

THE EXPERIENCE OF YOUNG ADULTS LIVING
WITH RELAPSING-REMITTING MULTIPLE SCLEROSIS

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Doctor of Philosophy

by

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YOUNG ADULTS LIVING WITH RELAPSING-REMITTING
MULTIPLE SCLEROSIS

Presented by Brenda K. Beshears

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DEDICATION

Thank you to my family: my husband-George, my adorable fun daughters-Angie and Kathy, my son-in-laws-Lance and Karl, my precious miracle babies-Lanie and Konnor and my newest grandbaby that will join us in September-“Baby K.” What can I say to those who know me best and love me in spite of it? You are the ones who truly know what a journey this has been. You have the lived experience of being in the moment with a wife, mother, and Nanya who decides to obtain a PhD. You have been the wind beneath my wings and the sunshine in my brightest moments.

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ABSTRACT

The purpose of this interpretive phenomenological study was to explore and interpret the experience of young adults living with relapsing-remitting multiple sclerosis (RRMS) who were diagnosed by a physician at least six months prior to the study. This study was important because, prior to this proposed study, there has been limited work focused specifically on interpreting the meaning of living with RRMS as a young adult.

In this cross-sectional study, I used convenience and purposive sampling techniques sequentially to recruit participants residing in a six-county area. I recruited six participants between 20 and 40 years of age with a medical diagnosis of relapsing-remitting multiple sclerosis. Data collection involved a series of three in-depth interviews in participants' homes or another private location of their choice. Interviews were transcribed, and data were organized and analyzed using Miles and Huberman's approach. Analysis was informed by the Heideggerian phenomenological method.

The findings from this study can be used to guide the development of interventions and support services for individuals and families with RRMS. This study will add to existing knowledge through dissemination of results related to the meaning of living with RRMS as a young adult.

CHAPTER ONE

INTRODUCTION

This study was designed to explore the meaning of the experience of living with relapsing-remitting multiple sclerosis (RRMS) for young adults. The first aim of the research was to interpret the meaning of changes that occurred in the lives of young adults since the RRMS diagnosis. A second aim was to understand how young adults make meaning of the expectations that others such as family members, friends, and employers have of them as they live with RRMS. A third aim was to explore how young adults learn new ways of being during exacerbations of RRMS.

Chapter One consists of several sections. First, the purpose of the study is presented. The research problem is discussed in detail. Next, the methodology of prior work is outlined. The significance of the research problem is introduced in conjunction with the impact it has on the public's health, family health, and on the work of health professionals. The rationale for undertaking a qualitative study of the experience of interest is presented in conjunction with the goals of the method of choice – interpretive phenomenology. This chapter was concluded with the research questions.

The Purpose of the Study

The overall purpose of this phenomenological study was to explore and interpret the experience of young adults living with RRMS. The study addresses an important clinical problem. The demographics associated with the incidence and prevalence of RRMS are critical considerations. Fong, Finlayson, and Peacock (2006) reported conservative estimates of 400,000 individuals affected with MS in the United States and 2.5 million people worldwide. They estimated that each week another 200 people are

diagnosed with multiple sclerosis. The age-adjusted prevalence of multiple sclerosis increased from 32.6 per 100,000 in 1984 to 226.7 in 2006 (Marrie, Yu, Blanchard, Leung, & Elliott, 2010). Relapsing-remitting multiple sclerosis is a disease of young adults with the onset primarily between the ages of 20 and 50 (Fong et al.; Isaksson, Ahlstrom, & Gunnarsson, 2005; Marrie et al.; National Multiple Sclerosis [MS] Society, 2008). The incidence and prevalence of RRMS are such that they constitute important concerns to an individual's health, family health, and public's health.

Multiple sclerosis is a chronic neurological disease with physical and cognitive components. It has an uncertain trajectory, one that can completely alter an individual's life (Fawcett & Lucas, 2005; Pakenham, 2007; Weiner, 2004b). The unpredictable nature of the disease can lead to work-related problems and then to financial difficulties (Abma, Oeseburg, Widdershoven, Goldsteen, & Verkerk, 2005). Further manifestations of the disease can result in social isolation or dysfunctional family functioning (Abma et al.; DeJudicibus & McCabe, 2007; Fawcett & Lucas; Fong et al.; Wynia, Middel, vanDijk, DeKeyser, & Reijneveld, 2008).

Several key issues have been the foci of prior research about MS in young adults, including diagnostic methodologies (Barkhof et al., 2003; Polman et al., 2005; Poser & Brinar, 2004), symptoms (Ascherio & Munger, 2007; Flensner, Ek, & Soderhamn, 2003; Gagliardi, 2003; Miller & Jewewski, 2001), and therapies (Coles et al., 2006; Liblau, 2009; Weiner, 2004a). Other researchers have focused on various topics pertaining to MS in adults, including: (a) health-related quality of life (Berlim & Fleck, 2003; Fischer et al., 1999; Glozman, 2004; Zwibel, 2009), (b) prediction of disability (Hirst et al., 2008), (c) effect on work (Lage, Castelli-Haley, & Olen-Burkey, 2006), (d) perceived stigma

(Grytten & Maseide, 2006) and (e) other psychosocial issues (Abma et al.; Fong et al.; Kleiboer et al., 2007; Rigby, Thornton, & Young, 2008).

In 2005, Fawcett and Lucas utilized a case study approach with one young adult attempting to ascertain the meaning of living with the reality of MS, but few scholars have undertaken similar studies. Through an interpretive phenomenological method, the meaning of the experience can be revealed from the individual's perspective (Ray, 1994). This method is applicable when the goal is to understand the experience as it is lived by those who are affected (Cohen, Kahn, & Steeves, 2000). Few studies have focused on the meaning of the experience for young adults with RRMS. There is insufficient knowledge about the meaning of the experience of living with RRMS for young adults. The need for this study is grounded in part on that conclusion, which will be explained in more detail within the next section.

The Research Problem

To establish the health-related rationale for conducting the study, a brief overview of multiple sclerosis is presented. This overview provides a synopsis of the pathophysiology of the disease. Then the methodologies of prior relevant research will be discussed followed by a detailed statement of the research problem, as well as its significance for family health, public health, and the work of health professionals. A brief description of the Heideggerian phenomenological method, with a discussion of the focus and goals of interpretive phenomenological research, will precede a personal reflection about the research problem.

An Overview of Multiple Sclerosis

In establishing the importance of this research problem, an explanation of the pathology of the disease and a description of the four main classifications of MS is imperative. Multiple sclerosis is a chronic condition that can result in a wide range of neurological impairments, from infrequent episodes of symptoms with complete resolution, to severe, permanent symptoms (Flensner et al.; Noseworthy, Lucchinetti, Rodriguez, & Weinshenker, 2000). One of the pathological hallmarks of MS is the inflammation and demyelination that occurs within the white matter of the brain (Holmoy, 2008; Miller et al., 2003). MS is characterized by progressive demyelination of the central nervous system (Mowry et al., 2009; Kos & Cross, 2001).

The nervous system is unique in the complexity of actions that it can perform. The neuron is composed of a cell body, a dendrite, and an axon that becomes the basic unit of the system. Most axons are covered by a myelin sheath made up of lipids and proteins giving them a white appearance leading to the label of white matter. Nonmyelinated axons appear gray in color leading to the reference of gray matter (Hausman, 2006). The myelin is a type of insulation that protects nerve fibers ultimately leading to an enhancement of conduction of the impulses. Myelinated nerve fibers transmit impulses rapidly in contrast to the slower demyelinated fibers.

A young adult who has a diagnosis of MS will experience episodes of myelin inflammation. This results in the formation of areas of scar tissue known as plaques, which block or can delay nerve conduction. Demyelination might be relatively benign to extremely disabling depending on the amount of communication disruption that occurs between the brain and other parts of the body. Demyelination occurs simultaneously in

various parts of the brain or spinal cord. This results in the complexity of symptoms seen with MS (Courts, Buchanan, & Werstlein, 2004).

Four distinct clinical courses of MS have been identified: relapsing-remitting, primary-progressive, secondary-progressive, and progressive-relapsing (Jelinek, 2000; Miller & Hens, 1993; National MS Society, 2010). Of the four types, relapsing-remitting (RRMS) is the most common. Initially, “approximately 85% of people are initially diagnosed with RRMS (National MS Society, 2010). Young adults who present with a RRMS experience exacerbations. In the midst of the exacerbation, they may have a limited decline in their level of functioning. Some have a return of complete functioning after the exacerbation ends; others continue to have functional limitations (Noseworthy et al.). Of persons with RRMS, 50% need assistance with walking within 15 years after the onset (Noseworthy et al.). Because RRMS is the most common form, this study included only persons with the relapsing-remitting form. Primary-progressive MS (PPMS) is characterized by gradual worsening changes in the neurologic function from the onset of the initial symptoms with no distinct relapses. Approximately 10% of individuals are diagnosed with PPMS (National MS Society, 2010). Secondary-Progressive MS (SPMS) follows a course of RRMS with approximately 50% of individuals developing SPMS within 10 years of diagnosis (National MS Society, 2010). Progressive-Relapsing MS (PRMS) is relatively rare, with approximately 5% of individuals experiencing a clear pattern of worsening neurological function from the onset with distinct relapses (National MS Society, 2010).

Methodology of Prior Relevant Research

Quantitative Studies

Researchers have measured constructs relevant to this study, such as disability, health-related quality of life, and perceived social support (Bosca et al., 2008; Compston & Coles, 2002; Isaksson & Ahlstrom, 2006; Phillips & Stuifbergen, 2006b). In addition, quantitative researchers have studied relationships between topics such as depression, caregiver attitudes, and perceived quality of life for individuals with MS (Alshubaili, Awadalla, Ohaeri, & Mabrouk, 2007), as well as the impact of the disease on marital relationships (O'Connor, McCabe, & Firth, 2008).

Quality of life (Stuifbergen, Seraphine, & Roberts, 2000) and health-related quality of life (HR-QOL) have been common constructs in research with persons living with MS. Quality of life is a multidimensional concept, and this can result in a lack of uniformity when it is measured (Berlim & Fleck, 2003; Casetta et al., 2009; Sredl, 2004). Researchers have used various HR-QOL instruments to evaluate the effects of disease-modifying therapies. Small sample size and other design issues such as lack of placebo control for comparison in those studies have made interpretation of results difficult in clinical research measuring HR-QOL (Rudick & Miller, 2008). Inconclusive results were found by investigators attempting to find relationships between two scales measuring disability and quality of life (Nortvedt, Riise, Myhr, & Nyland, 1999a). However, studies with larger sample size measuring specific constructs on quality of life had significant findings (Phillips & Stuifbergen, 2006b). Researchers have focused a great deal of attention on measuring quality of life in persons with MS with mixed results. Young adults diagnosed with RRMS have many health-related changes occurring in their lives,

but there is little understanding of the meaning they attach to the changes. Interpreting the meaning of these life changes was one of the aims of this study.

Disability is a possible outcome for young adults living with RRMS. It is a common construct measured in research with persons who have RRMS. Kurtzke (1983) developed the Expanded Disability Status Scale (EDSS) to measure neurological impairment and disability in clinical trials of MS. Hoogervorst and colleagues (2003) compared the EDSS with the INTERMED, a screening instrument to assess case complexity. They found additional value to add the INTERMED tool to gather information in the biological, psychological, social, and health care domains. However, MS researchers, measuring neurological impairment, continue to use primarily the EDSS for measurement of disability in persons with MS (Alshubaili et al.). One of the aims of this study was to explore how young adults learn new ways of being during and after periods of exacerbations. This exploration added to a deeper understanding of how young adults perceive their existence when faced with exacerbations.

Self-care is a construct that has been evaluated with individuals diagnosed with RRMS. A self-care nursing framework was used to guide the development of an activity of living scale for persons with MS (Gulick, 1987). The intended use of the scale was to “promote participation of MS persons in assessing their daily functioning” (p. 278). The ultimate goal was to improve self-care of individuals with MS. It is important to identify any physical or cognitive changes that occur in young adults diagnosed with RRMS. The changes that occur have meaning. It is also important to determine the individual’s level of awareness of changes that occur with exacerbations from RRMS. One of the aims of

this study was to interpret the meaning of changes for young adults after a diagnosis of RRMS.

In sum, in studies with persons with RRMS, most researchers have focused on measuring constructs. Qualitative work is needed to understand the meaning of these constructs to young adults living with RRMS. The focus of this study was on meaning for the young adult, how young adults find meaning with exacerbations they experience, and how they find meaning in day-to-day activities. Interpretive phenomenological studies could add to the knowledge base related to young adults living with RRMS. Few researchers have used this method with individuals with RRMS, those identified have been with older adult participants. Investigators have not used an interpretive phenomenological method to explore experiences of young adults. Prior to this proposed study, there has been limited work focused specifically on interpreting the meaning of living with RRMS as a young adult. This study adds to existing knowledge related to the meaning of living with RRMS as a young adult.

Qualitative Studies

One of the earliest recorded accounts of MS was dated between 1822 and 1848 within a diary of Augustus D'Este, the grandson of George III of England (Butler & Bennett, 2003; Pearce, 2005). This was a diary recording and could have been published in this century as a case study reflecting the individual's experience of living with symptoms. Augustus suffered his first attack at age 28 and died at the age of 54. The diary reflected symptoms of his illness that included progressive weakness, numbness, difficulty when walking, painful spasms, and depression, providing enough information

to establish a posthumous diagnosis of MS (Pearce). These symptoms continue to be associated with MS (Polman et al.).

Qualitative studies about persons with MS have pertained to various topics including caregiver expectations (Abma et al.), influence on couples (Blank & Finlayson, 2007; Courts, Newton, & McNeal, 2005), and aging with MS (Dilorenzo, Becker-Feigeles, Halper, & Picone, 2008; Finlayson, VanDenend, & Hudson, 2004). These studies have used semi-structured interviews (Blank & Finlayson; Dilorenzo et al.; Finlayson et al.), case studies (Abma et al.), and focus groups (Courts et al. 2005). Several other scholars have used phenomenological methods to study aspects of the MS experience. Embrey (2008) evaluated palliative care services for people with MS. Communicating the diagnosis of multiple sclerosis was the focus of a study conducted by Solari et al. (2007). They did not specify which type of phenomenological philosophy, if any, was used to guide their studies (Embrey; Solari et al.).

