or adolescents may have more difficulty adjusting to MS because they are already facing constant challenges of development and childrearing. Adjustment difficulties that children face related to economic problems are connected to ~~caused by~~ the parent's reaction to economic stress.

Parenting with MS

The physical, psychological, social, and economic stressors that~~t a~~ parents with MS may face not only affect~~s~~ them individually, but also their children. Physical symptoms that parents with MS experience may be visible ones, such as difficulty walking or tremors, as well as invisible symptoms such as fatigue, visual problems, and bladder or bowel problems. Children may not understand that their parent's symptoms may be permanent. The invisible symptoms are usually more difficult to understand. The children may misinterpret fatigue as lack of interest in playing with them. Parents who have problems walking or using their arms may require help in caring for their young children. Cognitive impairment, such as memory problems or executive functioning problems, may be difficult for children to understand; they frequently interpret these as the parent not listening or not caring (Crawford & Miller, 1998).

The Response of the Child when Their Parent has Multiple Sclerosis

There have been limited qualitative studies completed on the meaning of MS on the children of a parent who is living with MS. However, empirical studies have been conducted on children's adjustment to their parent's MS. In an early study, Arnaud (1959) found, by their response to Rorchach blots, that children whose parents had MS had higher levels of body concern, dysphoric feelings, hostility, constraint in personal relationships, and dependency longings (Yahav et al., 2005~~, Vosburgh & Miller, 2004~~). Additional findings were that these children also demonstrated a false maturity reaction. The younger children showed a higher level of anxiety. Not all of the children who participated in the study were negatively affected by their parent's illness. The differences may be related to the parent's symptoms (DeJudicibus et al., 2004). Peters and Esse (1985) found that parents were concerned about their relationship with their children and their children's behavior problems.

Buck and Hohmann (1981) found that children who had a father with a spinal cord injury did not differ from children with healthy fathers on ~~Minnesota~~the Minnesota Multiphasic Personality Inventory (MMPI), in sex role orientation, body image, fathers' behavior, or interpersonal relations. However, male children who had fathers with disabilities were found to be more reserved, tough minded, realistic, conventional, and practical, while their daughters were more unconventional, imaginative, and self –assured than children who had a father who did not have a disability.

The role of the children in families that are affected by MS will be altered as the parent's abilities change in relation to exacerbations, remissions, and increased disability. They include shifts in the division of labor, as~~:~~ children may be asked to complete the household tasks that were the responsibility of the chronically ill parent. The increase in the number of responsibilities of chores decreases the amount of free time the children have for recreational activities. The family often must change its schedule to accommodate the parent's need for rest, and dietary changes may control the family meals. The parent may use denial as a coping strategy, and therefore not be available to their children to ventilate emotions (Blackford, 1998).

Since chronic illness is so stressful, the family may develop inappropriate coping behaviors. There may be a role reversal, where the parent becomes the "child" and the child takes the role of the "parent". This reversal of roles may lead to physical and psychological health problems due to the additional stress it creates (Johnson~~,~~ & Martin, 1992).

Swartz and Kraft's (1999) findings suggest that there is no~~t a~~ relationship between the family environment and the patient's physical functioning. However, families that had~~ve~~ high levels of conflict, and who were perceived as more controlling, were linked with poorer psychological functioning. Families that encouraged greater independence and self sufficiency were associated with patients perceiving themselves as less disabled and having better mental health functioning.

Lackey and Gates (2001) investigated adults who were caregivers of a chronically ill family member when they were younger. From the various services they provided, bathing their parent was the most difficult. This may be related to the reversal of roles, or they were too young to manage the task. The children who were responsible for taking care of their siblings and caring for the household duties found that these tasks required them to miss time with their friends and extra school activities. As adults, they felt that they were not given adequate information concerning diagnosis, prognosis, and instruction regarding the care they provided. Care giving can be rewarding for the children as long the tasks are clearly defined, supervision is provided, and the youngster is not given total responsibility

Children who have a parent with MS are thought to be to be at a higher risk for anxiety, body preoccupation, hostility, and inhibitions in interpersonal and dependence related needs (Yahav et al.,~~, Vosburgh, & Miller,~~ 2005). Cross and~~&~~ Rintell (1999) found that many children believe that they have caused their parents' MS, or affected its progression~~.~~. Children also question if the disease is contagious, worry that is fatal, and do not correctly judge its effect on their parent. The study also found that children who have parents with MS show signs of emotional distress and need information that is tailored to their developmental level. The information needs to be repeated in more mature format as the children progress through the stages of development. Parents should also be aware that MS is a psychological and social challenge for the whole family (Yahav et al., 2005; Cross & Rintell, 1999).

The effects of MS on individuals and their families have been researched in a variety of ways. Parenting issues and the effect of parental chronic illness on ~~children and adolescents~~children are essential to understanding the l~~L~~ived experience of MS.

Theoretical Framework

C~~This study will utilize c~~oping theory and the Family Systems Illness Model ~~Family System-Illness model~~ (Rolland, 1994, 1999) will ~~as~~provide ~~theoretical~~the theoretical frameworks for this study. It is important to consider the individual living with MS in the context of the family system. The family plays an important role in~~to~~ providing~~e~~ emotional support and care giving to the person with the illness. The coping strategies that individuals and families use when MS is diagnosed will have an impact on their adjustment to the illness.

Coping with MS

Coping can be viewed as a set of responses, cognitive or behavioral, that people use to deal with stressful events. It is a reaction to a stressor that reduces, resolves, or replaces the negative stressful state. There is a long-standing and widely held belief among researchers and practitioners in the mental health field that the ways people cope with the demands of a stressful life event makes a difference in how they feel emotionally. Despite this conviction, there is little understood about the ways that coping affects the emotional response. Some theoretical models emphasize a unidirectional causal pattern in the way emotion affects coping, both by motivating it, and impeding it. However, the relationship between emotion and coping in stressful encounters is bidirectional, with one affecting the other. Coping includes cognitive processes, such as denial, suppression, repression and intellectualization, and problem-solving behaviors that are invoked to reduce or manage anxiety and other upsetting emotional states (Folkman & Lazarus, 1988). Living with MS can involve coping with a variety of difficulties and stresses, such as dealing with progressive physical disability, accepting the uncertainty of the future and living with symptoms that are variable and often invisible to others, such as strange sensations, fatigue, pain and cognitive difficulties.

A number of factors can affect the impact of, and adjustment to MS~~.~~. These include the person's personality, previous experiences of similar events, the natural progression of the disease, the level of support, and their perception that the adjustment strategies will lead to outcome modifications (Airlie, Baker, Smith & Young, 2001).

There is a body of research that has explored the relation between spirituality and adjustment to MS. Makros and~~&~~ MacCabe (2003) completed two studies; in the first study they found that individuals with MS who had a high level of spirituality and religiousness had high quality of life scores, psychological well being, and lower levels of anxiety and depression. To ~~further~~ investigate further the researchers~~,~~ completed another study. The findings of the second study indicated that people who had high levels of religious direction experienced a reduced quality of life and higher depression and anxiety. The results of this study are inconsistent with the previous research that showed that people with high levels of religious orientation had~~ve~~ lower levels of depression, anxiety, and a high quality of life. Makros and~~&~~ MacCabe reported that the second~~is~~ study had a smaller number of participants than the first study, which may have reduced the dependability of the findings. In their study McNulty, Livneh, and Wilson (2004) found that spirituality predicted psychosocial adjustment to MS. They indicated that a person's spiritual beliefs, values, feelings, and ideas are connected to religious, cultural, and philosophical life experiences. A person's spirituality has a strong influence on their ability to adjust to MS. Second, their study showed that uncertainty and spiritual well being have both direct and indirect effects on adaptation to MS and efforts should be made to address both through educational and clinical interventions.

The impact of chronic illness and psychological stress is related to the ability to effectively cope. Coping strategies have been identified as active or avoidant. Active coping are those strategies that directly affect the stressor, such as taking action to eliminate the problem, or thinking about the stressor in a more positive way. Avoidant coping strategies are behaviors that are intended to draw attention away from the stressful problem, such as denying that there is a problem. Avoidant coping has been identified as the least effective for a positive outcome. Active coping, such as information seeking and cognitive restructuring, has been associated with a better outcome for chronically ill adults (Kotchick,et al., ~~Forehand, Armstead, Klein, & Wierson,~~ 1996).

Family Coping

Families that have coped well with a crisis prior to MS tend to cope better with the disease. Due to the uniqueness of the illness, the amount of time the family takes to adjust to the illness varies (Johnson & Martin, 1992) which justifies investigating coping within the family systems framework. They believed that the coping ability of one family member may influence, and be influenced by other family members. They specifically addressed the coping styles of parents, and how they affect the coping style of children. In their research Kotchick, et al. (1996) found that the parental~~s~~ coping style predicts child functioning .When parents practiced avoidant coping styles, their children had increased internalizing and externalizing of problems. The coping style of the family member with a chronic illness has a ripple effect on the entire family. The coping style of children when a parent has MS is related to the coping style of the healthy parent of the same gender (Steck et al., 2001).

Folkman and Lazarus (1988) highlight the importance of the appraisal of events. They proposed that people first appraise an event~~s~~ by considering if it will cause harm or loss, threaten harm or loss, or offer a challenging opportunity. Second, people must decide if they can manage the situation, and determine the coping resources available. Specific types of demands caused by an illness should induce different types of coping responses. McCubbin, Caudle, and Patterson (1995) put forward the concept of pile up ~~to show~~to show the additional effects of multiple stressors on the family. “Pile up” can include previous stressors that exist in the family such as existing developmental difficulties, or new demands, such as a chronic illness like MS. Different types of stressors cause family members to cope in unique ways.