Using a Heideggerian phenomenological method, Miller and Jezewski (2006) described the experiences of 20 men and women ages 39 and 64 with MS who were being treated with glatiramer acetate. The investigators found that the diagnosis of RRMS involved a difficult adjustment period. The decision to begin therapy with glatiramer acetate was viewed by the participants as a solution to regain control over their sense of self. Findings from the study included the importance of supporting individuals during and after the period of diagnosis. In addition to focusing on one particular type of treatment, Miller and Jewewski focused on older adults some of whom had been diagnosed for 21 years.

In contrast, the focus of my study was different in several respects. My research questions were broader, I was not interested in just treatment and I was interested in a different population. I had a broader focus for the meaning of RRMS. As noted above, selection of either descriptive or interpretive phenomenology is stimulated by the research problem and contributes directly to the nature of research aims. Thus, the work presented here is the first study framed in interpretive phenomenology that focuses directly on the experience of young adults with RRMS.

A Detailed Statement of the Research Problem

There are several reasons why this study with young adults was necessary to understand the meaning of living with RRMS. First, prior researchers have focused mainly on the nature of the disease rather than on the experience of persons living with the disease. Furthermore, investigators have focused on older adults living with MS rather than young adults. I am going to next address the significance of the research problem to the public's health and family health.

The Significance of the Research Problem to the Public's Health and Family Health

Impact on the Public's Health

The topic of young adults living with RRMS is directly relevant to the Healthy People 2010 strategic management approach to health improvement. A key objective of Healthy People 2010 (U.S. Department of Health and Human Services, 2000) is to increase quality of life while addressing the focus area of disability and secondary conditions. RRMS is diagnosed during young adulthood when society expects individuals to be at their highest level of productivity. Young adulthood is the time in life when people are establishing themselves as productive members of society, integrating

vocational goals, and developing the capacity for social responsibility (DeJudicibus & McCabe, 2007). A diagnosis of RRMS might alter the trajectory of societal expectations for the young adult. This issue is germane to one of the specific aims of this study.

At the beginning of the 20th century, life expectancy was 47.3 years. Americans are now experiencing an increased longevity of life. Over the past 100 years, life expectancy has increased dramatically for every age group. Today a young adult diagnosed with RRMS at the age of 25, can expect to live with this condition for an additional 53 years. This fact has a substantial economic impact on individuals, families, and society (DeJudicibus & McCabe, 2005). MS has a different economic impact compared to other chronic illnesses, affecting young adults at the onset of their prime working years, resulting in a loss of lifetime earnings (Phillips & Stuijbergen, 2006a; Scheinberg et al., 1980; Smith & Arnett, 2005). Current research continues to support the belief that the disease does not dramatically reduce life expectancy. Instead, deterioration in functional status is probable (Cheung & Hocking, 2004).

In Missouri, actual statistics of how many individuals live with RRMS are not available. However, there are two National MS Society Chapters located in the state. The Gateway Chapter serves 5700 individuals over a 90-county area that covers the eastern half of Missouri and the southern one-third of Illinois. The MidAmerica Chapter serves approximately 6000 individuals over a 105-county area covering all of western Missouri and eastern Kansas. Significant numbers of individuals in Missouri and neighboring states are affected by MS. The disease also affects the families and communities of individuals with MS.

Impact on Family Health

Multiple sclerosis affects the entire family (Buhse, 2008; MacAllister, Boyd, Holland, Milazzo, & Krupp, 2007). Remaining independent often requires assistance from a caregiver (McKeown, Porter-Armstrong, & Baxter, 2004). Day-to-day management of this disease takes place in the home (Townsend, Wyke, & Hunt, 2006). Family members might experience a feeling of never-ending work when involved with the care of one with a chronic illness such as MS (Boeije, Duijnste, & Grypdonck, 2003). The onset of MS in young adulthood and its long, unpredictable course leads to a high level of uncertainty when planning roles that family members might need to assume (DeJudicibus & McCabe, 2005). Uncertainty associated with this disease of young adults might be part of the concern expressed by this population of individuals.

MS results in a heavy economic burden to individuals and families (DeJudicibus & McCabe, 2005). Annual costs for the disease in the U.S. are estimated to exceed \$9 billion. Medications to treat MS are expensive (Ivanova et al., 2009). The annual cost for the interferon treatment is \$10,000 to \$13,000 per year (Prosser, Kuntz, Bar-Or, & Weinstein, 2004). Other costs include physician visits, hospital stays, laboratory tests, and travel expenses. Researchers have found that 80% of individuals have health insurance, but 28% of those individuals and their families felt the benefits were inadequate to cover the costs of the illness (Catanzaro & Weimer, 1992). This economic burden can lead to social isolation, depression, and coping difficulties that will affect general well-being of families (Courts et al., 2005; DeJudicibus & McCabe, 2005; Gulick, 2007).

Family developmental tasks that occur for each stage of the life cycle are not altered by MS, but the disease adds new demands and challenges (Courts et al., 2005). Responsibilities continue and other family members are often the ones who add these new demands (Courts et al., 2005). Caregivers might have conflicting feelings about multiple sclerosis and about the person with the disease due to the changing roles within the family (Buhse). Caregivers are not always familiar with the disease itself or the unseen symptoms of the disease. The unfamiliarity often leads to various feelings, including guilt, anger, or resentment (Abma et al.; Boeije et al., 2003; Cheung & Hocking; Grytten & Maseide, 2005). Families are often hesitant to talk to health professionals about these feelings. This hesitancy can then create a dysfunctional family environment affecting the care needed for the individual with RRMS.

In spite of these difficulties, there are also benefits that sustain families over the long course of a chronic illness (Pakenham & Cox, 2008). These benefits identified by Pakenham and Cox included enriched relationships, inspiration, and relationship opportunities. Few scholars have explored ways in which young adults and their families focus on difficulties or benefits of experiences associated with RRMS.

Relevance to the Work of Health Professionals

Due to the lack of studies related to the families of young adults and their experience with MS, it is difficult to know how health professionals need to proceed. Thousands of articles have been published regarding facts about MS; hundreds of books are in print discussing nurse's plans of care for MS patients. In the Netherlands, MS nurses were appointed to educate patients, assist them with work, and family matters. The nurses assigned to that education project reported a lack of understanding related to the

MS patient's expectations (Abma et al.). A core curriculum text identifies what nurses believe people with MS should be taught, but it was not based on the patient's perspective (Halper, Costello, & Harris, 2006).

Phenomenological studies are needed that focus on the meaning of the experiences of younger adults who have RRMS. This will provide health professionals evidence to understand and meet expectations for the young adult population. This is important because health professionals have identified that the needs of MS patients are challenging and that their concerns should be described. Young adults diagnosed with RRMS have many health care needs in addition to educational needs. Without studies that focus on the meaning of living with RRMS as a young adult, scholars do not know their precise needs. This study was undertaken to help to fill this knowledge deficit.

Undertaking a Qualitative Study about the Experience of Interest

All research that can illuminate answers to questions surrounding RRMS is important, but the area needing additional attention is the interpretation of the meaning of the young adult's experience. The prior quantitative studies are valuable in describing incidence of the disease and measuring certain variables associated with it, but such studies cannot capture the complexity of the experience. There are other valid ways to discover knowledge. Participants' viewpoints are important to consider as a characteristic of both quantitative and qualitative research (Denzin & Lincoln, 1998; Speziale & Carpenter, 2007). However, an essential goal of qualitative research is to be close to the data (Richards, 1998). Qualitative researchers believe that this can best be accomplished by methods such as interviewing or observation that lend themselves to understanding and interpreting the individual's experience.

Scholars have explored many aspects of MS primarily using quantitative methods. A limited number of qualitative studies have been completed with people who have RRMS. Few scholars have used a Heideggerian approach to understand how an individual with RRMS makes sense of being in their world (Miller, 1997). “Heidegger not only gave us a philosophy, he gave us a way of understanding what it means to exist, what it means to be” (Lemay & Pitts, 1994, p. 94). I chose to use an interpretive phenomenological method to study the experience of living with RRMS for young adults. I believed with that approach I could uncover new and useful information about the meaning of the experience of living with RRMS for young adults.

The Focus and Goals of Phenomenological Research

Husserl developed the philosophy of descriptive phenomenology (Speziale & Carpenter). The process of intuiting which is basic to the method results in an understanding of the essence of data (Speziale & Carpenter). This process includes setting aside what is known about the phenomenon that will be investigated (Husserl, 1913/1962; Omery & Mack, 1995). Whereas this descriptive method has inspired many researchers, a Heideggerian interpretive method is more appropriate for this study, in which the interest is to explore meaning, rather than to describe the essence or internal logic of an experience.

Heidegger studied and developed his philosophy under the guidance of Husserl (Heidegger, 1972/1969). The focus of his philosophy included the concepts of language, being, and time (Heidegger, 1998/1967). Very early in life we begin to learn to express language, discern expressions, and become autonomous (Munhall & Boyd, 1993). This is often the beginning of sharing with others our reality. “To the phenomenologist, there is

no reality separate from the reality of the world as available for, to, and through experience” (Omery & Mack, 1995, p. 139). It has been noted that researchers who choose the phenomenological method are generally inspired by it, rather than creating or implementing a cookbook approach (Porter, 1998). With Heidegger’s (1971) works, this inspiration might come from language, poems, the historical context of the person’s experience, or from within. Heidegger (1971) wrote of the nature of language. He postulated that the power of the experience is within language.

“The Heideggerian phenomenological view of the person arises from the ontological question, what does it mean to be a person?” (Leonard, 1989, p. 40). The research method associated with this philosophy is interpretive phenomenology. The interpretation is developed as the researcher and participants co-constitute a context for interpreting the meaning of an experience. The Heideggerian method is a path that involves listening to the person talk about their experience. It is also committed to resolute understanding. For this reason, this method might appear to use only common sense and be simple. However, the Heideggerian method is an engaged, profound way of listening where we actively seek to understand (Orbanic, 1999; Pieranuzi, 1997). Heidegger’s constant strategy was to show the process of undertaking, and how people accomplish the undertaking precedes the attainment of whatever goal people have set (Steiner, 1989).

I believe that it is important for the qualitative researcher to be inspired by the method and by the topic studied. I am inspired by the Heideggerian method because I feel a personal connection with the basic tenets of his work. I believe that language is critical to understand personal lived experiences and I have been continually inspired by writings

related to time and being (Heidegger, 1972/1969). The experience of the young adult who is living with RRMS was explored by using the Heideggerian method. I believed it was perfectly suited to my research questions.

A Personal Reflection about Relapsing-Remitting Multiple Sclerosis

Interpretive phenomenology uses the researcher as the data collection instrument, uncovering meanings in the participant's narratives (Miles & Huberman, 1994). Prior to interviewing young adults with RRMS, I had to first clarify my own experience with this phenomenon and examine the research questions that have personal significance.

My personal interest in the phenomenon of young adults living with MS began when my prospective son-in-law was diagnosed at the age of twenty-one with RRMS. As an athlete, Lane [a pseudonym] was acutely aware of changes with his gross and fine motor skills. While in training for baseball, he experienced tingling of his face, paralysis of the limbs, and blurry vision. Without direct observation, an emergency room nurse suggested it was a virus. The symptoms rapidly progressed and medical care was sought at a campus health clinic. He was observed at the clinic for 12 hours. During that period, his grip became weaker, his gait became unsteady, and his fear became tangible. Within 24 hours, a definite diagnosis was made of MS. My daughter became his primary care provider and I became his health care advocate. He was discharged, and I became his home health nurse, giving intravenous methylprednisolone at very high doses. This is the treatment of choice to manage exacerbations. The goal of the treatment was to decrease inflammation that often leads to remission. Within those first 24 hours, he did not know how his life would change. Suddenly, he could not walk without assistance. He was very

sick, and very apprehensive about completing college, finding a job, and remaining independent. He questioned the meaning of life and the meaning of this experience.

After ten days of treatment, he returned to college to complete his senior year of engineering. He experienced feelings of depression, anger, sadness, and uncertainty. Grytten and Maseide (2005) found in their research that stigma might exist with a chronic illness such as MS. As a couple, Lane and his fiancée, Annie [a pseudonym], felt this stigmatization. Some of their acquaintances walked to the opposite side of the street so they would not have to talk. Others suggested that they should cancel their wedding. Many had questions about the disease and together they learned. Maintaining social relationships was difficult during the period immediately following the diagnosis.

Lane described his days as good if he could walk without assistance. As a couple, they identified what was important to them in life. They were married three months after the diagnosis. They graduated from college, chose jobs close to family to have support if needed and Lane chose not to tell his co-workers. Gradually, a few would find out. He was reserved about disclosing information related to previous reactions of people when they were told of his diagnosis. My daughter described it as living a well-choreographed dance where each performer has a specific part. Those observing only see what the performers choose them to see (A. Dunham, [a pseudonym] personal communication, November 2007). As trust develops between the young adult or the family member and others in society, they are willing to include those on the periphery of their dance as participants. It is at this time that they can share what the meaning of MS for them is and how it affects their lives. It takes a great deal of courage to share information with others

when there is uncertainty associated with the response to a silent illness or to a chronic illness that has an unclear trajectory.

Within one year of diagnosis, Lane's physical status deteriorated rapidly. An immune-modulating therapy was recommended by a MS specialist. He struggled with the side effects of the therapy. These side effects included severe flu-like symptoms, pain at the injection site, and the indirect effect of cost of the medication. He persevered because he desired the normal life that he remembered before the diagnosis. Over the last ten-years, there have been many exacerbations with many symptoms. His story has become my inspiration. On the ten-year anniversary of his MS diagnoses he participated in the 50-mile three-day walk for MS to raise awareness and money for research. After the rapid advancement of his condition during the first year following his diagnosis, his neurologist now refers to him as her miracle patient.

There is meaning for young adults, their families, and health-care providers in the experience of living and dealing with a diagnosis of RRMS. Through this story, I have shared my passion for this topic. I have grasped the meaning of the experience from one young adult and his wife. I believe that it is crucial to expand knowledge by exploring the meaning of this experience for other young adults.

In addition to my personal background with RRMS, I have conducted prior research using Heideggerian hermeneutics (Heidegger, 1972). In this work, I had the opportunity to work with Dr. Nancy Diekelmann who has published widely (Diekelmann, Allen & Tanner, 1989; Diekelmann, 2001; Diekelmann, 2003) and is one of the experts in using interpretive phenomenological methods in nursing education. An outcome of our work with Dr. Diekelmann was an NLN Nursing Education Research Grant awarded to

the private mid-western college with whom I am affiliated. The opportunity to be involved in those studies influenced my decision to continue to use this interpretive phenomenological approach. In addition, I have been inspired by the writings of Heidegger (1971), who observed that we could be touched in the innermost nexus of our existence by the stories that are told.

My decision to use the approach of Miles and Huberman (1994) for data analysis is consistent with interpretive phenomenology. Miles and Huberman (1994) described the goal of qualitative data analysis as that of uncovering meaning in data. Finally, interpretive phenomenology is a suitable background for the approach I have chosen for my analysis. For reasons that I will explain in Chapter Three, I planned to use the approach of Miles and Huberman (1994) to analyze data.

Research Questions

The primary research question will be, "What is the meaning of the experience of living with RRMS for the young adult"? The subsidiary research questions will be:

1. For young adults, what is the meaning of changes that might have occurred since the RRMS diagnosis?
2. How do young adults make meaning of the expectations that others have of them while living with RRMS?
3. How do young adults learn new ways of being during periods of exacerbations?

Summary of the Research Problem and the Purpose of the Study

Each young adult with RRMS is unique in terms of the presentation of the disease symptoms and the manner in which the disease is manifested. There might be some

commonalities in the experience related to the uncertainty of the disease state; each young adult's experience has similarities as well as differences. Researchers to date have not explored the commonalities of the young adult's lived experience or the unique aspects of the young adult's lived experience.

The purpose of this study was to explore the experience of the young adult who lives with the chronic illness of RRMS. It was designed to foster an understanding of the young adult's concerns related to the experience. This study was a basis for proposing education and support for the young adult after receiving a diagnosis of RRMS.

CHAPTER TWO

REVIEW OF THE LITERATURE

Conceptual frameworks are to connect concepts in a meaningful way (McEwen & Wills, 2002). The organizing framework of Hinds, Chaves, and Cypess (1992) complements the Heideggerian phenomenological method that will guide this study.

The Organizing Framework of the Study

The organizing framework used for understanding the context of experience is critical (Hinds et al.). In this study, the work of Hinds et al. has been selected as the organizing framework, in part because it is consistent in several ways with Heidegger's philosophy. Hinds et al. posited that the understanding of humans, their health and related phenomena was dependent on an ability to evaluate the multiple contexts from which the phenomena exist. Failure to utilize context in research and practice might lead to inaccurate interpretation or application of the findings (Hinds et al.). When Heidegger spoke of being and language, he stated, "When the issue is to put into language something which has never yet been spoken, then everything depends on whether language gives or withholds the appropriate work" (Heidegger, 1971, p. 59). The applicability to this study is for the researcher to be cognizant of the interview questions and answers and to be aware of non-verbal body language.

Hinds et al. conceptualized context as "four nested, interactive layers that are distinguished from each other by (a) the extent to which meaning is shared, (b) the dominant time focus, and (c) the speed with which change within the layer can occur and be perceived" (p. 65). The four nested, interactive layers were further identified as: (a) metacontext, (b) general context, (c) specific context, and (d) immediate context.

As a socially constructed way of knowing, the metacontext "is a source of explanation for and an indirect influence on behaviors and events" (Hinds et al., p. 67). Like the general context, it can change, but it does so slowly. It is seen primarily in the context of reflection on and incorporation of the past while setting conditions for the future. This is the broadest layer that has an indirect effect on the individual. The most indirect effect on the individual with MS within this study includes general characteristics of chronic illness. Information regarding family development and young adult development is also included as part of the metacontextual layer.

General context is a layer that changes gradually, but is typically more stable than the specific and immediate layers. "This layer of context is characterized by a general life frame of reference that has evolved from an individual's interpretations of past and current interactions" (Hinds et al., p. 67). This context has evolved from a lifetime of experiences. The individual has attached meanings and interpretations to events throughout life. These experiences affect the present and immediate layers of events. Young adults have learned cultural expectations that society has of them. When diagnosed with a chronic illness, the general context includes: (a) the nature of MS, (b) epidemiology of MS, (c) genetics of MS, and (d) families managing a chronic illness.

The next layer, specific context, can change rapidly. It is influenced by the "immediate past plus relevant aspects of the present situation" (Hinds et al., p. 65). Hinds et al. identified time of day, individual mood, presence of others, and other environmental factors as factors that influence this "individualized, unique system of knowing" (p. 65). Access to the health system, economic and employment issues, perceived social support,

the diagnosis of RRMS, and the impact this disease has on a young adult couple are issues related to this study.

The focus of the immediate contextual layer is on the present that identifies boundaries of the phenomenon, relevant aspects of the experience, and facilitation for predictions of behaviors. “Immediacy is the major characteristic of this context layer” (Hinds et al., p. 65). Heidegger might have referred to this layer as “being in time” (Heidegger, 1996). An example related to my research study would be exploring how young adults find new ways of being during periods of exacerbations with RRMS. Constructs related to the present with a young adult managing RRMS includes: (a) psychosocial aspects of the disease, (b) symptoms, (c) cognitive and emotional changes (d) treatment options, and (e) adaptation.

The Context of the Experience of Interest

Not all four layers are always included as the focus of studies (Hinds et al.). Within this study, a decision was made to focus on each of the individual layers previously outlined (Hinds et al.). “Meaning is derived from purposeful interactions with the layers” (Hinds et al., p. 68). There is a great deal of literature related to various aspects of multiple sclerosis. In the review below, this literature is organized using the contextual framework described above, beginning with the metacontext of chronic illness. Viewing the context of a young adult's experience in this way will be helpful in creating a historical perspective and provide direction for general to specific areas of interest.

Metacontext

The researcher must continually seek out the metacontextual layer because it can go unrecognized (Hinds et al.). It is omnipresent with a predominant orientation to the past. This concept fits well with Heidegger's (1959) philosophy of pre-understanding. Pre-understanding is the personal experiences, cultural traditions, and history that each individual has as part of their life experiences. The importance to this research study and the literature related to this study is the socially constructed source of knowledge that this layer offers to the meaning of the experience. This layer is important to the young adults affected with multiple sclerosis and to researchers attempting to find and understand life experiences of young adults with RRMS. With regard to the young adult's experience of living with RRMS, the indirect influences include: (a) characteristics of a chronic illness, (b) family development and the family life cycle, and (c) the developmental level of young adults.

Characteristics of Chronic Illness

Chronic illnesses are characterized by their permanent continuing nature and by the fact that they are not curable and/or have some residual features that impose limitations on physical, psychological and social functioning (Partnership for Solutions, 2001). In 2000, there were approximately 125 million Americans classified as having a chronic illness. By 2020, that number is projected to increase to 157 million and by the year 2030, the number will increase exponentially to 171 million (Partnership for Solutions). The individuals affected might not be able to work, might have a decreased quality of life, and might incur considerable amounts of direct and indirect medical costs (Morewitz, 2006). In addition to the adjustments that must be made related to the disease

state, the illness might also affect a person's independence, self-esteem, and social well-being (Goldstein, 2006). In the late 1800s and the early 1900s, the prevalent belief was that people who were different from the majority were harmful to the community (Gallo, Breitmayer, Knafl, & Zoeller, 1991). Society values appearance, physical prowess, vigor and health. Little is known of the experience of living with a chronic illness against these background values.

Including the broad concept of chronic illness within the metacontextual layer enables researchers to understand the importance of this issue. Management of chronic illness does not occur in isolation, but includes those closest to the individual. Those individuals are often friends or family.

Family Development and the Family Life Cycle

Individuals are born into a family and are influenced by the culture and behaviors of which they become part. "Families comprise persons who have a shared history and a shared future" (McGoldrick & Carter, 2003, p. 376). This aspect of the definition of a family has remained constant while virtually every other aspect of defining families has become varied and complex (Walsh, 2003).

Family development and the family life cycle are two concepts related to family studies that are used interchangeably but should be defined. Family development is the broader concept and refers to essentially all coevolutionary processes related to family growth (Nichols & Pace-Nichols, 2000). This includes changes in work, relocation, serious illness, or other changes in family life that have a profound impact. When analyzing normal significant events in the life of a family such as a birth and marriage, the family life cycle is the concept that is used. Problems that have arisen with utilization

of the family life cycle are its prescriptive manner. The reality is that in today's families, all people do not marry, have children, and launch the oldest child based on the dictates of society. Family developmental tasks are thought to run parallel to individual development (Duvall, 1971).

Family forms have also experienced transformation. This transformation has been referred to as a postmodern family (Walsh). These family forms include single parent households, dual-earner families, stepfamilies, intact nuclear families, unmarried couples, and adoptive families for single parents. Researchers must be cautious in using stereotyping to classify families. Families should be defined as inclusive related to how they are functioning and in the way in which they provide support (Walsh).

Families with the ability to accomplish family tasks while promoting the growth of individual members are considered healthy families or optimal functioning families (Walsh). Even the most optimal functioning families might be affected in times of stress. Family studies have identified that there are normal stressors that are expected and there are uncommon and unpredictable stressors that tend to affect the family dynamics more severely (Walsh). When a family has effective problem-solving strategies, they manage all stressors more effectively (Walsh).

Families are viewed as resilient when they have the ability to adapt to new situations and possess the necessary resources to meet the challenges (Stetz, Lewis, & Houck, 1994). In a study with a group of 786 persons with MS conducted in 1997, the most frequently identified domain of quality of life was family. This was identified as more important than functioning to maintain independence, spirituality, or socioeconomic security (Stuifbergen & Rogers, 1997).

The work of the young adult within context of the family consists of separating from the family of origin without losing that part of who they are (McGoldrick & Carter). This might be compromised for young adults who have been diagnosed with MS and need additional family support. During their young adulthood, individuals establish themselves as productive members of society, integrating vocational goals, developing the capacity for intimate relationships, and accepting social responsibility (Falvo, 1991; Miller, 1992). For a young adult with chronic illness, tasks such as marriage, childbearing, child rearing, obtaining higher education, and employment might be affected.

Participants in this study might be single, married, divorced, or widowed. They may be in various stages of the family life cycle. Individuals in Stage I are married without children. Those in Stage II are childbearing families with a newborn or young child. Stage III families have preschool children. Families in Stage IV have school-aged children and Stage V families have teenagers. Some of the participants could be part of a family who are in Stage VI preparing to launch their oldest child (Nichols & Pace-Nichols). The participants will be from 20-40 years of age, placing them in Stage I through V of the family life cycle as individuals or in Stage VI of the family life cycle if they are single and living at home with their parents.

Developmental Level of Young Adulthood

Erikson (1950) wrote of the eight stages of man. Developmental tasks were included in each stage. The tasks were believed to build on one another. Mastery of the major tasks within each stage was essential preparation for the sequential task. The underlying assumption of these stages was that individuals must be aware of and ready to

interact with a broader social world at each stage. The developmental tasks of each stage must be met in some form in order to have an “integration of all” (Erikson, 1950, p. 271).

Levinson (1996) utilized Erikson’s work as a basis for his work, which he called seasons of the life cycle. Setting the age limits for the young adult period is more arbitrary than for other age spans. The beginning and end of this phase is determined more by the individual’s acceptance of adult responsibilities than by a specific age. The primary developmental goal of early adulthood should be completed between the ages of 18 to 40 years of age. This includes establishing a place in society, choosing an occupation, starting and raising a family, and pursuing personal aspirations (Levinson, 1996). There is a consolidation of adulthood at the approximate age of 30 and a midlife transition between 40 and 45 years of age (Levinson, 1996). The criteria used to identify young adults will follow the life-span developmental approach of setting the age of 20 to 40 as the target group.

A critical developmental task that young adults deal with involves establishing and maintaining intimacy. This is in contrast to developing a sense of isolation. In attempts to reach the goal, the young adult might be confronted with the challenges of developing close ties with friends, choosing a career, and integrating sexuality into a meaningful, long-term relationship (Corbin & Strauss, 1984; Eisenberg, Sutkin, & Jansen, 1984; Levinson, 1996). For a young adult with RRMS, tasks such as marriage, childbearing, and child rearing might be affected in varying degrees.

Summary of the Metacontext

Many challenges accompany a diagnosis of chronic illness. For families, the chronic illness might challenge previously held assumptions, change family roles, and

alter familiar patterns. Families might grow closer or they might come apart under the stress. Regardless, the broad context of chronic illness might have a direct impact on quality of family life leading to indirect effects on the young adult's ability to cope with the changes in their life (Campbell, 2000). The developmental level of the young adult is embedded in the metacontextual layer as an indirect effect on their daily life.

General Context

The following section is related to the general context of young adult's living with RRMS. The general contextual layer is more stable, as change occurs, but at a slower pace. Initial experiences with illness are viewed through the world of families. Through centuries, the nature of RRMS has shown little change (Pearce). Genetic studies with families are helpful when studying RRMS. The foci of interest within this layer are families managing chronic illness, the nature, epidemiology and genetics of RRMS.

Nature of Multiple Sclerosis

Numerous researchers have conducted studies focused on identifying the cause of MS (Compston & Sawcer, 2002; Munger, Levin, Hollis, Howard, & Ascherio, 2006; Torkildsen, Knappskog, Nyland, & Myhr, 2008). The disease is routinely classified as an autoimmune disorder of the central nervous system. Community concerns in east Kansas City, Missouri, prompted researchers to examine correlations between spills from a closed oil refinery and the prevalence of MS. Findings revealed no significant differences between cases in the community bordering the refinery and the state average (Neuberger et al., 2004). Kurtzke (1995) indicated in an earlier epidemiological study that MS is a place-related, acquired disease with high, medium, and low geographic risk areas.

Central myelin and the cells that form central myelin, the oligodendrocytes seem to be the primary targets of immune attacks in MS. Without myelin, axons act as a live wire, randomly conducting impulses. The demyelination process might be relatively benign to extremely disabling, depending on the amount of communication disruption that occurs between the brain and other parts of the body (Compston & Coles; Hubsby & Sears, 1992; Nair, Frederick, & Miller, 2008).

Epidemiology of Multiple Sclerosis

Multiple sclerosis (MS) is an unpredictable, chronic, neurological disease with the age of onset identified as between the ages of 20 and 50, (Buhse; Roach, 2004; Weiner, 2004a). A determining factor in the prognosis of MS is age. Data obtained from 1990 to 2004 from Alberta, Canada showed age-specific prevalence rates higher between the ages of 30 and 60 in 2004. The prevalence rates rose from 300/100,000 in 1990 to 700/100,000 in 2004. A longer disease duration related to life expectancy was attributed to the change in prevalence. Another factor thought to be significant was improved diagnostic techniques (Warren, Svenson, & Warren, 2008).