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Vash and Crewe (2004) describe the resources that are important for families to possess in coping. The resources are emotional, intellectual, ~~personality~~ physical and personality factors ~~physical~~. Emotional stability is important, and in order to facilitate the adjustment process, a loving nature is necessary. The ability to accept things as they are, and knowing that an individual has the power to influence the future is also important. Families with these qualities can rebound from a crisis. Families with high intelligence have the ability to understand complex medical information, and are able to plan ahead to prepare for any problems. The ability to use community resources during a time of crisis is an important asset. The family that has a member ~~that~~ who is assertive will fare better when outside goods and services are required. Family members ~~that~~ who are in good health have the advantage when they are called upon to perform extra duties, for example additional household chores, or care giving.

The child's age can be important in processing and coping with parental illness. Younger children have more primitive thinking, and require greater nurturance. They attempt to create a sense of order to comprehend reality by forming routines and developing relatively absolute mental structures of reality. Children have a higher need for physical care and nurturing than adults. For the youngest members of the family, illness can have an unsettling effect because of the disruption of the family routine, difficulty in understanding the nature and complexity of the illness, and the feelings of rejection due to the parent's unavailability or absence. Older children tend to be more advanced in their thinking, and are capable of identifying their parent's illness and the problems arising from it. Older children are likely to have the same reaction to illness as adults which include feelings of loneliness, helplessness, apprehension, disappointment in their future, or the future of the family. The older child may also display anger towards the sick parent. For adolescents, there is often embarrassment and shame about the illness. Children also feel that they must keep feelings to themselves, so that they do not upset their sick parent (Johnston & Martin, 1992).

Family Systems

Von Bertalanffy is recognized for developing general systems theory in the 1920’s and advancing the idea in 1958, when he combined philosophy, psychology and neurophysiology to formulate the proposal for general systems theory (Rodway, 1974). The general idea of systems theory is that a system has a defined set of elements that have a consistent relationship with each other. The ~~principle~~ theory specifies that when elements are combined in a consistent pattern, the outcome is greater than the parts alone. Systems are organized to construct boundaries around the system, which define what is inside and what is outside the system~~.~~. They are usually hierarchically organized, and consist of subsystems which are part of the larger system. For example, a family system has parental and children subsystems, while t~~. T~~he family is part of a larger system, such as the neighborhood (Prochaska & Norcross, 2003).

Family Systems-Illness Model

Coping with the stress and uncertainties of parental illness can be a challenge for ~~children and adolescents~~children. Rolland’s Family Systems Illness Model ~~Family Systems-illness model~~ (1994, 1999) offers a psychosocial plan to address this issue and to make it a more manageable~~.~~. To assist with the process, the family should become familiar with the expected pattern of practical and emotional demands of the illness, the different phases of the illness, as well as the individual, couple, and family stages of development. This allows the family to remain informed of the changes of the illness, and the developmental issues of the family. Finally, families must be aware of multigenerational legacies that guide their constructions of meanings about health problems and care giving.

The traditional medical disease classification system was designed to establish a medical diagnosis and treatment plan, with little consideration of the psychosocial demands on the patients~~'~~ or their families. The Family Systems Illness Model ~~family Systems Illness model~~ focuses on three areas: a~~1~~) Psychosocial types of illness; b~~2~~) developmental phases; and c~~3~~) important family systems variables.

Rolland (1994) proposes a classification system that defines a connection between the biological and psychosocial aspects of chronic illness. He believes that chronic illness can be grouped according to specific biological similarities, and differences with distinct psychosocial demands for the patient and family. Illness patterns will vary depending on the specific illness in terms of onset, course, outcome, disability, and the level of uncertainty concerning its course (Rolland, 1994, 1999).

Illness can be classified as having an acute onset, or gradual onset. For acute illness, there is a short time for affective and practical changes. Families will be required to use crisis management skills.   The course of illness can take three paths, progressive, constant, or relapsing. MS can follow all three paths depending on the individual (Halper & Holland, ~~et al.,~~ 2002). Families that have a member with MS must live with continuous change, and the continued prospect of role adjustment, which can cause anxiety

There is a profound psychological effect when the chronic illness leads to a shortened life span. A crucial factor is the family member's initial expectation whether the illness causes death, and the amount of anticipatory loss. The unpredictability of MS, and the inability to determine the progression of the disease, is hindered by anticipatory anxiety. Ambiguity about what is coming and how much time the family has before the disease worsens may cause family dysfunction. Combining the onset types, course, outcome incapacitation, and uncertainty levels, we can develop a system for classifying illnesses by similarities and differences that create different psychological demands (Rolland, 1994, 1999).

Rolland (1994, 1999) describes the three major developmental phases of illness: crisis, chronic and terminal. The crisis phase includes the period prior to diagnosis when the patent is having symptoms with no diagnosis, and the initial period after the diagnosis. This time period holds the key to a number of coping strategies for the individual with the illness and the family. This includes creating new meaning for the disorder that assists in the maintenance ~~and~~ of control by grieving the loss of the family as it was prior to the illness, and~~.~~ accepting that the change is permanent by undergoing crisis management~~,~~; at the same time the family develops flexibility, ~~and~~ coping skills, and adjusts to the loss or threatened loss. Learning to live with the symptoms of the disease, and forming a relationship with the healthcare team while becoming a member of the interdisciplinary treatment team, will assist with the adjustment to the illness~~.~~ . During this phase, the professionals have a huge influence over the family's sense of competence at achieving these tasks.

The chronic phase is when the family starts living with the daily issues of chronic illness. Problems such as care giving, relationship concerns between family members, preserving or redefining individual or family goals, and maintaining family development goals within the constraints of the illness are dealt with during this phase. Rolland emphasizes that the family must maintain a normal life during this phase~~se (Rolland, 1994; 1999~~. ~~).~~

During the terminal phase, the family must cope with grief and loss issues~~.~~. The family must shift from controlling the disease to letting go. The best coping strategies involve emotional openness and dealing with the practical tasks (Rolland, 1994, 1999).

Each of these phases serves a role for adjusting to chronic illness. The psychosocial demands can be assessed in relation to each phase of the illness, and priorities can be determined. It also allows clinicians to measure change over time, and evaluate the relationships between the healthcare professionals and the patient and family members.

When chronic illness enters the family each member is forced to look at the present and future simultaneously. The illness must be placed in the developmental framework of the illness, the individual, and the family life cycle (Rolland, 1999). Because the illness becomes a part of the person’s life, it will affect that person. However, it will also affect family members. How they are affected depends on the illness, age of onset, and the stage of the family life cycle. When a parent develops MS during the childrearing years, the family’s ability to stay on course is almost impossible. During family life cycle transitions, the illness can distract from normal development, resulting in the family becoming static as a result of the illness (McDaniel et al., 199~~9~~2).

Communication between the parent and the child or adolescent is important. Children have the ability to sense danger and loss. When a parent attempts to protect their children by not telling them about their diagnosis, the children develop fears that may be more destructive than learning about their parent’s illness. ~~Children and adolescents~~Children have resilience and must be exposed to adversity.

In his model, Rolland (1994, 1999)~~,~~ addresses some of the common family skews that develop when chronic illness enters the family~~.~~. Triangulation may occur when the illness becomes the third member of the couple’s relationship. When there are parental relationship issues, a parent’s illness can serve as a strong partner to the ill partner to gain control. Children will be pulled into the dysfunctional relationship and learn unhealthy ways to gain attention. A major concern occurs when the relationship between the parent and the child~~/adolescent~~ revolves completely around the illness. This may happen when the family does not advance past the initial crisis stage, when the family has to focus on the illness to learn of ways to cope. Another concern is when the spouse becomes the caregiver. Cheung and Hocking (2004)~~,~~ found that spousal care givers described loss of self, loss of partner, loss of support, loss of lifestyle, and problems with future planning. Some additional challenges that families face when a parent has MS include role shifts when the children take on the responsibilities of caring for their parent.

Living with the uncertainties of an unpredictable illness such as MS~~,~~ can be a challenging task for the entire family. Rolland’s Family Systems Illness Model provides a framework for helping families~~,~~ and helping therapists understand families that are facing these challenges.

Multiple Sclerosis Treatments

The management of MS is best achieved through a partnership with health professionals, the patient with MS, and his/her family. There is currently no cure for ~~MS,~~MS; however there are disease-modifying drugs that are able to lessen the severity of the attacks, and slow the progression of the disease and possible future disabilities~~.~~ (Halper & Holland, 2002). In addition, there are many treatments that will help the person with MS understand and cope with the challenges of the disease. On an interpersonal level, peer support groups, counselors, social workers, and caregivers/partners are available to provide the individual with emotional and psychological support (Thannhauser, 2005).

Interdisciplinary Care Teams

The effects of MS are not only biological, they are also psychosocial. It is not feasible for a medical team to address all of the needs of an individual with MS and their family. For that reason, a comprehensive approach to address the complexity of a chronic illness, and its impact on the family, was developed. The health care interdisciplinary teams consist of a group of people, including the patient, which has a shared purpose~~,~~ to process complementary and overlapping skills~~.~~. There are specific team functions with the goal of a positive outcome for the patient (Kalb, 1998; Wiecha & Polland, 2004).

Health care teams date back to the 1940s and early 1950’s~~.~~. Physicians Cherkasky and Silver promoted a team approach, including a physician, nurse, and social worker to provide primary care services. The teams emphasized health services and prevention. There are three recognized health care teams. On multidisciplinary teams, members work independently. There may be meetings to discuss the progress of the patient, but there is generally very little communication outside a shared medical record. A rarely used health care team is the transdisciplinary team. On these teams, the members become familiar with the roles of the other members to the extent that the duties become interchangeable. These teams are almost impossible to operate, so they are not utilized often. Interdisciplinary teams fall between multidisplinary and transdisplinary on the continuum. On interdisplinary teams, members work together interdependently to develop goals and work from a common treatment plan.