Nisipeanu & Korczyn (1993) conducted studies evaluating the relationship between a common psychological stressor and relapses in MS. A group of 32 young men with MS exposed to war stress was studied. The number of exacerbations following the exposure was much lower than expected, suggesting that not all stress conditions increase exacerbations.

Disability resulting from the disease progression of RRMS is of great concern to the patient and other health care providers. Predictions of disability to understand long-term outcomes of MS were the purpose in a 20-year prospective population-based study

(Hirst et al.). Isaksson, Ahlstrom, and Gunnarsson studied the quality of life and eventual impairment in patients with MS.

Genetics of Multiple Sclerosis

The study of twins has given important information about genetics and MS. "It is generally believed that MS is a complex genetic disease, and a search is underway to find genes that are linked to this disease (Weiner, 2004a, p. 276). Compston and Sawcer completed a genetic analysis of multiple sclerosis. Genetic analysis is predicated on the "assumption that MS is one disease" (p. 262). Through their studies, Compston & Sawcer speculated that different categories of susceptibility genes would eventually be identified. These categories of genes will determine the susceptibility to the inflammatory process; determine specificity to develop multiple sclerosis from the process of inflammation; identify genes relevant for pathogenesis in isolated populations; determine phenotypes; and determine modifying genes that make the clinical course different for each individual. Studies have also linked genetic susceptibility with environmental factors (Ascherio & Munger; Compston & Sawcer; Torkildsen et al.).

One of the more recent studies was conducted in Europe with 2,310 individuals from 1,083 families. The aim of the study was to determine if familial factors influence the natural history of MS. The investigators found that age of onset was similar between sibling pairs but not parent-child pairs. There was no familial concordance found with disease severity. Overall, the results of the study support the belief that familial factors do significantly influence both susceptibility and the clinical course, but not the severity of MS (Hensiek et al., 2007).

Families Managing Chronic Illness

Cohen (1993) researched how living under conditions of sustained uncertainty became part of the fabric of the everyday life of families and transformed their taken-for-granted world. Once a diagnosis is made of a chronic illness, the person and family begin moving through the stage of acceptance, where feelings such as shock, disbelief, denial, and confusion might be experienced. Despite the fundamental acceptance of emotions as a major part of the human condition, there is little factual knowledge of the part emotions play in patient adaptation to illness (Bowman, 2001). The family tackles the most critical emotional task of grieving for lost abilities and potential experiences.

Day-to-day management of a chronic illness takes place in the home and is the primary responsibility of the ill person or a family member (Corbin & Strauss, 1991). “Our problems are framed by the formative of our family’s past, the present tasks it is trying to master, and the future to which it aspires” (McGoldrick & Carter, p. 375). In a study about the impact of chronic illness on family relationships, strain on personal life was found to be the most disruptive factor for partners of those living with a chronic illness (Baanders & Heijmans, 2007).

Chronic illness in one family member can profoundly affect developmental goals of the family. The transition periods in the illness life cycle are times when families reevaluate the appropriateness of their previous life structure in the face of new illness-related, developmental demands (Rolland, 1987). When the onset of a chronic illness coincides with a normal transition family life cycle, one might expect issues related to previous, current, and anticipated loss will be magnified. Upheaval, rethinking, and change often characterize transition periods, creating a greater risk for the illness to

become ignored when planning for the next developmental period. This can be a major precursor of family dysfunction in the context of chronic illness (Rolland, 1994).

Situational crisis within families can also arise because of chronic illness. A situational crisis was identified as emotional distress such as depression reduced the family's ability to cope with the chronic illness (Holmes & Deb, 2003). Holmes and Deb found that government innovations needed to be considered that allow family needs, such as respite care to be available. Health policy also needs to adapt to the changes in family composition of smaller families and to spousal carers as the primary caregiver (Cheung & Hocking).

Identifying families as an important support for individuals has been widely recognized in the literature for many years. Rolland (2003) provides a normative health paradigm for health care providers to assess and intervene with families facing the burden of a chronic illness. "Families can achieve a healthy balance between accepting limits and promoting autonomy" in the face of uncertainty (Rolland, 2003, p. 485).

Summary of the General Context

Issues related to the nature of MS, epidemiology, and genetics with a focus on families managing chronic illness are all concepts moving closer to the purpose of this study. Collectively, these issues are moving closer to concerns of an individual living with RRMS while remaining separate from the actual experience.

Specific Context

The specific context of an experience is concerned with the immediate past and relevant aspects of the present. The immediate past of the specific context is influenced by conditions such as the time of the day, mood, or personal and environmental factors

(Hinds et al.). The individual attaches meanings and interpretations to each experience and event throughout their life. This experience has an impact on both present and immediate layers of other events. It is important within the specific layer to evaluate what is known about health system access that is relevant to the present. This is a concern of Healthy People 2010 (U.S. Department of Health and Human Services), identifying the need to reduce barriers for health care. The following literature review relates to the specific context of concerns for young adults with RRMS. This includes: (a) health system access, (b) economic and employment issues, (c) perceived social support, (d) the diagnosis of RRMS, and (e) the impact of RRMS on the young adult couple.

Health System Access

Neri and Kroll (2003) explored the consequences young adults with disabilities perceive as the result of inadequate access to health care services. Barriers to health access were found to be associated with lack of health insurance, low income, and minority status. Lack of access to durable medical equipment or primary care led to social consequences affecting relationships with families, friends, and colleagues. Manifestations of the social consequences included depression, experiences of feeling devalued, and a greater dependence on others. Additionally, modifications of existing social roles followed. Respondents in the study reported less social interaction resulting from the inadequate access to health care services that might have improved their mobility. A young adult woman with MS verbalized difficulty locating a physician who was knowledgeable about her MS symptoms (Neri & Kroll). Other respondents felt misunderstood and devalued by their doctors who did not provide for their needs in a knowledgeable and timely manner. Progress is being made in the United States with

environmental barriers such as building accessibility. A need remains to ensure health care access is addressed by all providers of care (Neri & Kroll).

Economic and Employment Issues

The introduction of treatment options has reduced absence from work in individuals with RRMS (Ziemssen, Hoffman, Apfel, & Kern, 2008). Researchers also have evaluated work reduction versus complete unemployment (Smith & Arnett). Smith and Arnett found that individuals who were working had a higher level of depression when compared to the nonworking group. This was an unexpected finding. More participants in the study were employed full-time than in previous studies.

A longitudinal survey was the quantitative method used in a study of 371 MS patients with a mean age of 38.9. Sixty-eight percent of the persons were female. There were 258 individuals with RRMS and the remainder had progressive MS (Morales-Gonzales, Benito-Leon, Rivera-Navarro & Mitchell, 2004). Approximately sixty-five percent of individuals with RRMS were found to be unemployed from disabilities related to their MS (Morales-Gonzales et al.). The advent of medications to treat various symptoms has been found to decrease the days missed from work for persons with MS (Lage et al.). These studies have all focused on the construct of work or absenteeism, but not on the meaning of this experience for the young adult. Additionally, the progression of this disease can lead to people being required to reduce their level of work, leading to additional economic issues (DeJubicibus & McCabe, 2007).

Catanzaro and Weimer conducted a nationwide survey of 604 families who had a family member living with MS to determine the economic impact of the disease on the family. They found that 80% of the families had insurance, but 28% of the families felt

the benefits were inadequate to cover the cost of the illness. DeJudicibus and McCabe (2005) found economic deprivation had direct effects on the subjective well being of families who had a family member living with MS. The effects identified were relationship strain, social constraints, and transportation concerns.

Perceived Social Support

Social support predicted marital relationship satisfaction within two separate groups of MS and persons with a motor neuron disease (MND). O'Connor, McCabe, and Firth (2008) conducted a study to investigate the impact of neurological illness on marital satisfaction and to determine if differences exist between neurological illness groups. Participants had various disease states including MS, Parkinson's disease, Huntington's disease (HD), or a MND. There were 423 patients and 335 caregivers. Marital relationship satisfaction was measured using the relationship assessment scale (RAS). A statistical difference was found for all of the illness groups; however, MS did not differ from the other illness groups. However, differences in themes were identified from qualitative data. Themes that arose with MS participants included "physical restrictions, economic factors, and dependency" (O'Connor et al., p. 123). The independent variable was illness type and the dependent variables were the number of social supports and satisfaction with social supports. Using a MANOVA, no significant differences were found between illness groups relative to the dependent variables. For both MS and MND patients, social support was an important predictor of satisfaction in the marital relationship (O'Connor et al.).

Diagnosis of Relapsing-Remitting Multiple Sclerosis

MS was a difficult diagnosis to make until advanced diagnostic tests became available in the 1970's (Talley, 2005). This was followed by the introduction of the magnetic resonance imaging (MRI) in 1981, which revolutionized the way individuals with MS were diagnosed (Poser & Brinar). New diagnostic criteria for MS were presented in 2001 by the International Panel on the Diagnosis of Multiple Sclerosis, which was chaired by Dr. W. Ian McDonald. Those criteria referred to as "McDonald's Criteria" are used internationally (Polman et al.).

Isaksson and Ahlstrom (2006) conducted a qualitative study with 61 MS patients. The aims were to describe beliefs of persons about MS before diagnosis and to describe experiences of initial symptoms. While waiting for a diagnosis, patients felt vulnerable due to communication problems, long waiting times, or a lack of compassion from health care providers. All participants expressed anxiety related to the symptoms, fear related to the unknown, and uncertainty related to the entire experience. Several expressed feeling depressed before they were diagnosed and experienced shame with symptoms that had no name. The feeling of vulnerability remained after diagnosis. Dalton and Gottlieb (2003) found that vulnerability could lead to strength if persons initially felt support from healthcare personnel and were treated with respect and understanding. Receiving the diagnosis then gave them a sense of control with a readiness to accept their illness.

The diagnosis of RRMS is made at the time in the life of young adults when society expects them to be at their highest level of production. During young adulthood, individuals establish themselves as productive members of society, integrate vocational

goals, develop the capacity for intimate relationships, and accept social responsibility (Clark, 1991; Mullins et al., 2001).

The Impact of RRMS on the Young Adult Couple

When the young adult becomes part of a couple, the primary developmental tasks include: maintaining their first home, establishing a means of support, planning for possible children, establishing acceptable roles, maintaining morale, allocating responsibilities, and interacting with the community (Courts et al., 2005). Within the context of developmental tasks, people expect to become caregivers for babies, children, and perhaps elderly parents. They do not expect during young adulthood to become the caregiver for their spouse in the midst of developing a career, providing for their family, and caring for their children (Courts et al., 2005).

Caregiver roles were identified as challenging when caring for the spouse in the midst of an exacerbation (Courts et al., 2005). Twelve people participated in a two-hour focus group. Eight men and four women were included. The husband's average age was 50 and 55 was the wives average age. Additionally, gender differences were found in how the spouse provided support and assistance. Men and women both spoke of being overprotective, while women pushed their husbands to be independent and men were protective of their wives' energy levels. MS sometimes led to role reversal. Courts et al. (2005) found a lack of public awareness of MS, healthcare barriers, and a concept of having an invisible illness.

There is a constant demand on resources for the young adult with MS and the partner. Problems might arise if the couple cannot make the adjustments necessary due to financial concerns or personal reasons. Corbin and Strauss (1988) wrote of the costs

accrued by the continuous accommodations young adult couples are forced to make in response to the inevitable demands placed upon them by chronic illness. "Accommodation is the day-to-day struggle of spouses to keep some sense of balance and give meaning to their respective lives. This struggle involves a constant juggling of time, space, energy, money, jobs, activities, and identities" (Corbin & Strauss, 1988, p. 6).

One observation identified by Corbin and Strauss (1988) was that neither husbands nor wives ever speak only of chronic illness in the present tense. They blend it into their life stories. It became part of a life trajectory that included stories of a before and after the diagnosis. The present was told in the context of a past event. Included in that life trajectory were stories of how their hopes or dreams were interrupted or changed. Corbin and Strauss (1984) postulated that when there is a chronic illness, each partner formulates a trajectory projection or a vision of the possible course that the illness and its management might take. From the trajectory projection, each partner develops a trajectory scheme or action plan for handling the illness. Each partner holds for their self, the other, and their relationship some vision, or hopes and dreams for the future. When illness strikes these hopes and dreams, both individual and mutual dreams are often greatly changed or even shattered. Individually and together, the couple must come to terms with these losses (Corbin & Strauss, 1988). Corbin and Strauss (1984, 1988) focused on a variety of chronic illnesses, not just multiple sclerosis.

Hainsworth (1996) examined chronic sorrow with spouse caregivers of clients who have MS. The sample consisted of ten participants. Of these individuals, 80% validated that they had experienced chronic sorrow at various times since the diagnosis of their significant other with MS. Triggers were identified that caused sorrow to recur. The

triggers varied from individual to individual, but typically included events such as the anniversary of the diagnosis, exacerbation of the illness, doctor appointments, realization of social losses, social stigma related to the illness, and routine medical tests.

Schwartz and Kraft (1999) examined relationships between patients' perceptions of spousal response when they were in the midst of an exacerbation versus when they were feeling well. Spouses were more negative about exacerbations that affected the patient's general mental health functioning than they were with physical exacerbations. The investigators also found families who viewed themselves as independent or who encouraged self-sufficiency correlated positively with the patient feeling less disabled.

Summary of the Specific Context

The immediate past for the young adult with RRMS includes access to the health system and the economic impact the illness has on persons. If diagnosed with RRMS during young adulthood, virtually every area of the young adult's life will be affected. If he or she is a part of a couple, it will also include the significant other and the impact the disease has on their relationship.

Immediate Context

The focus on this layer is the present. It includes relevant aspects of the situation closest to the experience and to the individual. First, the psychosocial aspects of RRMS are discussed within this contextual layer. I will include relevant information related to symptoms of RRMS that can profoundly affect the young adult's experience while living with the disease. Additionally, treatment options are an issue that has a direct impact on the young adult. A discussion of adaptation related to the chronic illness of RRMS will conclude this section.