On the surface it appears that participation in an interdisciplinary team would not be a challenge; however, in healthcare, physicians are used to calling the shots, are trained to be in control, and expect to be. Some members of the team can be resistant to sharing the power. Additional difficulties may be related to the philosophy of the different disciplines. Social workers' and counselors' education stress~~es~~ the importance of interprofessional collaboration as central to service delivery. Physician training stresses "fixing" the problem with little regard for the psychosocial and personal circumstances. Another problem may be related to the differences in communication. Each discipline has its own jargon, and some of the same words may have different meanings for the members. Some of the difficulties that teams face may be overcome through changes in clinical training. The important skills for the team members to have include ~~:~~ communication skills and problem solving abilities (Cooper & Fishman~~,2003~~, 2003; Wiecha & Pollard, 2004).

Family therapist's role

Family therapists can play an important role in treating individuals who have MS and their families. Two treatment models that can be utilized are post modern theory and Narrative therapy.

Post modern theory

Post modern theory took shape in the 1980's, as accepted practices were deconstructed in literature, education, religion, political science and psychology (Nichols & Swartz, 2004). Traditional epistemology believes that knowledge derives from learning and cognitive processes, while post modernists' posit that knowledge results from social processes, such as language use and interpersonal relationships and are not objectively knowable independent of the observer. (Nichols & Swartz, 2004; Slife & Williams, 1995~~;~~ ~~Nichols & Swartz, 2004~~). Two post modern ways of knowing are social construction and hermeneutic modes of engagement. Social constructionists look for common views of the world that are created, and shared by most people in a society. Hermeneutics is the practice of interpretation, through practical understanding of phenomena (Slife & Williams, 1995; Van Manen, 1990~~; Slide & Williams, 1995~~).

Weingarten (1998) discussed the differences between the modernist and post modernist worldview. She pointed out that modernists observe persons to compare thoughts, feelings, and behaviors with the pre-existing norms. The modernist uses these norms to plan ~~the~~ interventions to place people into the pre-existing norms~~.~~. She is concerned with this process, because it separates the therapist from the client with whom she is working. This puts her in the expert role. In the narrative perspective, the client is the expert and their knowledge must be brought forward. The second dilemma that Weingarten discusses~~d~~ is the power differences~~.~~. The modernist believes that all of the participants in therapy have equal power. This is rarely true, and when it is ignored the power differential is sustained. The post modern narrative therapist is not considered an expert; their role is to listen carefully to the stories people tell about their lives. By telling and retelling their stories, being listened to, and, responding and being responded to, alternatives to the problem saturated story will emerge.

Families will attempt to create meaning from the illness experience (Kleinman, 1988). It is important for therapists to enquire about the belief system of the family, and the meaning that they associate with MS. The family meanings around illness may have developed across generations, culture, and prior personal experiences with illness.

The narrative model can be implemented to assist the client with adjusting to MS. A Problem perceived as external is looked at as more manageable, not as restrictive, and less chronic. Some questions used by narrative therapist might be: What impact has the illness had on you and your family and your relationship? What impact can you or your family have on the course of the disease? Such an approach may help the individual living with MS adjust by paving the way for active coping (Wynne, Shields, & Sirkin, 1992).

Narrative Therapy

Michael White, a social worker from Australia, is the leading figure in Narrative movement. In the late 1970's White developed the idea of externalizing problems (~~(~~White & Epston, 1990).~~, year).~~ . From this point of view the person has a problem affecting them, rather than something they are doing. David Epston, a therapist from New Zealand, is another important figure in the narrative movement. Epston ~~(year)~~ pioneered the use of writing letters to his clients to reinforce new stories and resolve old stories~~.~~. He maintains that clients need supportive communities to sustain their new narratives (White and Epston, 1990) ~~(Nichols & Swartz, 2004).~~ Narrative therapy finds it useful to externalize illnesses, such as MS, therefore allowing the family members to team up against an unwanted enemy (Nichols & Swartz, 2004).

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Perham~~,~~ (1997) shared his experience of providing narrative therapy to families that are experiencing MS. He discussed the importance of families telling and retelling the stories and sharing the challenges that they face. Perham advised narrative therapist to not us be overly optimistic, and push the belief that the family “will get through this” or always “look on the bright side”. This closes the ability for the families to jointly share their fears and pain. Eeltink and Duffy (2004) described narrative therapy as a way for individuals with MS to build on their own and their family’s strengths, and to restory the meaning of living with MS. The new stories can have positive outcomes, with humor, faith and hope.

N~~The n~~arrative therapy is a useful tool to assist family therapists with providing clinical intervention for individuals who are living with MS and there families~~.~~. The ability to cope well with the illness will lead to better adjustment of the individuals with MS and their families.

Summary

This study will focus on the lived experience of ~~children and adolescents~~children who have parents with MS. The lived meaning of the parents will also be addressed. Earlier research has shown that the parent’s ability to cope with the disease has an effect on the emotional response and adjustment of their children. The ~~main~~ research questions for ~~this study~~ this study are~~is~~: ~~What are the emotional responses of children and adolescents that who have a parent with MS? Secondary questions include: a1) DoHow esdoes the a parents’ coping style effect the children and adolescents adjustment? and b2) how dDoes having MS affect parenting abilities?~~ (a) What are the emotional responses of parents and children in a family where a parent has MS? and (b) How do parents and children cope in a family where a parent has MS~~?~~?

These questions will be explored using qualitative methodology, specifically phenomenology.

CHAPTER III

METHODOLOGY

Introduction

Chapter III will discuss the qualitative research method selected for this study. It will also explain the rationale for selecting this method, and the process used to invite the participants. The manner that data will be collected will be discussed, and finally, the data analysis method will be described.

Methodology Rationale

For the purpose of this study, a qualitative research design, specifically phenomenology, was selected because the research question involves understanding the complexity of individual's perspectives in context. Unlike quantitative research, which has a worldview that universal truth exists, the goal of qualitative is to discover each individual's truth. Qualitative researchers believe that ideas about the world are constructed in the minds of individuals, and meanings attributed to events are socially important. Phenomenology describes the meaning of lived experiences of several people, a shared phenomenon. It is a systematic attempt to describe the structures of consciousness, of space, time, body, and human experiences as we live them (Creswell, 1998; Groenewald, 2004; Heppner, Kivlighann & Wampold, 1999; van Manen, 1990). In this study the researcher's background as a family therapist will be an asset in providing a richer and better understanding of the participants' construction of the world (Heppner, et al.).

Phenomenology

The origins of phenomenology began with the work of Kant and Hegel. As early as 1765, the term phenomenology started to appear in philosophical writings and occasionally in Kant's writings. However, Hegel was the philosopher who constructed a well-defined technical meaning. He described phenomenology as (a) knowledge as it appears to consciousness; and (b) the science of describing what is perceived, sensed and what one knows in his/her own immediate awareness and experience. The German philosopher, Edmund Husserl (1859-1938), is regarded as the pioneer of phenomenology in the twentieth century (Groenewald, 2004; Moustakas, 1994). It was the philosopher Decartes that had the most influence on Husserl, specifically in the development of the concept of Epoche. Epoche, or bracketing, is the suspension of one's beliefs in the reality of the natural world (Moustakas, 1994; van Manen, 1990).

Sampling Strategy and Participants

There are a limited range of sampling strategies appropriate for phenomenological research. It is a requirement that all of the participants experience the phenomenon being researched, thus criterion sampling was used for this study. There were five parent/child pairs interviewed for the study. All of the participants in the study were a parent with a definite diagnosis of MS, and their child/adolescent between the ages of 11 and 18. Individuals who did not have the physical or cognitive ability to participate in a ninety minute interview were excluded from participating in the study

Method of Inviting Participants

The participants were recruited through the local National Multiple Sclerosis Society (NMSS) self help groups. With written permission from the NMSS governing board, the researcher attended local self-help groups, and presented information about the study, including the request for parent/child pair participants. Informational Research Study Flyers (Appendix D) were distributed so that individuals who were interested in volunteering for the study could contact the researcher. Potential participants were interviewed to confirm their appropriateness to participate in the study.

Procedures

Prospective participants who responded to the flyers were given a general description of the study and the time commitment required for participation. The voluntary status of their participation and their right to stop participation at any time during the course of the interview was explained. It was explained that the risks involved in completing the inventories were not expected to exceed those ordinarily found during routine psychological testing. Contact information for the investigator was provided to the potential participant. Participants were assured they could call the researcher anytime during the duration of the study and afterwards, if necessary.

If the individual was interested in participating in the study, the researcher scheduled a 20 minute initial interview with the volunteer participant that was held in a location that was convenient, safe, and accessible, where the participant's confidentiality would be maintained. The researcher presented informed consent forms for the parents to sign for themselves (Appendix E) and their child/adolescent (Appendix F), and an assent form (Appendix G) for the child/adolescent. The researcher explained each form, and answered any questions that the participants had.

In-depth interviews ask participants to open up about intimate aspects of their lives; therefore it is important that they are fully informed about the purpose of the study, and how the information that they disclose will be used. The informed consent form included the following information:

1. The participants were informed that they were being asked to participate in in-depth interviews concerning living with MS, or having a parent that is living with MS. They were also advised that the research was being conducted as part of a Doctor of Philosophy degree in Counseling at the Adrian Dominican School of Education at Barry University. They were informed that the goal of the research was to develop a structural description of how the phenomenon of parental MS is experienced.

2. The researcher informed the volunteers that participation in the study was voluntary. If the participants choose not to participate there would not be any negative consequences, and they had the right to withdrawal from the study at any time.

3. They were advised how to contact the researcher and the dissertation chair if there were any problems.

4. They were made aware that risks involved in participating were minimal, but should they experience any emotional distress they could schedule a counseling session with the researcher at any time.

5. There was an explanation that there are no expected direct benefits of participating in this study, however participating may increase understanding of parental MS.

7. Participants were told of the confidentiality process and that their names would not be used in the study.

8. Information was provided on how the participants could obtain a summary of the findings of the study.

Once full informed consent was given by the selected participants, the participants were asked to complete a Demographic Information Form (Appendices A and B), and then the researcher scheduled a time to conduct 60-90 minute interviews with the parents and 60 minute interviews with the children. The interviews were conducted at a location where the participants felt comfortable, safe, and at ease enough to speak openly (Seidman, 1998). The interviews were tape recorded and transcribed verbatim by a professional transcriber, who signed a Confidentiality Agreement Form (Appendix H).

Interview Process

This study utilized in-depth interviews to make sense of people's behavior in a natural setting. The interviews were semi-structured, with the interviewer having a list of ten prepared questions (Appendix C), which led to follow-up questions. Care was taken not to lead the respondent to the researcher's previous held beliefs about living with MS. The researcher asked the participants to share their experience of having a parent with MS, or being a parent with MS, and how they cope with family MS.

The interviews were an interactive, informal process. The interviewer prepared a series of questions with the aim of evoking a comprehensive account of the person's experience of living with MS, or the experience of having a parent with MS. Prior to the start of the interview, the researcher asked the co-researcher to take a few moments to focus on the experience. The interviews began with a social conversation to develop rapport, and create a calm and trusting feeling (Moustakas, 1994). The researcher set aside all preconceived notions (bracketing or epoche), to gain an understanding of the essential structures of the participant’s responses. All previous knowledge and experience was disqualified. The researcher looked at all information as if it was the first time that it was seen or heard (Moustakas, 1994; van Maden, 1990). The researcher avoided turning the interview into a therapeutic session. The goal of the interview was to learn, not treat the participant. If the interviewee appeared to be in distress the interviewer stepped back from what was causing it (Seidman, 1998).

Confidentiality of Information

Confidentiality of the information was maintained by assigning each participant an ID number. All of the parents were assigned an even number. Youth participants were assigned an odd number. The participants were assigned a letter to identify the pair that they were a member of. Only the researcher had access to the identifying information and it was kept in a locked file cabinet separate from the data collection instruments. The consent forms were also kept in a locked cabinet separate from the data collection forms. All of the data was reported in aggregate form with no identifying information. When quotes were used the names were changed and the identifying personal pronouns, for example he or she were modified. All of the data collected, including electronic data, was stored in a locked file located at the researcher’s office. The forms, audiotapes, and transcripts will be kept for a period of five years, and then destroyed.

Data Analysis Procedures

Data analysis for phenomenological research generally follows the following steps. First the interviews are transcribed. The second step involves reading and re-reading the transcribed interviews to achieve a holistic and intuitive understanding of the phenomena. It is important for the researcher to bracket all preconceived perceptions and judgments. Then the original protocols are divided into statements or horizonalization. Horizons are endless, and can never be exhausted no matter how many times they are reviewed, there are always new meanings to be discovered. Even when we discontinue the process, no prospect lasts for ever; the contents of conscious life appear and disappear (Moustakas, 1994). Next, repeated or non relevant statements are removed, and referents or specific words that highlight the meaning are highlighted. The units are changed into cluster of natural meaning units. Lastly, major themes are constructed to explain the meaning attributed to living with MS (Moustakas, 1994; van Maden, 1990).

Trustworthiness and Validly

Ensuring the trustworthiness and validity in qualitative research is important. Maintaining strict adherence to accepted phenomenological research procedures will assist in the creditability of the research. Validity, in qualitative research, deals with the assumption that the researcher reports what is observed, and that this is in fact what really transpired. To assist in maintaining the truthfulness and validity of the research, this researcher employed two methods of investigator triangulation. First, a peer debriefer who has experience in MS and who will sign a Confidentiality Agreement Form (Appendix H) read the transcribed interviews and reviewed them for meaning. The peer's interpretation were compared to the primary investigator's interpretations. The second method included the co-researchers reading their transcribed interview, and making changes or comments.

Summary

Using a phenomenological approach, the goal of this study was to increase understanding of how parents and children cope with parental MS. This researcher believes that a parents' ability to constructively cope with MS will lead to better psychological outcomes for their children, and that family therapists who provide intervention to families living with MS will achieve a deeper understanding of how MS affects families as a result of the findings of this study, and that the insights gained will be helpful to family therapists.

CHAPTER IV

RESULTS

Introduction

The purpose of this chapter is to analyze the data collected using a phenomenological research method. The objective of this study was to understand the lived experience of parents and their children in families where a parent has MS. In the first section of this chapter an overview of the demographics and description of the families are provided. In the second section, the data was analyzed using the process described by Moustakas (1994). The participants’ tape recorded interviews were transcribed. The transcriptions were read through several times allowing the researcher to achieve a sense of the whole and develop an intuitive understanding of the phenomena. Next the non relevant statements were removed and specific words were clustered into natural meaning units. Lastly, major themes were constructed to explain the meaning attributed to living with MS or having a parent that is living with MS.

Textural Data of Participating Families.

Participants in the study included five parents living with MS and their children. Four of the families were Caucasian and one Hispanic. Four of the parent participants were female, and one male. The ages of the parents range from 39 and 48. The higher number of female participants mirrors the data indicating women are affected by MS more than males. All of the parent participants were married, and rated their marital relationships as satisfactory. Three of the parents had relapsing-remitting MS, one had secondary progressive, and one was not sure of the type. The shortest time frame since a parent’s diagnosis was two years and the longest was twenty-one years. Table 1 presents the parents’ demographics.

Table 1

Parents’ Demographics

	1	2	3	4	5
Age	45	39	48	45	38
Gender	M	F	F	F	F
Marital Status	Married	Married	Married	Married	Married
Ethnicity	Caucasian	Caucasian	Caucasian	Hispanic	Caucasian
Education Level	High School	Some college	Undergraduate college degree	High School	Some college
Religious Affiliation	Blank	Catholic	Blank	Blank	Catholic
Current work status	Unemployed	Unemployed	Unemployed	Unemployed	Employed/self employed part time
Receiving disability income	Yes	Yes	Yes	yes	
Type of MS	Secondary Progressive	Relapsing-remitting	Relapsing-remitting	Unsure	Relapsing-Remitting
Age symptoms first appeared	25	36	44	36	36
Year when symptoms first appeared	1985	2003	2002	1997	2004
Age when first diagnosed	26	36	44	36	37
Year when first diagnosed	1986	2003	2002	1997	2005
Self rating of severity of MS symptoms in the last year	Moderate	Moderate	Mild	Moderate	Moderate

Self rating of mobility	Able to walk at least one city block w/o aid	Able to walk at least one city block w/o aid	Able to walk at least one city block w/o aid	Able to walk at least one city block w/o aid	Able to walk at least 15 feet with aid
Overall rating of Physical health	Poor	Fairly good	Fairly good	Fairly good	Fairly good

The children participants include three females and two males; ages ranged from 11 – 14. All of the children rated their peer relationships as satisfactory or above. The children tended to rate their parents physical health at a higher level than the parent’s self rating. Both the parents and the children rated their family’s overall relationship at satisfactory or above. Table 2 presents the children’s demographics.

Table 2

Children’s Demographics

	1	2	3	4	5
Age	11	12	12	13	14
Gender	Female	Female	Male	Female	Male
Ethnicity	Caucasian	Caucasian	Caucasian	Hispanic	Caucasian
School status	Full time student	Full time student	Full time student	Full time student	Full time student
Number of siblings	1	1	1	2	1
Who do you live with?	Both parents	Both Parents	Both parents	Both parents	Both Parents
Parent with MS	Father	Mother	Mother	Mother	Mother
Your age when you found out your parent had MS?	5	9	8	4	13
Overall rating of your parents physical health	Excellent	Good	Excellent	Good	Fairly good

Description of the Participating Families

Family 1

Family one consisted of a Father, Mother, and two daughters. The father and his eleven year old daughter were interviewed for this study at their home. The father, age 45, has been living with MS for 21 years, the longest of all of the participants. He identified the type of MS as secondary progressive. At the time of diagnosis he was working as a truck driver. His major symptoms include numbness, and tingling and weakness in his legs. He rates his overall physical health the lowest of all of the participants. The entire family is involved in the National MS Society (NMSS) peer self-help groups and other family programs.

Family 2

Family two consists of a 39 year old Mother with MS, her husband, and two children. The mother and her 12 year old daughter selected the researcher's home office for the interviews. The parent has been living with relapsing-remitting MS for approximately four years. Her symptoms that cause the most problems are weakness and the inability to use an arm. The participant's sister is also living with MS. The family is involved with the NMSS, and the client provides support to individuals newly diagnosed and others living with MS.

Family 3

The third family that participated includes a 48 year old Mother with MS, her spouse and two sons. The youngest son, age 12, agreed to participate in the study. The interviews took place in the participant's home. The mother was diagnosed with relapsing-remitting MS in 2002 at age 43, making her the oldest out of all of the participants when she was diagnosed. The family is active in community and MS programs.

Family 4

The fourth family is made up of a mother living with MS for 10 years, her spouse and three children; two that live at home and an older daughter with children who lives close by. She is unsure of the type of MS she has. The middle child, age 13, agreed to participate in the study. The participants choose to be interviewed in their home. The child participant is this family has a lot of responsibility to take care of her younger sibling due to the parent's symptoms which includes extreme fatigue. The parent and children are involved with NMSS peer-support groups.