Psychosocial Aspects of MS

Of the many psychosocial issues related to MS, stigma has a significant impact on the individual (Heatherton, Kleck, Hebl, & Hull, 2003). It is defined as "a mark of shame or discredit, an identifying mark or characteristic as a specific diagnostic sign of a disease" (Mish, 2002). Stigmatization arises from a social intolerance of those who are not considered normal (Joachim & Acorn, 2000). Stigma is a term now frequently found in the literature that is associated with chronic conditions such as MS (Edmonds, Vivat, Burman, Silber, & Higginson, 2007; Grytten & Maseide, 2005; Grytten & Maseide, 2006; Joachim & Acorn). Stigmatization is also noted with symptoms of MS such as depression (Kanter, Rusch, & Brondino, 2008). For the young adult with MS the stigma, rather real or perceived, often leads to social isolation (Grytten & Maseide, 2006). The young adult's developmental stage compared to an aged person complicates the issue due to the loss of self-esteem, self-identity, and the overall diminishing sense of self (Erikson, 1968; Grytten & Maseide, 2005; Fong et al.). Unfortunately, modern society continues to carry a social intolerance of those who are different from society's norm. This attitude leads to stigma being attached to the individual with the chronic illness (Grytten & Maseide, 2005).

Sherbourne and Stewart (1991) identified five categories of functional social support. The five categories included: (a) emotional support, (b) informational support, (c) tangible support, (d) affectionate support, and (e) social companionship. The study was focused on perceived functional support rather than actual received support. The social network was viewed as a structural element of links. Individuals were considered

pieces of links in the chain. Interactions between individuals completed the link leading to the social network (Hilari & Northcott, 2006).

Physical Symptoms of RRMS

Researchers have focused on individual symptoms of RRMS and how symptoms affect quality of life, work, and social expectations for persons (Isaksson et al., 2005; Janssens et al., 2003; Johnson et al., 2004; Noseworthy et al.; Sa, 2008). Based on conservative estimates, at least half of all persons with MS experience motor symptoms (Miller, 2006; Noseworthy et al.; Petajan, 2000). Somatosensory sensory symptoms might be some of the first symptoms reported by persons with MS. Common manifestations of brainstem symptoms include blurred vision, optic neuritis, double vision, and facial paresis (Arrese et al., 2008; Chen & Gordon, 2005). A loss of balance is indicative of cerebellar involvement (Miller, 2006). RRMS typically starts with bladder, bowel, and sexual disturbances manifested by urinary urgency, failure to empty the bladder, fecal incontinence, or erectile dysfunction (Noseworthy et al.).

Spasticity associated with MS can reduce energy, inhibit motor control, and interfere with sexuality or vocational responsibilities (Lisak, 2001). Symptoms of fatigue are a complex combination of temperature changes, upper motor neuron weakness, and demyelination of the nerve fibers with exertion (Flesner et al.; Giovannoni, Thompson, Miller, & Thompson, 2001; Miller & Hens). Pain experienced as neurological or muscular is described as tingling, burning, tightness, or painful spasms (Noseworthy et al.; Svendsen, Jensen, Hansen, & Bach, 2005). Communication difficulties can result from speech impairment production or from cognitive deficits.

Sexual dysfunction is common in MS but rarely discussed by physicians (Fraser, Mahoney & McGurl, 2008). Sexuality is a normal and fundamental part of a young adult's life. It is unfortunate that sexual health remains a neglected area of care in medical areas (Fraser et al.). Earlier researchers have said ignoring sexual problems is equivalent to discrimination (Dupont, 1995). For the young adult with MS, this can be a serious threat to their self-esteem and relationships.

Gagliardi utilized a naturalistic case study method to conduct telephone interviews with eight individuals living with MS. The participants of this study were between 47 to 71 years of age. This study focused on the word sexuality and what feelings were associated with the word. Findings from this study identified different definitions of sexuality. Sexuality was viewed as a form of self-expression, self-affirmation, and the way a person thinks and acts toward others. My study will include younger adults and if the issue of sexuality is a part of the interview, it will be within the context of the meaning of changes related to the disease rather than meaning of the word. It is important to explore symptoms within the context of meaning of the experience for the young adult.

Cognitive and Emotional Changes due to RRMS

When in the midst of an exacerbation, young adults with RRMS often report cognitive changes to their families (Brassington & Marsh, 1998). Problems associated with this impairment affect concentration, memory, and information processing (Shevil & Finlayson, 2006). Relationships between MS lesion burden and cognitive dysfunction can only be assessed by an MRI (Sperling et al., 2001). Investigators agree, "poor cognitive

performance is associated with increased total lesion volume” (Sperling et al., p. 115). An estimated 43-72% of individuals have associated cognitive impairment with RRMS.

Shevil and Finlayson conducted a qualitative study to explore the impact of cognitive changes on the lives of four individuals with MS who had different life roles. All of the participants experienced cognitive changes, while the severity of the change differed between the participants. The full-time worker had difficulty remembering people’s names and their affiliations, while the parent struggled to remain focused. A 55-year-old retired woman was concerned with her inability to organize tasks. This individual had to retire early related to her cognitive changes. The overall findings showed that cognitive changes associated with MS do have a significant impact on daily life, desired roles, and perceived quality of life.

Phillips and Stuijbergen (2006b) investigated the influence of metamemory on the quality of life with a sample of 482 individuals diagnosed with MS. The construct of metamemory was defined as “self-report of memory ability and skills” (Phillips & Stuijbergen, 2006b, p. 428). The researchers asked respondents to complete a battery of self-report instruments related to quality of life, depressive symptoms, severity-of-impairment, self-efficacy, and health promoting behaviors. The longitudinal study took place over a seven-year period. Findings were “consistent with prior research...that components of metamemory are significantly correlated with neurological disability (operationalized as functional limitations), duration of disease, depressive symptoms, age, and quality of life” (Phillips & Stuijbergen, 2006b, p. 432). “Depressive symptoms had a higher impact than other variables in the final regression model on quality-of-life prediction” (Phillips & Stuijbergen, 2006b, p. 428).

Depression, fatigue, and sleep difficulties are some of the more common symptoms associated with MS (Clark et al., 1992; Lobentanz et al., 2004; Siepman et al., 2008). The role of disability, depression, and anxiety was examined in correlation with cognitive functioning recently by investigators (Siepman et al.). The major findings from this study included a significant association between neuropsychological test scores and disability. Those with higher disability had more difficulty with timed tasks that related to memory, attention to detail, and information processing. Another significant finding from this study related to depression. It was found to be associated with all neuropsychological test scores with the exception of visual spatial learning, attention, and information processing speed. Siepman et al. reported the co-occurrence of cognitive impairment and symptoms of depression could be caused by the disease process. They did conclude that cognitive impairment was associated with higher disability, but not with symptoms of depression.

Treatments Following RRMS Diagnosis

From the late 1970s to present, MS research focused on the autoimmune reaction. Treatment was focused on steroids and immune-system regulators (Rolak, n.d.; Goodin, 2006). The treatment of choice for an exacerbation continues to be corticosteroids. Trials to date indicate the length of exacerbations is shortened, but no alteration of the course of the disease occurs with steroids (Compston & Coles, 2002; Goodin).

Prior to 1993, there were no effective interventions to alter the course of RRMS. Betaseron was approved by the Food and Drug Administration in 1993, followed by glatiramer acetate in 1995, Avonex in 1996, mitoxatrone in 2000 and Rebif in 2002 (Mao-Drayer & Panitch, 2006). These agents improve the natural history of MS by

reducing the number of relapses and slowing progression. Individuals administer disease modifying drugs by self-injection daily or every 48 hours. Beta interferons are proteins with complicated immune-modifying properties. Although the beta interferons are well tolerated, there are numerous side effects that might affect the overall quality of life (Jacobs, 2001; Johnson & Calabresi, 2001; Whitaker et al., 2001).

One of the few phenomenological studies describing the lived experience of individuals with RRMS was conducted by Miller (1997) in two outpatient MS clinics in Western New York (Miller, 1997). The participants in the study ranged from 40 to 59 years of age. Twelve themes were identified including coping, fear, and getting to know MS. All participants relied heavily on social networks to cope with the disease. One recommendation from this study was to conduct a similar study within a different clinical setting to determine if the findings would be generalizable.

There is still no cure for RRMS, although the course of the disease may be altered or slowed with medication. The medications currently available are expensive, require frequent injections, and lifestyle adjustments (Miller & Jezewski, 2006). When diagnosed with MS, prompt treatment with an interferon agent has positive results as evidenced by the reduction of exacerbations, gadolinium-enhancing lesions, T2 lesion burden, accumulation of brain atrophy, and a delay of onset of progression (Weiner, 2004b). These medications have transformed the management of RRMS (Goodin).

Recently in Hong Kong, researchers found that treatment with glatiramer acetate was associated with a reduction in patient-reported fatigue rating and in days missed from work. This correlated with decreased clinical symptoms (Ziemssen et al.). There is a window of therapeutic opportunity available with the current treatment options. It is

important to begin treatment early to avoid the cascade of events leading to tissue injury and further disability (Coles et al.).

Research into treatment options is ongoing and continues to look promising. The past few years have brought significant progress in the field of MS research. Studies related to the role of genetics and susceptibility, inflammation, and T cells, gene microchip array, as well as the mechanisms of demyelination and identification of myelin antigens have been completed (Bjartmar, Kidd, & Ransohoff, 2001; Gilten et al., 2001). Future direction of treatment options for RRMS might include stem cell transplants. Current treatments are directed at limiting the cumulative damage to the brain tissue (Aikins & Freedman, 2006; Coles et al.).

Adaptation to and Management of RRMS

Pakenham (1999) researched the use of a stress and coping model of adjustment to MS. One hundred twenty-two patients were interviewed and completed self-administered scales at two separate times, 12 months apart. They found limited support for the stress buffering effects of coping and social support. They also found adjustment to MS improves over time. This finding was believed to be related to the fact that young adults are not psychologically prepared to deal with a severe health diagnosis leading to initial stress related to the diagnosis. Individuals with MS perceived that when diagnosed with MS, they were told to "go away and live with it," leading to additional stress related to the diagnosis (Johnson, 2003, p. 82).

Summary of the Immediate Context

I have included in the immediate context those issues that are immediately relevant to the young adult when speaking of the meaning of living with RRMS. These

include the psychosocial aspects of RRMS, symptoms, treatment, and adaptation. These are all constructs that relate to day-to-day life with RRMS. The immediate context is reflected in the Heideggerian method as existence (Heidegger, 1959).

Summary: Relationships among Layers of Context

In summary, I will place the relationships of the four layers of context (metacontext, general context, specific context, and immediate context) into perspective with this study. The metacontextual layer must be consciously included to avoid being unrecognized (Hinds et al.). For this study, this layer provided an overview of chronic illness. Family development and the family life cycle are important components to identify; they should not be overlooked.

The general context includes how the young adult perceives access to health care. Concerns related to barriers or access might arise during the interviews. MS is referred to as a disease of young adults; therefore, the developmental level of this age group was included in the general contextual layer. The overview of MS with epidemiology and genetics is crucial information. Young adults who are planning families might have concerns related to these topics. An understanding of this experience can emerge from the analysis of these multiple contexts surrounding this phenomenon.

The specific context is the environment, both internal and external, that the young adult identifies as being significant in the overall experience. I have included within this context several important aspects of this issue. Studies related to the construct of perceived social support and the impact of RRMS on the young adult couple is discussed first. This is followed with economic and employment issues that could have a more immediate effect on the young adult. The cognitive and emotional changes that occur

with RRMS were separated from the physical aspects of the disease and research specifically addressing these areas.

The immediate context is the context in which the researcher will explore the young adult's experience in living with MS. This includes the diagnosis, symptoms experienced, disability concerns, and the treatment chosen or being evaluated as an option. Each of these areas relate immediately to the individual living with RRMS.

After the interview data have been obtained and analyzed, I will be able to draw conclusions about the degree of relevance that each of the various layers of context has had on the experience of the young adults in my sample. I will discuss findings relative to each contextual layer in Chapter Five.

CHAPTER THREE

METHODS

Philosophical Underpinnings of the Method

Phenomenology has been identified as a philosophy, an approach, or as a research method (Omery & Mack). Research strategies are tools utilized by an investigator to illuminate certain aspects of reality. Phenomenology is the strategy utilized when seeking the meaning or the essence of an experience (Morse, 1998). Heidegger redefined phenomenology as something that can become visible through speaking (Palmer, 1969). This occurs with the Heideggerian method as the meaning attached to situations encountered in day-to-day life returns "to that unitary structure of Being from which they all originally emerged" (Macann, 1993, p. 63). Heideggerian hermeneutics is a path that blends hearing, narratives, and listening. It is a research approach committed to complete understanding (P. Brown, personal communication, December 2008). Two essential components of Heidegger's philosophy have direct relevance for the method: the historical context of the person's world, both past and present, and the Hermeneutic circle (Koch, 1995). Each is explained below.

The Historical Context of the Person's World

Language is a very important component of Heidegger's (1971) philosophy. The word *Dasein* is an everyday German word typically translated as an individual's meaning of existence. Heidegger broke this word down into two components. The two components of the word were "Da," which is translated as "there," and "Sein," which is translated as "being" (Heidegger, 1959, p. 9). Included in this translation is a "historical existence in the world" (Heidegger, 1959, p. 9). Persons can take everyday experience for granted, as

well as the meaning of such experiences. Heidegger postulated that such meaning must be explored in the historical context of the originating experience if it is to be understood (Macann, 1993). This meaning that can be taken for granted has also been referred to as the pre-ontological understanding of being (Macann; Koch).

The Hermeneutic Circle

Each research participant brings a pre-understanding of the experience of interest to the interview that includes cultural influences, as well as a personal understanding of the world (Koch). The researcher brings a personal pre-understanding of the experience of interest to the interview, as well. The researcher draws upon that personal pre-understanding to explore the pre-understanding of the participant. Thus, the investigation might appear to move in a cyclic manner, which can be referred to as the Hermeneutic circle.

In facilitating the interview, the researcher recognizes that certain pre-suppositions, assumptions, or conclusions about the experience are already operative prior to the interview. “Heidegger articulates that presuppositions are not to be eliminated or suspended, but are what constitute the possibility of intelligibility or meaning” (Morse, 1994, p. 120). These presuppositions, which the researcher must acknowledge within self, enable the participant to reveal, become the history, background, or context of the Hermeneutic circle.

Macann offered useful advice for the interpretive phenomenological researcher. “It is important not to try to get out of the circle but to get into it, and go round it in the right way” (p. 65). Heidegger (1959) warned of the danger of being led astray by hastily developed theories. Instead, the researcher should relate the participant’s story back to the

experience. The focus and type of questions asked should evolve as part of the actual experience of the interview (Heidegger, 1959). Interviews should go beyond surface appearances and guide the interviewer to ask “why” (Heidegger, 1959, p. 5). The writing, thinking, and reading of the researcher all become part of the Hermeneutic circle.