Family 5

The last family consists of a mother with MS, her spouse, and two sons. The youngest son, age 14, who is the oldest child participant, agreed to be part of the study. The family chose to be interviewed in their home. This parent had the most recent diagnosis of the five participants, in 2005. She also rated her mobility lowest among all of the study participants. At the time of diagnosis the participant was working in the medical field which gave her additional insight into the disease. The parent participant is involved in NMSS peer support groups.

Interviews

The researcher completed five parent/child in-depth interviews that consisted of ten prepared questions which led to additional follow-up questions. Care was taken not to lead the respondent to the researcher's previous held beliefs about living with MS. The researcher asked the participants to share their experience of having a parent with MS, or being a parent with MS, and how they cope with MS being part of the family.

Summary of Parents' Interviews

The first interview question the researcher asked the parents was "Tell me about your diagnosis of MS." The participants shared various responses to the initial diagnosis. One called their mother in a panic and said "I'm dead," and was not convinced that it was not a terminal illness until after doing research on the disease. Two of the participants took a month to recover, one in the hospital, and the other at home in bed. This caused them to suffer additional emotional distress because they were unable to care for their young children which included a toddler. One of the mothers described her diagnosis as: "One of the scariest and worst times of my life." Another participant received her diagnosis while at work and described the experience as "troublesome" and "scary." She was working in a high paced demanding setting. After the diagnosis she was unable to maintain the job. She explained that her profession is part of her identity, and felt people would not respect her if they knew she has an illness. Still another participant felt that she was immune and could not have MS.

The second part of the question investigated "What symptoms do you find particularly troublesome?" The answers reflected the varied symptoms that are common in people living with MS, such as numbness, vertigo, dizziness, weakness, fatigue, elimination problems, and emotional difficulties such as panic attacks, anger, and depression. Two participants described mild to moderate cognitive problems, including memory loss and spatial difficulties.

The second interview question asked the parent participants to describe how they cope with MS and the stressors it creates. All of the participants discussed the importance of being active in MS peer support groups. Four indicated that taking a leadership role in the groups, and knowing that they help others, assists them in coping with the illness. Three of the participants gave details on how their family and friends help them cope. Three revealed that they have faith that God has a plan for them and this helps them cope. Additionally, all of the participants shared the positive effect that prescription medication had on emotional problems they experience, such as depression, anxiety, and panic attacks.

When asked specifically, “How MS affected or changed your parenting?” All of the parents responded that MS has made them better parents. They described how they were given the opportunity to spend more time with their children because they were either not working, or had reduced their working hours. One of the parents explained that since their diagnosis they did not miss any of their children’s school activities.

The fourth interview question, “What is your perception on how your MS diagnosis is affecting your child?” and the fifth question, “What are some concerns you have about how your MS is affecting your child?” ended up being merged due to their similarities. One parent thought that her child had grown up too fast. The child was responsible for more house hold chores, and had to assist with the care of her younger sibling. Another parent felt that seeing her sick might affect the child mentally, and the parent was concerned that it was difficult for the children to see the disease progress.

The sixth interview question asked parents,"How having MS affected your relationship with your child?" The participants, in general, did not feel that MS had a negative impact on the relationship with their children.

The seventh interview question explored how having MS affects their family. Participants discussed the additional stress that MS places on the family, especially when they are having an exacerbation. All of the parents felt that, after the initial adjustment to the diagnosis, they are closer. One participant discussed how they felt concerning the impact on their spouse. They discussed the difficulty involved when the spouse could see them deteriorating. Another participant discussed the intimate relationship problems, and her concern that her spouse was affected. The participants also discussed the problems that their family of origin had with their diagnosis. One of the participants has a sister with MS, but explained they are very different and therefore, they do not provide support to one another. Some of their parents blamed themselves, others felt powerless because they could not make their child better. All of the participants identified economic issues caused by their inability to maintain employment.

The eighth interview question asked if they have found anything positive from having MS (in regard to their family members and life in general). All of the participants discussed new friends that they have made in the peer support groups that "will last a lifetime." In general, the participants described the diagnosis as a "wake up call," and it made them realize that their families are the most important thing in their lives.

The ninth interview question asked the parent participants to give advice to other parents who have MS, and what they would tell them. The parents felt that it is important to be honest with your children about MS, and educate them about the disease.

Lastly the researcher gave the parents the opportunity to share additional information that that they considered to be important with reference to living with MS. The participants shared their strong belief that remaining positive is important for a good outcome to the disease. Additionally, they made the recommendation to families living with MS to take one day at a time. One of the participants simply said "it is what it is."

Summary of Children's Interviews

The children were interviewed separate from their parents. They appeared to be Nervous initially, however after a short time they appeared to be more comfortable with the interview process.

The first interview question was "What is it like living with a parent who has MS?" Two of the children described having a parent with MS as hard due to their parents' inability to participate in family activities they did prior to the diagnosis. Another participant felt that the family is not as close as it was prior to their parent becoming ill, because they are not able to spend as much time together doing fun things. One participant felt that she is required to help out more with her younger sibling, such as changing diapers. Another child described everything as "normal" except when their parent was first diagnosed and could not get out of bed for a long time. One participant felt it was not that bad because her parent did not look like they have MS, except when she can not walk, and has tremors

The second interview question asked "What is your perception of how your parent is coping with MS?" All of the child participants seem to feel that their parents were coping with MS "very well" or "pretty good." Two of the children felt that it was helpful that their parents remained active. Another felt that it was beneficial when their parent took naps.

The third interview question asked, “How does having a parent with MS impact you?” One of the respondents felt that they had more responsibilities and chores than their friends and described conversations with their friends where they get upset. They feel like telling their friends to stop complaining because the participant has more chores than they do. Another participant shared how her parent get stressed when she goes to get her shot, and ends up “yelling and screaming” and the child participant ends up screaming back at her parent. This usually results in both of them feeling bad because they don’t like yelling. One of the participants described it as “hard” but she had to get tougher to deal with it.

The fourth interview question looked at how they cope with their parent having MS. One of the participants described a situation where they helped their parent in the support groups. The child communicated that being involved in their parent’s peer support groups helps them cope also. Another respondent explained how they talk to their friends and parents when they have problems. Two of the participants attended MS Kids Camp, where they have the opportunity to meet other children that are affected by MS. One of the respondents described how they help their parent by taking care of their sibling and helping give the injection. Another participant described that they cope by helping their parent with their medication and making their parent coffee or tea when they are not feeling well. One of the participants explained how they want to be left alone, and listen to music.

The fifth interview question investigated some things that they worry about with having a parent with MS. All of the participants shared that they were worried that their parent's symptoms would get worse. The main concern is that their parents will not be able to walk, while another child is afraid that their parent might go blind.

The sixth interview question asked how their parent's MS has affected the relationship they have with their parent. One of the participants did not feel that the relationship was affected negatively due to the MS because her parent stays active and they still have fun together. Four of the children responded that they are closer now than they were prior to the diagnosis.

The seventh interview question "How does your parent having MS impact the family?" One participant described how their mother gets upset at shot time. They felt that this impacts the entire family in a negative way. They described how hard it is to see their parent sad. Two of the participants described situations where their parent can not participate in family activities because they are too tired.

The eight interview question asked the child to share if they have found anything positive about having a parent with MS. One participant felt that they have been given opportunities to do fun things such as going to Sea World. In addition the participant explained that while other students might make fun of people with handicaps, they think they are just like other people, except they have a harder time doing some things.

The ninth interview question gave the child the opportunity to explain what advice they would give to other children who have a parent with MS. One participant explained that they would tell other children to just go on with their regular life. Another participant would tell them MS is not contagious, and not to worry because they will be fine. One child would explain that when you have a parent with MS you need to be understanding when they can’t do some things.

The last question, gave the child the opportunity to share everything that they feel is important with reference to living with a parent with MS. Most of the participants did not have any additional comments; however one simply stated that they would be really happy if they find a cure.

Textural Description of Findings

The four major themes that emerged in this study are support, priorities, family relationships, and emotions. The prevailing theme was peer support. All of the parents and children felt that peer support was important to help them cope with MS. The children also felt that they benefited by their parents involvement with the groups. The families discussed how their priorities changed after they were diagnosed. Family closeness was a theme that rose from the data. The families felt that MS brought the family closer at times; however it also impacted their family time together. The parents made family time a priority over work. All of the participants openly discussed the influence of the emotional problems that they were having due to having MS, or a parent with MS, and its impact on the family. Table 3 shows the major themes and sub-themes. Tables 4 and 5 represent the prevailing theme statements for both the parents and the children.

Table 3

Themes and Sub Themes

SUPPORT	**PRIORITIES**	**FAMILY RELATIONSHIP**	**EMOTIONS**
Help others Kids camp Telephone calls	Family	Closeness Support Fun Get to know More time together	Anxiety Depression Fear Anger Alone Stress Panic Dr. Jekyll, Mr. Hyde Denial
Friends Family support	Self care God	Yelling Not close	Happy

Table 4

Parents' Prevailing Themes Statements

Support

"I make daily calls to people with MS, a lot of them are newly diagnosed and I'm helping them through that time and I really think it takes my mind off of it and off me."

"…to be able to help other people out….I think that is the main positive thing about having MS".

"He/she helps others; he/she has grown to help others".

"It's just a matter of you know I don't let it affect me because you know the support. group…I'm tough".

"Support groups are the best".

"I have met some wonderful people and I love going to the meetings, Honestly, I think those are my time-out, my go out time".

"He/she (youngest child) thinks the MS support groups that we have cookies and food".

Priorities

"God's working with us all; God gave us this disease for a reason."

"Sometimes I say God gave me this because He wants me to stay home with my kids".

"I'm there daily actively developing him/her every day".

"I was there every minute he/she was swimming".

"We have a new pact….As a family we're gonna go back in exercising and trying to be healthier and be better".

"When you're given a diagnosis on MS you really have to go above and beyond and take care of your self."

"After getting sick the most important thing in my life was to stay healthy".

"…I think I really appreciate time, family, what I have much more I mean it was an unbelievable difference".

"I missed a lot of time seeing him/her that wasn't my priority. Suddenly my priorities changed, They're my life now, They're my priority."

"I always thought parenting was an important aspect, and so is my career, but I realize my priority was my two kids."

"I think all of have realized that everyday counts a little more."

Family relationships

"I have support…. My husband/wife are there and they love me so much it's unbelievable."

"…he/she's my buddy; it has ……he/.she's there 100%".

"We were kinda' drifting apart….we have never been so close. MS has really brought us so much closer'."

"...It made us closer as a family".

"I am there daily actively developing him/her every day".

""…positive, because I've been able to not work, and stay home with my children…more time together".

"I think we've become closer".

"Every function he/she goes to I'm there".

"It's crazy because my husband/wife …He/she still says he/she wants to make believe I don't have it".

"Oh this MS, you always get lost with this MS…And I'm like you know I have MS, but you (spouse) have MS too, multiple stupidity".

"My husband/wife gets stressed pretty easy"

Emotions

"What bothers me is the anxiety, ...It's like a ball of yarn that's just winding and winding and winding and winding and it's just my whole body churns…"

"During the day, I get so angry my jaw tightened up".

"When it's really bad I take medication… like when the electricity's not flowing properly, I don't know how to describe it".

"When I don't take my pills I get like Doctor Jekyll and Mr. Hyde".

"I would panic to the point I would get tremors".

"I was always crying, I hated it…I was real depressed".

"I still get scared because my arms feel worst at times. I feel like is that something in the future for me you know”.

Table 5
Children’s Prevailing Themes Statements

Peer support

“I help him (with the support group) “.

“There was a couple of times I felt uncomfortable talking about it (MS) because it make him/her feel sad or something, so it’s tough and that’s why I go to kids camp”.

“It’s good when I see other kids (parents also have MS), …and we talk about it and it’s better, I get along with them better”.

“I think he/she’s doing good with it. He’s/she’s helping other people and with those type of calls and everything, he’s/she’s talking to other people about it, I think he/she’s doing very well.”

“I talk to friends about it…”

Priorities

“…It kind of opened my eyes to the problems of life and stuff like that.”

Family relationships

“I think it’s brought my family closer”.”

“We still have fun together”..

“I think it got better…know each other better”.

“It makes us closer”.

“Can’t be close as much”.

“My Dad/Mom is more stressed and stuff. So he yells at us more”.

“My brother/sister isn’t home anymore, and I guess we used to be close and stuff.”

Emotions

“When he/she starts getting sick then it starts affecting us. Everyone gets stressed out”.

“He/she seems happier”.

“The shot gets him/her really angry”.

“I see him/her happy not really sick and that makes me happy.”

“I like to be alone sometimes to just think about it…”

Summary of Prevailing Themes and Sub Themes

This study summarized the lived experience of MS, a family perspective, into four themes. All of the participants identified peer support groups as a beneficial tool for coping with MS. The parents described the positive feelings that they have after attending group meetings. The participants shared times in their lives when they were feeling stressed, depressed, anxious about symptoms they were having. They revealed instances where they reacted negatively towards their families. After attending peer support meetings and sharing their concerns with others with MS, they were able to cope better. After the diagnosis the parents made the children and family their priority, this helped to achieve a closeness that did not exist prior to the diagnosis. The parent’s communicated that before they were diagnosed they spent a lot of hours parted from their families trying to get ahead financially. After they were diagnosed, they realized that their families were more important than material things, however because of the reduction in work hours they have had to make financial adjustments “finances are tighter”. One participant revealed that they were drifting apart from their spouse prior to being diagnosed;

however, after the diagnosis they felt close again. They had to join together as a family to fight the disease. Furthermore, parents put their health in the forefront. The participants communicated that when they feel healthier they are able to function better, allowing the family to spend additional quality time together. The described exercise the exercise routines that they follow to maintain strength and flexibility which they hope will delay progressing of the disease. The participants communicated that God had either become part of their lives or their faith was renewed. They explained that this allowed them to understand that there is reason that they have MS.

Parents and children clearly felt that the emotional impact influenced the family in a negative way, and felt it was the most troublesome symptom. The participants all described emotional responses to the diseases, with anxiety and depression being the most common. In addition the children described times when their parents were too tired to do household chores, or take care of their younger siblings. The shared their disappointment that they have to help by doing household chore, or caring for their younger siblings. One participant disclosed that they felt that their relationship with their parent that does not have MS and their sibling is negatively affected due to their parent having MS.

Conclusion

The results of this study will assist family therapists in understanding the emotional response of children that have a parent with MS. How parent’s coping style affects the children’s adjustment? And last, if MS affect parenting ability.

Chapter V

SUMMARY AND CONCLUSSIONS

Introduction

The purpose of this study is to understand the lived meaning of parents and their children in families where a parent has MS. This chapter includes restatements of the problem, restatement of the methodology, and meanings of the researcher's findings. A discussion of how the findings compare with previous research findings and how the findings relate to coping theory and medical family issues is also presented. The limitations of the collected data will be discussed. Recommendations for therapists that work with families living with MS will be presented and recommendations for further study will be detailed.

Restatement of Problem and Rationale

Multiple sclerosis (MS) is a common neurological illness that can be diagnosed at any age; however it is usually first diagnosed between the ages of twenty and forty. Individuals are not only affected by the physical symptoms, such as vision problems and debilitating fatigue, they also face emotional problems such as depression and anxiety. The inability to adjust to the physical and emotional aspects of the disease will not only negatively influence the individual with the illness, but their entire family including their children. Adapting to the illness not only requires adjustment after the initial diagnosis, but continuous adjustment, due to the unpredictable nature of the disease. Consequently, it is important that family therapy interventions are developed to assist the families that are facing chronic illnesses, specifically MS.

Restatement of Methodology

Participants for this phenomenological study were recruited through the local National Multiple Sclerosis Society (NMSS) self help groups. With written permission from the NMSS governing board, the researcher attended local self-help groups, and presented information about the study, including the request for parent/child pair participants. Informational Research Study flyers were distributed so that individuals who were interested in volunteering for the study were able to contact the researcher. Eight parents responded to the flyer and showed interest in participating in the study. However, three had to discontinue after the initial interview was completed due to personal problems. At the initial face-to-face meeting the parents signed written consent forms for themselves and their children. The children signed the assent form inform involving minors. Additionally, both the parents and children completed demographic surveys.

In-depth interviews were conducted separately with the parent with MS and their child consisting of question concerning their experience of Living with MS, or having a parent with MS. The interviews were tape recorded and transcribed.

Meaning of Research Findings

The data analysis of this study found common themes that developed from both the parents and children’s interviews despite the interviews being conducted separately. The prevailing theme was support, both the parents and the children felt that being involved in a peer support group in the role of a leader, or a participant, helped them, or their parent cope with MS better. In addition, the parents and the children identified that the family became more of a priority after the diagnosis. This helped improve the families' relationships. Finally, both the parents and the children identified positive and negative emotional responses to having MS in the family.

Feedback from the participants

All of the families were given the opportunity to provide feedback for the study. The overall response was agreement with the findings, One of the participants explained that the family decided to share the transcripts of the interviews, including the spouse that did not participate in the interviews. They determined that they are doing a good job parenting their child. Another seemed happy that they had the opportunity to see the transcripts, because are useful tool to help him/her continue on the path to self improvement. Lastly, one of the parent participants agreed that it was a true reflection of the interviews; however she was surprised that she sounded so "dumb."

Findings in Relation to Theory

Due to the erratic nature of the symptoms it can be difficult to make a definite diagnosis of MS. Because of that, stress is often one of the first emotions that can be linked to the illness (Halper & Holland). The parent participants in this study reported that they experienced symptoms of the illness prior to the diagnosis being made. One participant, describe a "tingling" from the chest down. Another participant related the symptoms to another medical issue that they were having. Still another had unexplained medical problems for years. One explained that they felt bad; however they knew it could be worse, such as cancer of AIDS because they had family members that died from those diseases. The participants faced uncertainty, which added stress to an already difficult situation.

Once the diagnosis is made individuals can experience grief and depression at any time. They often grieve the loss of the loss of the able-bodied individual that no longer exists (Harper & Holland, 2002). The parent participants in this study were not able to maintain employment due to their illness. After the initial disappointment of not being able to work they found that their family became the priority. Three of the participants who tied their self- worth to their profession were having the most problems. Two were attempting to return to work part-time.

People with MS are at a significantly higher level for mood disorders. An estimated 25% - 50% experience major depression. Individuals with MS also face higher levels of anxiety than the general population (Aikens et al., 1997: Kroencke, Denney, & Lynch, 2001). The entire parent participants were currently taking psychotropic medication either on a daily basis or as needed due to depression or anxiety.

When a person is diagnosed with MS, the entire family is affected. The family members are exposed to the psychological, economic, and social stressors that often accompany the disease (Rigby, et al., 2003: Eeltink & Duffy, 2004). Families with children may have more difficulty adjusting to economic issues, due to the extra expense brought on from childcare. The families that participated in this study had to make adjustments related to their economics. The parents with MS were contributing financially to the household prior to their diagnosis, and because they were unable to work the families had to make adjustments such as eating dinner out less often, the children not being to have the same spending money, and fewer family vacations.

When a parent experiences symptoms the children may not understand. All of the symptoms of the disease may not be visible such as walking difficulty; and some may be invisible such as fatigue. The children may have difficulty understanding the situation and interpret these as the parent not caring (Crawford & Miller, 1998). The children that participated in this study were active in the NMSS and were highly educated in the symptoms of MS, however they still had difficulty understanding the extent of their parent's symptoms, and how they influence daily activities.