The Aims of this Work Relative to the Interpretive Approach

There is a paucity of interpretive work focused on the experiences of young adults who are living with multiple sclerosis. For instance, there is little information about what it means for a young adult to be diagnosed with RRMS. One aim of this study was to interpret the meaning of changes that have occurred in the lives of young adults since the diagnosis. Other foci were to understand how young adults make meaning of the expectations others have of them and explored how young adults learned new ways of being during periods of exacerbations from RRMS. This study was designed to yield practical knowledge that can be disseminated to the young adult living with RRMS, to health care professionals, and to the public.

In this chapter, I described the data collection and analysis procedures for this study of the experience of young adults living with RRMS. The work was informed by Heidegger’s (1959) phenomenology, but to ensure a systematic approach in data analysis, I followed the text analysis method recommended by Miles and Huberman (1994). Other scholars whose work has been informed by interpretive phenomenology have found this data analysis method beneficial when coding data from multiple interviews (Boswell, Dawson, & Heininger, 1998; Carr, 2007; Evans, 2008). Evans conducted a longitudinal study to identify barriers for students from diverse backgrounds in nursing programs. Data analysis was conducted following methods outlined by Miles and Huberman (1994)

using a matrix to document cross-comparisons of interview responses. Similarly, Boswell, Dawson, and Heining (1998), who explored quality of life as defined by adults with spinal cord injuries, used Miles and Huberman's templates to code interview responses.

The approach of Miles and Huberman (1994) is particularly appropriate to use when conducting an interpretive phenomenological study because it is very systematic. This enables the researcher to document both data and findings in ways that are clear to follow, so that the context of the emerging data is clearly organized (Miles & Huberman, 1994). The "methods are manageable and straightforward" (Miles & Huberman, 1994, p. 3). The method of Miles and Huberman (1994) requires that the researcher stay focused on words and their meaning, just as Heidegger (1971) suggested in early writings.

Design

The initial plan was to recruit at least six but no more than eight young adults who had been diagnosed with RRMS and to complete a series of three interviews during a three- to five-week period, every week or 10 days, based on the feasibility for the participant. A general plan for data collection in this study included the processes of sampling, recruiting, and interviewing. Non-probability sampling was used. Although three interviews were planned with each participant, the design was cross-sectional rather than longitudinal, as a short span of time was involved. A cross-sectional design is appropriate in phenomenological studies such as this one, when the aim was interpretation or description (Macnee & McCabe, 2008). Through interviews, data were obtained to explore the meaning of the experience of living with RRMS. Data were

analyzed using Miles and Huberman’s method (1994). The original plan for data collection and data analysis is shown in Table 1.

Table 1

Original Plan for Data Collection and Analysis

ACTIVITY	MONTHS						
	1	2	3	4	5	6	7
Recruit and interview participants 1 & 2							
Transcribe recordings and analyze data for participants 1 & 2							
Recruit and interview participants 3 & 4							
Transcribe recordings and analyze data for participants 3 & 4							
Recruit and interview participants 5 & 6							
Transcribe recordings and analyze data for participants 5 & 6							
If needed recruit and interview participants 7 & 8							
Transcribe recordings and analyze data for participants 7 & 8							
Finalize data analysis							

As the study progressed, some changes were warranted in the plan for data collection and analysis as described below and as shown in Table 2.

Table 2

Actual Progression of Data Collection and Analysis

ACTIVITY	MONTHS						
	1	2	3	4	5	6	7
Recruited and interviewed Participant 1	■						
Transcribed recordings and analyzed data for Participant 1		■	■				
Recruited Participant 2	■						
Interviewed Participant 2		■					
Transcribed recordings and analyzed data for Participant 2		■	■				
Recruited and interviewed Participant 3				■			
Transcribed recordings and analyzed data for Participant 3				■	■		
Recruited and interviewed Participant 4					■		
Transcribed recordings and analyzed data for Participant 4					■	■	
Recruited and interviewed Participants 5 and 6						■	
Transcribed recordings and analyzed data for Participant 5 and 6						■	■

Recruitment did not commence until the MU Health Sciences Institutional Review Board approved the study protocol (see Appendix A). This study was conducted in a rural Midwestern area. The series of three interviews with each participant was completed over a six-week period. Data collection occurred at the participants' homes or another private location convenient for the participants. As shown in Table 2, over a

6-month period, I recruited and interviewed six participants. My advisor and I conferred and agreed that I had sufficient data to address the research questions. At that point, I discontinued recruitment activities. I undertook data analysis concurrently with interviewing and continued analysis for another two months using an interpretive phenomenological method.

Sampling

A non-probability sampling strategy was used for this study. The goal of interpretive phenomenology is to search for the unity of meaning of the experience (Speziale & Carpenter). The goal of this study was not to ensure that each young adult in the Midwest could be included by random selection, but rather that the researcher would obtain a greater understanding of the experience of some young adults with RRMS. According to Speziale and Carpenter, “Individuals are selected to participate based on their first-hand experience with the phenomenon of interest” (p. 29). Therefore, I recruited young adults who had the experience of having been diagnosed with RRMS.

Characteristics of Prospective Participants

RRMS is a disease of young adults (Alshubaili et al.) so before establishing inclusion criteria for this study, it was important to define the term “young adult.” I defined the term as that part of the lifespan between 20 and 40 years of age, based on the work of Erickson (1968) and Levinson (1978). The inclusion criteria for this study were: (a) having been diagnosed with RRMS by a physician at least six months before enrolling in the study; (b) being between the ages of 20 and 40; and (c) being willing and able to relate experiences during interviews of 60 to 90 minutes in length.

Sampling Technique

I used convenience and purposive sampling techniques sequentially, following the method described by Porter (1999). For convenience sampling, the investigator's access to potential participants was a key consideration. The geographically accessible population (GAP) consists of persons residing within the area that was feasible for the researcher's travel (Porter, 1999). Data collection involved a series of interviews, and travel to the participants' homes was necessary. I chose the geographic region within 100 miles of my home; that six-county region included Boone County, which has a higher population density than other nearby counties.

The next stage of sampling was purposive. This involved selecting participants based on their knowledge of the phenomenon of interest and their willingness to share that knowledge. The goal of using this sampling technique was to develop a rich or dense description of the phenomenon (Speziale & Carpenter). This goal was achieved by recruiting young adults who met the inclusion criteria.

Gender and Minority Inclusion

Although I attempted to recruit persons of both genders, all participants were women. It was probable that more women than men would be recruited due to the demographics of the disease. White women have twice the MS risk of white men (Kurtzke, 2005). Ethnicity was not considered as an inclusion criterion. This decision was made primarily related to the rather minimal number of eligible, accessible African-Americans. Of Missouri residents, 11.2% are African-American (U.S. Census Bureau, 2000). In the rural mid-western region where the study was conducted, there is little ethnic diversity. Furthermore, compared to white persons, the MS risk to persons of other

ethnicities is not as great (Kurtzke, 2005). All six of the participants were white women. One African- American female contacted me to express interest in the study and scheduled an appointment for the initial interview. She did not follow through with her appointment. Repeated attempts to reschedule were not successful.

Sample Size

The issue of sample size presents unique concerns in qualitative research. The goal is to examine data from each individual to glean the lived experience at that moment in time. For this reason, the sample is kept small in interpretive studies. The sample size for phenomenological research has ranged from 5 (Hayes, 2001) to 10 (Johnson, 1998; Whittemore, Chase, Mandle, & Roy, 2002), which is considered appropriate and adequate for a phenomenological study (Morse, 2000). I planned to recruit at least 6 but no more than 8 participants to provide a rich description of the experience. A series of three interviews with six participants yielded sufficient data to address the research questions.

Recruitment

Porter (1999) stated, “When a relatively rare clinical population is the focus of a proposed study, and inclusion criteria are to be employed in sampling, the number of potentially eligible participants is a critical concern” (p. 796). I recruited participants from six counties (the GAP) using public advertisements, MS support groups, and local physician’s offices. Only one participant responded to a public advertisement, the other five participants were recruited based on personal referrals. The following section described how the eligible, accessible population (EAP) was calculated from the GAP.

Number of Potential Participants

To establish the size of the EAP, the number of potential participants who might meet the inclusion criteria was identified as living in the six-county regions (the GAP) at the time of the 2000 U.S. census. Age is one of the inclusion criteria. Thus, I considered the number of persons between 11-31 years of age in the year 2000 in Missouri, is the population now between the ages of 20 to 40. There were 820,227 persons in that group. These persons comprise the broadest target population related to the age group that I could easily access. Next, I purposively selected five counties in Missouri and one neighboring county in Illinois to determine the actual target population based on age. To get a general view of the county population based on age, I chose the largest city in each county (U.S. Census Bureau). To obtain the total population within the county, I included the age range of 20 to 44 (U.S. Census Bureau), as shown in Table 3.

Table 3

Estimated Number of Young Adults (20-44 years) in a Six-County Area in 2009

City / County	Population		
	City	County	Total
Canton, MO / Lewis County	1,040	1,323	2,363
Columbia, MO / Boone County	40,122	3,252	43,374
Hannibal, MO /Marion County	5,891	1,265	7,156
Monroe City, MO / Monroe County	789	1,509	2,298
New London, MO / Ralls County	75	2,411	2,486
Quincy, IL / Adams County	13,146	8,794	21,940
GRAND TOTAL	61,063	18,554	79,617

After the GAP was estimated, the size of the EAP was determined (Porter, 1999). Once the size of the population of interest had been identified, the parameters related to the phenomenon of interest were applied. Few databases exist to determine the actual number of MS cases in the United States. Data related to this disease are not collected by the Centers for Disease Control (CDC) or the U.S Department of Health and Human Services. According to a neurologist at a major mid-western Health Sciences Center, it is not possible presently “to estimate the actual prevalence of MS in Missouri” (Dr. Naismith, personal communication, February 25, 2009).

To obtain a general estimate for the prevalence of MS, I used statistics reported by other researchers. In the United States, reports from 22 to 177 cases per 100,000 people have been reported (Mayr et al., 2003; Neuberger et al.). The highest reported prevalence of 177 cases was in Olmsted County, Minnesota. Seventy-seven percent of individuals in the study were 15 to 44 years of age (Mayr et al.). In Jefferson County, Missouri, the average number of cases was 107 per 100,000 (Neuberger et al.). This figure lies within the range of 22 to 177 cases per 100,000 reported by Neuberger et al. Reports from Neuberger et al. identified 19 participants between the age of 30-39 and 11 individuals who were younger than the age of 30. The remaining participant ages ranged from 40 to 70. All had been diagnosed as having definite, probable, or presumed MS. Using these data, the minimum of eligible volunteers in the six-county region would be 22 and the maximum would be 177.

In addition to estimating the EAP based on the number of available young adults in the GAP, I calculated the number of young adults who had been seen in an acute care facility during the year 2006 resulting from MS complications. During 2006,

18 individuals had inpatient hospitalizations for MS complications in the Missouri counties (Missouri Department of Health & Senior Services, 2008). Statistics for 2006 were not available for Adams County, Illinois. Data from 2003 and 2004 included 13 individuals who were admitted through the emergency room to the hospital for MS complications in Adams County, Illinois (Illinois Department of Public Health, 2008). Applying all available parameters, I believed the EAP of young adults with MS was sufficient to enable recruitment of enough participants.

In summary, based on data in Table 3 and other data, the EAP for this study ranged from 13 (actual ER patients) to 107 (estimate of maximum number). I planned to recruit 6 to 8 young adults with RRMS between the ages of 20 and 40, and based on the EAP, I concluded that there were enough eligible volunteers in the six-county region. If needed, St. Louis County was within a 100-mile radius of my home, and eligible volunteers in that region could have been recruited.

Recruitment Procedure

Working within a six-county region permitted me to use several recruitment sites. These included: (a) the National MS Society support group in Adams County, Illinois; (b) the Quincy Medical Group's office; (c) Blessing-Physician Services offices; (d) recruitment advertisements in the *Quincy Herald Whig* and other local newspapers; (e) the National MS Society website; and (f) the National MS Society support group in Marion County. To recruit participants from the National MS Society support groups, I contacted the facilitator of the groups in Adams and Marion County to ask permission to speak at the support group meetings to explain the study and answer questions related to participation. Afterwards, I left recruitment packets, including a recruitment letter and

advertisement (see Appendix B and D) for potential volunteers. My contact information was available on the recruitment letter and advertisement. Pre-addressed, stamped postcards (see Appendix C), and my telephone number was included in the packet, so that volunteers could notify me of their interest in the study.

Second, I contacted neurologists in the Quincy Medical Group, at Blessing-Physician Services in the Quincy area, and in Columbia to explain my study. I was granted permission to place an advertisement in office elevators and foyers. Third, I placed advertisements in the *Quincy Herald Whig*, and the *Hannibal Courier-Post*. In addition, I contacted the National MS Society representative and requested that the ad for my study be placed on their website.

Recruitment Outcomes

In addition to the six above, two individuals expressed interest in the study after hearing my presentation at the National MS Society support group in Marion County. One additional volunteer expressed interest after a friend's referral. After I discussed the criteria with them, I found that they did not meet the age criterion. They were all over the age of 40. I thanked them for their interest and explained that they were not eligible. One potential volunteer learned about the study through the National MS Society website. She telephoned to express interest and arranged to meet at a convenient location. She did not keep the appointment. I telephoned her later; she said she was tired and had just forgotten. The appointment was rescheduled at her request, but she called to cancel and asked to reschedule later. I left several messages to set up an appointment, but she did not return my calls. I left a final message thanking her for her interest and giving her a date that my recruitment would end. I did not hear from her.

The six volunteers who later agreed to participate in the study were recruited as follows. I received a postcard from a volunteer who read the advertisement in the *Quincy Herald Whig*. I called her on the date and time specified on the returned postcard and she declared her interest in the study. I briefly explained the study and answered her questions. One volunteer saw the advertisement in a medical office. She then e-mailed me to request information, saying she had been hesitant to call me until one of her friends told her about the study and repeatedly encouraged her to contact me. I responded, obtained a telephone number, and called her to explain the study. Four volunteers who later agreed to participate called me after a friend or family member encouraged them to take part in the study.

Thus, of the ten persons who expressed interest or volunteered for the study, only one participant was recruited as a direct result of proactive efforts on my part. The most productive method of recruiting was from a type of snowball effect (Polit & Beck, 2008; Speziale & Carpenter). That is, individuals in the community saw advertisements in the paper or in physician offices and contacted friends with RRMS to encourage them to participate. A total of five participants contacted me after a friend or colleague told them about the study. With the help of interested persons in the community, the efforts I undertook to publicize the study were sufficient for recruitment.

Human Subjects Considerations

This study protocol was submitted to the Health Sciences Institutional Review Board of the University of Missouri, Columbia, Missouri, requesting an expedited approval for the study of human participants, because risks to participants were minimal. According to Burns and Groves (2005), researchers have an obligation to protect human

rights and recognize the ethical responsibilities that are assumed when any research begins. The focus and the content of the study were made explicit in the contact letters, informational material, and the informed consent. Participants were assured of anonymity. The voluntary nature of participation was made explicit and they were free to withdraw from the study at any time. Appropriate procedures were implemented to maintain participants' rights to privacy and confidentiality. This included locking all interview recordings, hard copies of interviews, and identifying information in a file cabinet. I will destroy the recordings after the dissertation has been approved.

The main psychosocial risk that could have accompanied participation in this study was distress when discussing certain things about the experience of living with RRMS. Some participants expressed sadness when talking about the period of the initial diagnosis, but none expressed a desire to stop the interview for that reason. In fact, they verbalized a sense of relief that they could share the experience during the interview. Participants had the right not to answer questions that made them uncomfortable. All six participants chose to answer all questions fully.

I weighed the balance between possible risks and possible benefits to participants throughout the study (Burns & Groves). I believe the study was beneficial and the participants did not suffer any undue risks. This belief was validated when the participants voluntarily said that they felt they benefited from the study and were sad when we had our final interview.

Gaining Informed Consent

When a volunteer contacted me by telephone or sent a postcard that included the telephone number, I screened the volunteer for all inclusion criteria. (See Appendix E, for

the protocol for the screening telephone call.) Of the ten volunteers, six met all inclusion criteria. As explained earlier, three volunteers did not meet the criterion for age and one did not follow through with plans to meet.

I scheduled a private meeting with each volunteer who met all inclusion criteria. I explained the importance of meeting at a private place, preferably her home, and we planned accordingly. The purpose of that meeting was to provide information about the study and present the informed consent. I gave a copy of the consent form (see Appendix F) to the volunteer and read the information about the study aloud. Before presenting the informed consent, I asked if she had any questions and I answered them forthrightly. Volunteers were told that there were no costs associated with being in the study. They did not receive any inducement to participate or any compensation. I emphasized that participation in the study was voluntary.

I gave each volunteer the opportunity to discuss the consent with family or friends prior to signing. All six eligible volunteers agreed to participate and signed the informed consent at the first meeting. They said they welcomed the opportunity to talk with an interested person about what it is like to have RRMS. I gave each participant a copy of the signed consent, and I retained a signed copy. Each participant had the option of beginning the first interview immediately after signing the consent or scheduling the first interview within two weeks. All six participants chose to begin the first interview immediately after signing the consent form.

The Participants

All six participants were married white females. The age range was 27 to 40 years ($M=35.3$). Five participants had children who were living in the home. Four participants

were employed full-time; two were not employed outside the home. One participant who was not employed outside the home had recently applied for disability; the family income had decreased since she had been unable to work due to her RRMS. Table 4 shows descriptive data about the sample.

Table 4

Description of the Sample

<i>Pseudonym</i>	<i>Age</i>	<i>Age at Diagnosis</i>	<i>Years Since Diagnosis</i>	<i>Children</i>
Ms. C	36	28	8 years	3 children – Ages 15, 12, and 8
Ms. J	27	17	10 years	1 child – Age 2
Ms. T	40	30	10 years	2 children – Ages 3 and 5
Ms. H	40	27	13 years	3 children – Ages 17, 15, and 13
Ms. M	30	29	1 year 11 months	3 children – Twins -8 years old and a 2-year-old
Ms. L	39	30	9 years	No Children

Setting

After a telephone conversation ensuring that all the criteria for participation were met, I scheduled an appointment for the first interview. Three participants chose to meet for all three interviews at their home and two participants chose a convenient location in a private office. One of the two that chose to meet away from her home made the decision based on having small children in her home. She did not think she would be able to concentrate if she was at home with the distractions. The second participant who chose

to meet in a private office did so based solely on convenience. One participant chose to meet at a convenient location in a private office for our first two interviews and chose to meet at her home for our third and final interview. This participant was much more open in her home than she had been in the private office. Regardless of the setting they chose, the intention was to create a private environment where the participant felt comfortable to discuss the interview topics. Inconvenience to participants was minimal, because interviews were arranged at a time and location that was convenient for them.

The Instruments

The Heideggerian phenomenological method (Heidegger, 1977) was used in this study. With language, the researcher becomes the instrument to ascertain the meaning of the experience. The interview is also an instrument to be utilized to discover meaning as the interpretation progresses (Heidegger, 1977). Thus, the context of the interview guide was critical in guiding the focus of data collection and data analysis.

Development of the Interview Guide

The Heideggerian phenomenological method requires that the interviewer continually focus on the experience of interest. Heidegger (1977) said, “But where have we strayed . . .” (p. xviii), implying that it would be easy for the interviewer to get off-target. The interview guide (see Appendix G) was developed to be both in-depth and semi-structured to foster a rich understanding of the lived experience. The interview guide included both broad and specific questions on key topics related to each of the three specific aims. I went from broad and general questions to narrower, specific topics. The broad questions were considered general topics, with more sensitive questions being reserved for later in the interview.

A topic of a broad question related to the first specific aim of this study was the perspective of the young adult of the experience of being diagnosed with RRMS. The narrow topic asked about feelings related to the meaning of the experience of being diagnosed with RRMS. The broad question meant to gather information associated with the second aim related to the social aspects of RRMS. As I got more specific, the questions focused on how a young adult with RRMS perceived social or personal expectations from others. An example of a broad topic focusing on the third aim was a discussion of talking about a usual day as a young adult living with RRMS. A narrow, specific topic became personal and specific by focusing on how a young adult described what it was like when the illness got worse. Demographic information was incorporated with the first interview.

To establish content validity of the interview guide, I discussed each question with my advisor and committee, who offered very specific guidance for improvement. Prior to my committee meeting, I asked a layperson who leads an MS support group and a nurse who specializes in the care of neurological patients to review the guide. They suggested a few minor changes, which I made with the approval of my advisor.

Interview Techniques

The interview was face-to-face, requiring planning and consideration of interviewing techniques. I was able to establish a personal, trusting relationship. I was courteous and sensitive to the participant during and after the interview. I monitored personal space of the participant to ensure that she was comfortable. I maintained open posture, encouraging the participant to speak freely. I spoke clearly and distinctly when asking the interview questions and I made every effort not to ask any leading questions.

The interview guide was structured so that I had specific questions planned for each interview in the three interview series. Each participant was asked the questions in the same order. I avoided deviating from the interview guide, unless the participant answered the question before I had the opportunity to ask it, which did happen during the open-ended interviews. When that occurred, I stated that I was interested in the topic that the participant had just discussed and asked if she had anything more to say about that topic. In that way, I ensured that I had obtained data pertaining directly to the question. It was only through establishing a relationship with the participants that I was able to discover the meaning of their experience. I found that trust was developed relatively quickly and the participants talked freely and without reservation.

After each interview with each participant, I reviewed data with my adviser, who guided me in identifying topics the participant mentioned that I did not fully explore. I formulated a list of individualized follow-up probes pertaining to those issues. I used the follow-up probes to introduce the next interview.

Data Recording and Management

All interviews were recorded with a SONY IC recorder. Within 72 hours of each interview, I transcribed the recordings verbatim using Microsoft Word 2007. My advisor reviewed each transcription before the next scheduled interview with that participant. Observational data relevant to the interview environment and the participant's nonverbal behaviors were inserted into the transcript at the appropriate points, as suggested by Miles and Huberman (1994). For instance, if the participant became tearful during their conversation, I made note of the emotion.

Confidentiality was ensured in various ways. The participant was assigned an identifying 3-digit number. Data were coded with the identifying number, rather than the name. The name was documented in a database with the assigned number. That database was placed in a locked file cabinet in a locked office. I was the only person with access to the locked cabinet. To ensure confidentiality, if the participant chose to mention family names during the interview, I inserted a substitute for the name when I transcribed the interview. I also placed all interview recordings in a locked cabinet in a locked office prior to and after transcribing. With my advisor's approval, after the dissertation has been accepted, I will destroy the recordings and the database linking identifying information with the designated participant numbers.

Reliability and Validity of Interview Data

The concepts of reliability and validity are multi-faceted. One criticism of interview data is that it lacks reliability. However, data that is rich in meaning provides its own sense of authenticity and reliability (Adler & Adler, 1998). The qualitative researcher should not view reliability and validity as absolute truth but rather as understanding (Maxwell, 2002). Validity pertains to the understanding that researchers seek to find through their chosen methods. "Different research approaches value different things. For qualitative researchers, validity as a form of truth is prized above reliability. It is addressed through the honesty, depth, richness, and scope of the data achieved" (Carr, p. 894).

Reliability of Data

To enhance reliability, each participant was interviewed three times (Speziale & Carpenter). The three interviews also enabled me to establish a trusting relationship with

the participants and I could repeat questions at different interviews. The fact that I as the interviewer also transcribed the data likely enhanced the reliability of the data (Speziale & Carpenter).

Interpretive Validity and Reflexive Validity

Interpretive validity pertains to evaluating the inference from the words of the participants (Maxwell, 2002). “Words and sentences must always be read in context if one hopes to apprehend the meaning that they bear” (Heidegger, 1977, p. xviii). Using the Heideggerian method, it is important to focus on the meaning of words and carefully analyze various forms of data including the language, unconscious beliefs, intentions, and values of the participants (Maxwell). Interpretive validity has also been referred to as reflexive validity; regardless of the term used, the ongoing goal of the researcher must be to grasp and understand the participant and the experience (Speziale & Carpenter).

Data Analysis

Utilization of the Heideggerian method (Heidegger, 1959) permitted me, as the researcher, to become enmeshed in the Hermeneutic circle (Palmer) of the experience. The circle included the participant, my personal background related to the experience, the interview environment, and the interview texts. As the interview process and the relationship of the participant unfolded, I found myself moving into the circle just as Macann described. I moved within the Hermeneutic circle (Palmer), finding myself intrigued by participants’ disclosures as I sought to understand meaning.

I created an interpretation of the meaning of living with RRMS as a young adult during the interview process with each participant. As data collection evolved, windows of understanding opened related to what it means to live with RRMS as a young adult.

Answers to the research questions began to unfold as the participants shared their experiences. Some participants shared additional data beyond their responses to interview questions, shedding new meaning on individual experiences.

Techniques derived from Miles and Huberman (1994) were used to analyze and code the data. Analysis of the data is described as “consisting of three concurrent flows of activity: data reduction, data display, and conclusion drawing/verification” (Miles & Huberman, 1994, p. 10). Data collection and analysis occurred simultaneously, generating for me as the researcher, an experience of living with data. Miles and Huberman (1994) provided an example of a guide for analysis. I followed the guide with the first three participants after transcribing their first interviews. Upon completing the first interviews, I discontinued use of the analysis guide. I found that I needed to set the interviews aside after transcription to avoid becoming overwhelmed from the experience. I had a deeper understanding of meaning if I briefly distanced myself from data after each interview transcription.

The richness of qualitative data lends itself to gaining a deeper understanding of the phenomenon under investigation. The investigator can easily become overwhelmed with the nuances of the event and “forget to think” (Miles & Huberman, 1984, p. 69). When speaking of losing one’s focus when trying to understand through language, Heidegger (1977) advised against losing the meaning of what is spoken.

The use of a method that is organized and systematic ensures that the researcher will make conscious decisions while organizing and analyzing data (Miles & Huberman, 1994). “Matrix construction is a creative yet systematic-task that furthers your understanding of the substance and meaning of your data base” (Miles & Huberman,

1984, p. 211). An example of how the data was analyzed using the matrix method (Miles & Huberman, 1994) is described and shown in Table 5 under the data display section. I focused analysis on each of the three aims in turn.

Data Reduction

Data reduction is the process used to simplify and transform the data from the field notes and recordings into “chunks” of data to code (Miles & Huberman, 1994). This phase also involved attaching codes to the data, recording reflections or other comments in the margins of interview texts, and sorting and shifting through the data identifying similarities and differences. Other activities involved in data reduction are isolating commonalities and differences, exploring these with participants in the next interview, and gradually building up a set of generalizations that cover the consistencies in the data (Miles & Huberman, 1994).

When I began the process of data reduction, my initial thought was, ‘I do not want to lose any of the meaning.’ Thus, I was very cautious about this step of transformation. I used brackets and highlights around content as I sorted the data and wrote my thoughts about data in the columns of the section.

Data Display

A data display is “an organized compressed assembly of information that permits conclusion drawing and action” (Miles & Huberman, 1994, p. 11). I used Excel tables as data display methods. An example of this, with cells containing fictitious data contrived for this purpose, is shown in Table 5. The goal is to organize the information in a manner that is compact but accessible. Just as with data reduction, data display is not separate from analysis, but rather it is an integral part of the analysis.

Table 5: *Example of Analysis with the Matrix Method using Fictitious Data*

	<i>Theme: Sadness</i>	<i>Theme: Identity</i>	<i>Theme: Pain</i>	<i>Theme: Family</i>
Participant #1	“I felt very sad.”	“I didn’t know who I was.”	“I hurt all over.”	
Participant #2		“I lost my identify.”		“I realized I needed my family.”
Participant #3	“I felt like a dark cloud was hovering over me.”		“I try to block out the pain.”	“I only had my family to turn to.”
Participant #4		“It was just weird; it was like I didn’t know this person.”		

I found the matrix method worked very well to display data, except in one respect. I had at least eight pages of data for one theme when displayed in a small column as outlined in Table 5. It was difficult to analyze each theme and compare interviews from each participant and between participants. After this realization, I changed the format of the matrix, so I could display data from all three interviews with each participant in one table, rather than displaying data from four participants on one table as shown in Table 5. An example of the formatting change with cells showing actual data is shown in Table 6.