The children's roles in families that are affected by MS may change in relation to the parent's exacerbations, remissions, and increased disability. The children my be responsible for increased household chores, which decreases their free time for friends and school activities (Blackford, 1998). The children that participated in this study described frustration over having to care for younger siblings, and having to help clean the house. The parents displayed mild stress over having to ask for the children's help, because they were able to maintain the home without assistance prior to their diagnosis.

Coping can be viewed as a set of responses, cognitive or behavioral, that people use to deal with stressful events. Coping includes cognitive processes, such as denial, suppression, repression, and intellectualization and problem solving behaviors that are used to reduce or manage anxiety or other upsetting emotions (Folkman & Lazarus, 1988). This study found that parents with MS and their children use peer support groups as a way to cope successfully with MS. However the family members, such as spouses and other children who do not participate in the groups, appear to have more difficulty adjusting to having a family member with MS. Johnson and Martin (1992) reported that the inability to cope by one family member may influence other family members. The family members in this study who did not participate in the peer support groups appeared to negatively influence other family member's ability to cope and adjust.

The child’s age can influence their ability to process and cope with parental illness. Younger children have more primitive thinking. They tend to create a sense of order and comprehend reality by forming routines and developing absolute mental structures of reality. Older children tend to be more advanced and are able to identify their parents’ illness and the problems associated with it. They are likely to have similar reactions that adults do such as anger, loneliness, helplessness, disappointment in their future, or the future of the family (Johnson & Martin, 1992). The children in this study were ages 11-14. The children displayed disappointment that things in the family had changed, and disappointment and concern about their parent’s wellbeing. However, the children were able to identify that the cause of the emotions are related to their parents MS.

Limitations of Data

Researchers self disclosure

The participants in the study were made aware that the researcher was diagnosed with MS. The disclosure may have assisted in the data collection process. This allowed the participants to understand the experience and the level of knowledge that the researcher has on the topic, therefore allowing the participants to be more candid in their descriptions of the challenges they face because of the disease. Because the researcher has personal experience with the illness, it was important to not allow her previous knowledge influence the interviews, and subsequent analysis of the data, by means of Epoch, or bracketing.

Source of data

The participating families were all intact families with both parents living in the home, with more than one child. The parents all had high school or above education, and were middle or upper middle income. Three of the parent participants were peer-support group leaders. Because the participants selected to take leadership roles, they may have unique perception on how to successfully cope with MS that differs from other individuals with MS. .

Recommendations for Family Therapists

Therapist working with families living with MS should include peer support groups in their treatment plan for families living with MS. The families in this study all reported that they are able to share their stories with other families that are affected by MS, thus allowing them to identify their strengths and giving and receiving support during difficult times. Among the interventions that family therapists working with individuals with MS and their families should include is dialog about communication. It is important for all of the family members to realize that no one can know what meaning or reality another assigns to an experience. In addition, families will benefit from Michael White's Narrative therapy technique of externalizing the problem where they search for times when they were strong or resourceful. Narrative therapists are not interested in the family's impact on MS, but rather in the how MS impacts the family (Nichols & Schwartz, 2004).

Suggestions for Future Study

The current research included interviews with both the parents living with MS and a child with a parent with MS to get their perspectives on coping with MS. It would be interesting to investigate the experiences of the entire family, including spouses to get better understanding on how MS affects the whole family system. Finally, the direction for future study can focus on the effectiveness of family versus individual counseling for families that are affected by MS.

Conclusion

The goal of this study was to explore the lived experiences of parents, living with MS and their children, and if the ability to constructively cope leads to better psychological outcomes for their children. It appears that parents with MS, and children that have a parent with MS benefit from participating in self-help groups. The parents described the satisfaction that they receive from helping other families with MS, by taking leadership roles in the groups. The parents in this study identified MS as positive influence on their parenting because it allowed them to see the importance of family, and allowed them to spend more quality time together. Both the parents and the children felt that the parent's diagnosis of MS helped the families realize that family is important, and that they must join to together to fight MS. The results of this study might be of interest to individuals who have a special interest in the phenomena, people who work in programs that assist families such as the NMSS, and family counselors who work with the families that have medical problems.

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APPENDIX A

DEMOGRAPHIC SURVEY - PARENTS

Please fill out this demographic survey so that we may obtain some general information about you. Your responses are confidential.

Please circle the number of your response or write in (where appropriate).

1. Your age: ________

2. Gender:
   1. Female
   2. Male

3. Marital status:
   1. Single
   2. Married
   3. Separated
   4. Divorced
   5. Widowed
   6. Domestic partner

4. What is your ethnicity?
   1. African-American
   2. Caucasian
   3. Hispanic
   4. Asian
   5. Other: ____

5. Educational level:
   1. Less than high school diploma
   2. High school diploma
   3. Some college
   4. Undergraduate college degree
   5. Graduate degree (Master’s Degree, Ph.D., J.D., M.D., etc.)

6. Religious Affiliation (If any): ___________________________

7. Current work status:
   1. Employed/self employed full time
   2. Employed/self employed part time
   3. Retired
   4. Unemployed
   5. Never employed
   7. Other: ____

8. Are you currently receiving disability income?
    1. No
    2. Yes

9. Type of MS:
    1. Benign
    2. Relapsing-remitting
    3. Secondary progressive
    4. Primary Progressive
    5. Progressive-Relapsing
    6. Unsure

10a. Age when symptoms first appeared: ________

10b. Year when symptoms first appeared: ________

11a. Age when first diagnosed: ________

11b. Year when first diagnosed: ________

12. Overall self-rating of the severity of your Multiple Sclerosis symptoms during the previous year.
    1. None
    2. Mild
    3. Moderate
    4. Severe
    5. Extremely severe

13. Self-rating of your mobility.
    1. Able to walk at least one city block without aid.
    2. Able to walk at least 15 feet with aid.
    3. Able to spend at least part of the day out of bed, but largely confined to wheelchair.
    4. Essentially restricted to bed.

14. Overall self-rating of your marital relationship:
    1. Very unsatisfactory
    2. Less than satisfactory
    3. Satisfactory
    4. Quite satisfactory
    5. Very satisfactory
    6. N/A

15. Overall self-rating of your family relationships:
    1. Very unsatisfactory
    2. Less than satisfactory
    3. Satisfactory
    4. Quite satisfactory
    5. Very satisfactory

16. Overall rating of your physical health:
    1. Extremely poor
    2. Poor
    3. Fairly good
    4. Good
    5. Excellent

APPENDIX B

DEMOGRAPHIC SURVEY – CHILDREN AND ADOLESCENTS

Please fill out this demographic survey so that we may obtain some general information about you. Your responses are confidential.

Please circle the number of your response or write in (where appropriate).

1. Your age: ________

2. Gender:
    1. Female
    2. Male

3. What is your ethnicity?
    1. African-American
    2. Caucasian
    3. Hispanic
    4. Asian
    5. Other: ____

4. Current school status:
    1. Not attending school
    2. Attending school part time
    3. Attending school full time

5. Number of siblings__________________

6. Who do you live with:
    1. Mother
    2. Father
    3. Both
    4. Other_________________

7. Parent with MS
    1. Mother
    2. Father

8. Your age when you first found out your parent had MS___________

9. Overall rating of your parent’s physical health:
    1. Extremely poor
    2. Poor
    3. Fairly good
    4. Good
    5. Excellent

10. Overall self-rating of your family relationships:
    1. Very unsatisfactory
    2. Less than satisfactory
    3. Satisfactory
    4. Quite satisfactory
    5. Very satisfactory

11. Overall self-rating of your peer relationships:
    1. Very unsatisfactory
    2. Less than satisfactory
    3. Satisfactory
    4. Quite satisfactory
    5. Very satisfactory

12. Overall self-rating of your satisfaction with your life in general:
    1. Very unsatisfactory
    2. Less than satisfactory
    3. Satisfactory
    4. Quite satisfactory
    5. Very satisfactory

APPENDIX C

INTERVIEW QUESTIONS

INTERVIEW QUESTIONS - PARENTS

1. Tell me about your diagnosis of MS. What symptoms do you find particularly troublesome?
2. Describe to me how you cope with MS and the stressors it creates.
3. How has MS affected or changed your parenting?
4. What is your perception on how your MS diagnosis is affecting your child?
5. What are some concerns you have about how your MS is affecting your child?
6. How has having MS affected your relationship with your child?
7. Tell me how your having MS affects your family.
8. Even in difficult situations, people often find positive meanings in their experience. Have you found anything positive to come from having MS (in regard to your family members and life in general)?
9. If you could give some advice to other parents who have MS, what would you tell them?
10. Have you shared everything you feel is important with reference to living with MS?

INTERVIEW QUESTIONS - CHILDREN AND ADOLESCENTS

1. What is it like living with a parent who has MS?
2. What is your perception of how your parent is coping with MS?
3. How does your parent having MS impact you?
4. Tell me how you cope with your parent having MS.
5. What are some things you worry about with your parent having MS?
6. How has your parent's MS affected your relationship with your parent?
7. How does your parent having MS impact the family?
8. Even in difficult situations, people often find positive meanings in their experience. Have you found anything positive about having a parent with MS?
9. If you could give some advice to other children who have a parent with MS, what would you tell them?
10. Have you shared everything you feel is important with reference to living with a parent with MS?

If you are a parent with multiple sclerosis with a child/adolescent, and both of you are interested in participating in a study on the experience of living with multiple sclerosis please read on..............

A doctoral research study is being conducted by
Joanne L. Nelson, LCSW

A doctoral candidate at Barry University
in the Adrian Dominican School of Education,
Exploring the experiences of parents and children in
Families who have a parent with Multiple Sclerosis

To participate or for more information please call or e-mail your contact information to **(407) 340-5344** or **anewviewcounseling@earthlink.net**

Study Requirements-Participate in one brief telephone contact to be screened for appropriateness of participation. Parent and child will participate in one ninety and maximum sixty minute interview, respectively. Participate in one follow-up session to review the interview transcript for accuracy.

Eligibility Requirements- Male and female parents who have a definite diagnosis of multiple sclerosis; their children ***between the ages of 11 and 18.*** The maximum number of participants is five parents and their children.

This is a research study and is not considered a therapeutic session.
Confidentiality will be carefully protected. Participation is entirely voluntary

APPENDIX E

Barry University
Informed Consent Form

Your participation in a research project is requested. The title of the study is The Lived Experience of Multiple Sclerosis: A Family Perspective. The research is being conducted by Joanne L. Nelson, LCSW, a Ph.D. student in Counseling Department at the Adrian Dominican School of Education department at Barry University, and is seeking information that will be useful in the field of counseling. The aim of the research is to understand the lived experience of MS for parents and their children.

In accordance with this aim, and if you decide to participate in this research study, the following procedures will be used:

- Participation in a brief telephone interview to screen for appropriateness of participation in the research study (less than ten minutes).
- Completion of Informed Consent forms for you and your child and completion of a Demographic Information form (twenty minutes).
- Completion of an in-depth audio taped individual interview concerning your experience of living with MS at a private setting convenient for you. The interview will consist of answering 10 open ended questions (60-90 minutes)
- Completion of a review of the transcripts of the actual interview to ensure accuracy (30 minutes).

I anticipate the number of participants to be five parent/child pairs. Your consent to be a research participant is strictly voluntary and should you decline to participate or should you choose to drop out at any time during the study, there will be no adverse effects whatsoever. Additionally, should you chose to withdraw your data (transcribed interview) prior to the conclusion of the study your request will be honored and the transcript returned to you in a timely manner.

The risks of involvement in this study are minimal, and are not expected to exceed that ordinarily experience during routine psychological assessments, such as fatigue**.** If the participant feels unable to complete the interviews, he/she may stop at any time. Should they experience any emotional distress they can schedule a counseling session with a colleague of the researcher that is a Licensed Mental Health Counselor. The initial session will be provided at no charge. Additional sessions will be provided at the customary fee of $50. Although there are no direct benefits to you, your participation in this study may help our understanding of ways in which the field of counseling can incorporate new techniques to facilitate the healing process in individuals experiencing MS.

As a research participant, information you provide will be held in confidence to the extent permitted by Florida law. Any published results of the research will refer to participant averages only and no names or other identifying information will be used in the study. Interview Question Forms, Demographic Data Sheets, transcripts, audio tapes, and the key codes will be kept in locked files in this investigator's office. Audio recordings will be erased and destroyed as soon the study is completed. The signed Informed Consent Form will be kept separate from the Demographic Data Sheet and Interview Forms. All raw data, including Demographic Data Sheets and Interview Forms will be destroyed after five (5) years in accordance with Florida laws and university policies and procedures.

The interviews will be tape recorded and transcribed verbatim by a professional transcriber, who will sign a Confidentiality Agreement Form

Additionally, for purposes of verification and reliability, a peer debriefer who has experience in MS will review the research findings, which will include access to the transcripts, analyses, and computerized database. That person will offer their interpretations of the data and such interpretations will be compared to the findings of the principal investigator. This individual will sign a confidentiality agreement to assure the protection of the client.

If you have any questions or concerns regarding the study or your participation in the study, you may contact me, Joanne L. Nelson, LCSW at (407) 340-5344, The Barry University Chair person, Dr. Eeltink, at (321) 235-8401, or the Institutional Review Board point of contact, Mrs. Nildy Polanco, at (305)899-3020. If you are satisfied with the information provided and are willing to participate in this research, please signify your consent by signing this consent form.

Voluntary Consent

I acknowledge that I have been informed of the nature and purposes of this experiment by Joanne L. Nelson, LCSW and that I have read and understand the information presented above, and that I have received a copy of this form for my records. I give my voluntary consent to participate in this study.

_________________________________ __________
Signature of Participant *Date*

_________________________________ __________
Researcher *Date*

APPENDIX F

Barry University
Parent Consent Form

Your child’s participation in a research project is requested. The title of the study is The Lived Experience of Multiple Sclerosis: A Family Perspective. The research is being conducted by Joanne L. Nelson, LCSW, a Ph.D. student in Counseling Department at the Adrian Dominican School of Education department at Barry University, and is seeking information that will be useful in the field of counseling. The aim of the research is to understand the lived experience of MS for parents and their children.

In accordance with this aim, and if you allow your child, who must be between the ages of 11 and 18, to participate in this research study, the following procedures will be used:

- Participation in a brief telephone interview to screen for appropriateness of participation in the research study (less than ten minutes).
- Completion of an Assent form for by your child and completion of a Demographic Information form (twenty minutes).
- Completion of an in-depth audio taped individual interview concerning your child’s experience of having a parent with MS at a private setting convenient for you and your child. The interview will consist of answering 10 open ended questions (**60 minutes with the option of splitting the interview into two 30 minute session if the child becomes fatigued)**
- Completion of a review of the transcripts of the actual interview to ensure accuracy (30 minutes).

I anticipate the number of participants to be five parents/child pairs. Your child’s consent to be a research participant is strictly voluntary and should he/she decline to participate or should choose to drop out at any time during the study, there will be no adverse effects whatsoever. Additionally, should he/she chose to withdraw his/her data (transcribed interview) prior to the conclusion of the study his/her request will be honored and the transcript returned to you in a timely manner.

The risks of involvement in this study are minimal, and are not expected to exceed that ordinarily experience during routine psychological assessments, such as fatigue. Should they experience any emotional distress they can schedule a counseling session with a colleague of the researcher that is a Licensed Mental Health Counselor. The initial session will be provided at no charge. Additional sessions will be provided at the customary fee of $50. Although there are no direct benefits to your child, his/her participation in this study may help our understanding of ways in which the field of counseling can incorporate new techniques to facilitate the healing process in individuals experiencing MS.

As a research participant, information he/she provides will be held in confidence to the extent permitted by Florida law. Any published results of the research will refer to participant averages only and no names or other identifying information will be used in the study. Interview Question Forms, Demographic Data Sheets, transcripts, audio tapes, and the key codes will be kept in locked files in this investigator's office. Audio recordings will be erased and destroyed as soon the study is completed. The signed Informed Consent Form will be kept separate from the Demographic Data Sheet and Interview Forms. All raw data, including Demographic Data Sheets and Interview Forms will be destroyed after five (5) years in accordance with Florida laws and university policies and procedures.

The interviews will be tape recorded and transcribed verbatim by a professional transcriber, who will sign a Confidentiality Agreement Form

Additionally, for purposes of verification and reliability, a peer debriefer who has experience in MS will review the research findings, which will include access to the transcripts, analyses, and computerized database. That person will offer their interpretations of the data and such interpretations will be compared to the findings of the principal investigator. This individual will sign a confidentiality agreement to assure the protection of the client.

If you have any questions or concerns regarding the study or your child's participation in the study, you may contact me, Joanne L. Nelson, LCSW at (407) 340-5344, The Barry University Chair person, Dr. Eeltink, at (321) 235-8401, or the Institutional Review Board point of contact, Mrs. Nildy Polanco, at (305)899-3020. If you are satisfied with the information provided and are willing to allow your child to participate in this research, please signify your consent by signing this consent form.

Voluntary Consent

I acknowledge that I have been informed of the nature and purposes of this experiment by Joanne L. Nelson, LCSW and that I have read and understand the information presented above, and that I have received a copy of this form for my records. I give my voluntary consent for my child to participate in this study.

___________________________________ __________

Signature of Participant *Date*

____________________________________ __________

Researcher *Date*

APPENDIX G

Barry University

ASSENT FORM INVOLVING MINORS

We are doing a research study that includes children such as you. We have explained the study to you, and we need to know whether you are willing to participate. Please sign your name below so that we can be certain whether you want to be in the study or not. Thank you.

____ I am willing

____ I am not willing

to participate in the research study which has been explained to me by

______________________________ ________________
Signature of Researcher *Date*

______________________________ ________________
Signature of Child *Date*

______________________________ ________________
Signature of Parent *Date*

APPENDIX H

Confidentiality Agreement

As a member of the research team investigating **The Lived Experience of Multiple Sclerosis: A Family Perspective**, I understand that I will have access to confidential information about study participants. By signing this statement, I am indicating my understanding of my obligation to maintain confidentiality and agree to the following:

- I understand that names and any other identifying information about study participants are completely confidential.
- I agree not to divulge, publish, or otherwise make known to unauthorized persons or to the public any information obtained in the course of this research project that could identify the persons who participated in the study.
- I understand that all information about study participants obtained or accessed by me in the course of my work is confidential. I agree not to divulge or otherwise make known to unauthorized persons any of this information unless specifically authorized to do so by office protocol or by a supervisor acting in response to applicable protocol or court order, or public health or clinical need.
- I understand that I am not to read information and records concerning study participants, or any other confidential documents, nor ask questions of study participants for my own personal information but only to the extent and for the purpose of performing my assigned duties on this research project.
- I understand that a breach of confidentiality may be grounds for disciplinary action, and may include termination of employment.
- I agree to notify my supervisor immediately should I become aware of an actual breach of confidentiality or situation which could potentially result in a breach, whether this be on my part or on the part of another person.

______________________________ __________ ____________________________

Signature Date Printed Name

______________________________ __________ ____________________________

Signature Date Printed Name