Table 6: *Example of Analysis with the Revised Matrix using Actual Data*

	It is a disease that affects family/friends/co-workers
Participant #101	<p>Interview 1 “My kids couldn’t be on my lap, because of the injection sites and pain.”</p> <p>Interview 2 “Friends, my children, whatever, I’m the rock. I’ve always been the one that takes care of everyone.”</p> <p>Interview 3 (Family process) “It really is. It really, truly is and they’re just as much a part of it as I am. They do understand how things go and what I can and can’t do.”</p>
Participant #102	<p>Interview 1 “It’s really hard for me because I can’t do what I want to do with her.” (Speaking of child)</p>
Participant #103	<p>Interview 3 “I did notice just this past two weeks, [teary] my five, she’ll be six, saying, ‘Mommy, I can help you with that. Mommy, let me do that.’ I’d be reading a book and I’d turn two pages at once because I couldn’t get ‘um’ to separate. That’s not an uncommon thing with books, paper books anyway, but she was noticing and she said, ‘Well, let me turn the page.’ She was turning the pages for me. As we were going through the book, I didn’t really think about, ‘Oh, well that’s because of the MS,’ I just thought, ‘Oh well, how nice.’”</p>
Participant #104	[This participant did not relate pertinent data about this theme]
Participant #105	<p>Interview 3 “I don’t know, she [child] sometimes gets the brunt of it because I’m like, ‘I can’t play right now, I have to rest.’ I don’t know she probably just thinks that’s normal, people sit in their chair and watch TV.”</p> <p>“I know as far as in the home situation, I kind of get tired of asking for help because it’s some of the things I feel like is his job and he should automatically do it. I have to be a constant reminder and so I hate to ask him to do my work because then I don’t know I feel like he would be overwhelmed with, ‘Oh, I have to do her work, plus I have to do mine.’”</p>
Participant #106	<p>Interview 2 “He’ll tell me now, ‘Don’t wear yourself out.’ He knows, so he listens and watches...for your cues. .for your cues.”</p>

Drawing and Verifying Conclusions

From the first interview, I began to consider what the words of each participant might mean. Throughout the study, I entered notes on the transcribed interview documents, and I noted my impressions as they occurred. Patterns began to emerge and simplistic labels were assigned to themes. Labels were revised multiple times, as some initial impressions changed and others were confirmed. My initial matrix included 38 themes, some with just a label such as ‘work’, other blocks within the matrix had data without a name (see Appendix H) and they all seemed important. Then the work evolved into phrases exemplifying the meaning of the experience. For example, when speaking of the possibility of changes, one participant said, “Yeah, that possibility was there. It was scary, but you have to know what’s going on.” The single word on my initial data reduction matrix was, “fear.” Later the theme evolved from the single concept of fear to, “Coming to know that RRMS can be scary.” The “competent researcher holds these conclusions lightly, maintaining openness and skepticism, but the conclusions are still there” (Miles & Huberman, 1994, p. 11).

The analysis document mentioned above served as an audit trail, documenting the progress of analysis over time. During this process, I dialogued frequently with my adviser verifying my interpretations of data. This resulted in the validity of meaning as it emerged. This process is an interactive, cyclical process, with the researcher moving between the modes of the method over time (Miles & Huberman, 1994). Themes that emerged from the matrix were analyzed. I was able to look at the commonalities and differences in my data displays for each participant and interpret data regarding each aim.

From the matrix, I made an index listing each research question and the themes that had emerged answering the question.

As explained in Chapter Two, the organizing framework of this study was the work of Hinds et al. (1992) pertaining to nested, interactive layers of context: (a) metacontext, (b) general context, (c) specific context, and (d) immediate context, which is consistent in several ways with Heidegger's (1971) philosophy. Therefore, as shown in the next chapter, I discerned which themes were most pertinent to each research question. Then for each research question, I organized the themes relative to each of the four contextual layers, yielding a rich description of the experience. The final analysis matrix consisted of 17 themes addressing Research Question #1, 7 themes for Research Question #2, and 5 themes pertaining to Research Question #3.

CHAPTER FOUR

FINDINGS

The purpose of this chapter is to present a phenomenological analysis of the experience of six young adult women who were living with relapsing-remitting multiple sclerosis (RRMS). The goal of this qualitative data analysis was to uncover meaning in data with the intent of having complete understanding (Miles & Huberman, 1994).

The analysis of these data was informed by Heidegger's (1959) phenomenology, and followed the text analysis method recommended by Miles and Huberman (1994). The chapter begins with two overviews. The first is philosophical, empirical, and methodological; it explains the notion of the participant's world of RRMS, its grounding in interpretive phenomenology, and the researcher's involvement in that world during interviews. The second overview is a brief sketch of the findings of the study. Finally, findings pertaining to each research question are presented in multiple, layered contexts to illustrate the complexity of the phenomena, using the organizing framework of Hinds et al. described in Chapter Two.

Overview: The World of RRMS

Dasein, for Heidegger, was being "in" the world (Macann). It was the experience of the average everydayness. Just as the *Dasein* concept included the thought that the person and the world are co-constituted, each participant co-constituted a personal world of RRMS. The world of RRMS was a different, smaller world than her social world. For each participant, the RRMS world included only a select group of people. It was within the RRMS world, in conversation with the persons she had chosen to include, that each participant felt free to express emotions about the diagnosis. As a researcher, I felt very

humbled that each participant invited me into her world of RRMS during interviews. The findings I report below unfolded within this RRMS world.

Overview: Summary of the Themes

The primary research question was: What is the meaning of the experience of living with RRMS for the young adult? The overall answer for that question is contained in this summary of the main themes constituting the findings. The themes are in italics.

The moment young adults began experiencing symptoms that eventually were diagnosed as manifestations of RRMS, the experience of living with RRMS began. Although relieved a diagnosis was made, the diagnosis of RRMS was a shock. A yearning for someone to talk to who could completely understand the experience followed a feeling of aloneness. They found themselves *wishing for an opportunity to talk to others like me*. The feeling of aloneness came from *finding that nobody really understands what it is like*. As they realized they *wanted to know more about RRMS while not wanting to know too much* they began *seeing life through a new lens*. From the time of the initial diagnosis, the young women found themselves *realizing that living with RRMS involved uncertainty* and recognition of *coming to know that RRMS can be scary*. They considered the uncertainty of the illness one of the hardest parts of the experience. A phenomenon *discovering that RRMS is frustrating* also became part of the broad contextual experience. At times, frustration was described as overwhelming. Some frustration came from a sense of losing control of their life. While *realizing that planning is important to help maintain a sense of control*, they were *trying to stay in control and make it all right for everyone*. This often involved planning for daily activities, family

outings, or even feeding their pets on schedule. They realized *learning to move past the moment of the diagnosis involved learning when to ask for help and how to let things go.*

Seeing the importance of charting my own course was instrumental in living with RRMS as a young adult. To accomplish this, they said repeatedly that they would not let ‘it’ [RRMS] rule their lives. Not letting it rule their lives led to *discovering that RRMS is in the backdrop of my life.* They chose not to make RRMS a focus of their life but instead they put it in the background and only thought about it out of necessity. Putting the disease in the background was possible as they began *learning to take the disease day-by-day, knowing the importance of listening to my body, and knowing I need rest when I feel the fatigue.* As the young adult placed the disease in the background of their life, these phenomena were all involved.

The context was structured by creating a world of RRMS smaller than their social world. They were very selective about this world. Creating the world of RRMS enabled them to maintain control over the larger portion of their lives when they felt no control over this very unpredictable disease. The smaller world of RRMS was where new ways of being occurred. This involved *redefining who I am, choosing who to include in the RRMS world, and making decisions about telling others who were not in the RRMS world.* Their close family and very close friends were invited to be part of the smaller world of RRMS. Creation of the smaller world of RRMS made recruitment challenging for this study. Five of the six participants became part of the study because of their friends who were part of the smaller world encouraging them to become involved. Research is part of the larger social world, rather than their smaller world of RRMS. They were hesitant to invite a stranger into their world of RRMS.

The world of RRMS created by these young adults was a protective mechanism and helped them by *knowing how other people respond to other people with RRMS*. It helped to understand stigma and preconceived ideas about how a young adult with a disability should look. The young women described it as difficult *deciding where you fit in a world that wants perfect people*. New ways of being include *finding that it takes planning to look normal*.

During an exacerbation, they had to reconsider being in the RRMS world. *Reliving the initial experience of what it was like to have the initial symptoms* occurred when they experienced any new symptoms. They were *deciding to fight the disease while wishing the medicine was not so hard to take*. If the exacerbation was severe and one that led to loss of employment or limited income, they began *seeing the economic impact of the cost of RRMS on my family*. During exacerbations, they also were *coming to know that wondering is part of thinking about the future* when living in a world with RRMS. They were *rationalizing my way into an understanding of how I ended up with RRMS*.

These young adults were not bitter or angry about their disease, but continually were *considering the ways in which my family support me* and talked about *realizing that health-care providers are a strong support*. Some of the women were sad when they considered what might happen if the disease progressed. Nevertheless, even in their sadness, there was strength and courage. They did not wish for the disease to be taken from them. Instead, they wished that they could help others understand, maintain their level of functioning, and continue taking care of their family and others.

Thus, in various ways, the six young adult women who took part in this study found meaning in living with RRMS. Having summarized the overall findings of the

study, I now relate specific findings for each of the three subsidiary research questions, relating themes pertinent to the layers of context detailed by Hinds et al.. The work involved creating detailed interpretive responses to the three subsidiary research questions. In the following paragraphs, the themes of the findings are summarized.

Findings Related to the First Research Question

The first research question was: For young adults, what is the meaning of changes that might have occurred since the RRMS diagnosis? In one sentence, the answer can be phrased in this way. The changes associated with the RRMS meant ongoing uncertainty and frustration, coupled with an ongoing realization of the need to devise other sorts of changes to make living worthwhile despite the disease.

Data addressing this question are organized into themes addressing each of the four layers of personal-social context (Hinds et al.). The four broadest themes relate to metacontext, because they captured socially constructed understandings (Hinds et al.). The metacontextual themes are: (a) *Realizing that living with RRMS involves uncertainty*, (b) *Discovering that RRMS is frustrating*, (c) *Coming to know that RRMS can be scary*, and (d) *Discovering that RRMS is in the backdrop of my life*. Three themes were viewed as representing general context, as having evolved from a person's past and current experiences (Hinds et al.): (a) *Seeing life through a new lens*, (b) *Wanting to know more about RRMS while not wanting to know too much*, and (c) *Learning when to ask for help and how to let things go*. Six themes, representing the immediate past, were understood as the specific layer of context (Hinds et al.): (a) *Learning to move past the moment of the diagnosis*, (b) *Choosing who to include in my RRMS world*, (c) *Deciding to fight the disease while wishing the medicine was not so hard to take*, (d) *Seeing the economic*

impact of the cost of RRMS on my family, (e) Coming to know that wondering is part of thinking about the future, and (f) Learning to take the disease day by day. Finally, four themes pertained to immediate contextual layer, with a focus on the present (Hinds et al.): (a) Knowing I need rest when I feel the fatigue, (b) Realizing that planning is important to help maintain a sense of control, (c) Making decisions about telling others who are not in my RRMS world, and (d) Knowing the importance of listening to my body.

Metacontext

Realizing that Living with RRMS Involves Uncertainty

As Ms. C reflected on the time of her initial diagnosis, she identified uncertainty as present from the beginning. Ms. C said, “I was trying to figure things out, and I told him [speaking of her husband] something’s going on and I can’t put my finger on it.” She initially described the uncertainty associated with the RRMS diagnosis as living in a gray world. It was not a black and white world but filled with patches of gray. She said, “There is always going to be those questions. I’d rather live in a black and white world. Unfortunately, you have that little gray area, and I have trouble with that. I don’t like gray. I want it one way or the other.” She continued, “I still question. I just still wonder. It’s always there.” Each woman described the realization that living with RRMS involved uncertainty. Ms. J described the uncertainty as “the what-ifs.” She said, “I think that is the hardest thing, the what-ifs, or what could tomorrow bring.” Ms. M expressed the same thought when she said, “I wonder, what if something else happens? And I’m feeling fine now. It’s so unpredictable.”

Fear related to the unknown was also associated with uncertainty. Ms. T described fear as something that accompanies new symptoms or returning old symptoms. As she

described an exacerbation, she said, “It started going down my arms. And I lost feeling in my hands, and my fingers, although they didn’t curl up into little claws, they felt as though they must have been. I couldn’t put on rubber gloves. When I went to put on rubber gloves, they felt like my kids when they were two and three, when you put gloves on them for the first time. Some fingers went in one hole, and some fingers went in the other hole and a couple of them together, then one folded over. I’m like, ‘This is bad. I can’t even put on gloves.’” She said, “This was my hands, and my hands are my livelihood. So, it was kind of tough!” She continued, “It could be my ability to walk; it could be one side of my body or the other, I just don’t know what the MS might bring. That’s the weird part about it.” Ms. H continued this theme by saying, “You don’t know with MS. You don’t know in three years what will happen. It was just the fear of the unknown.” She used an analogy “I’m just here like a loose tooth, not knowing.”

Uncertainty related to understanding the symptoms of the disease was identified as a challenge for Ms. C. She said, “Yet you wonder, is this a flare up? Do I really know that it’s flaring up or is this something old? That’s kind of a hard thing to tell to make the difference.” For Ms. L the uncertainty was the worst part. She said, “I mean that’s the worst part. It’s not knowing what’s wrong.”

Discovering That RRMS is Frustrating

Frustration becomes a part of the RRMS experience. Ms. C stated that, “It’s frustrating because you don’t know what will happen and scary for down the road and how everybody else is going to deal with it.” When young adults have to make changes that affect their life resulting from the RRMS diagnosis they describe the experience as frustrating. Ms. C said, “Change on a personal level means frustration.” Speaking of

changes when she had to quit her job due to continued symptoms, Ms. J replied, “Frustrating, very, very, frustrating.” Ms. C related, “When you have those bad days, and you can’t do that and you have to give that up, it’s frustrating. It’s frustrating because it’s something you don’t want to have to do.” Even simple pleasures in life can become frustrating when RRMS is a part of the story being told. Ms. J was excited about taking her two-year-old to the zoo. She said, “This trip with my daughter, going to the zoo, I want to walk around with her. I want to do what I would normally do, but I can’t. I have to go in a wheelchair, and that frustrates me.”

Sometimes the frustration becomes overwhelming. It is at those times that Ms. C says, “I have no choice. I’ve compared it at times when I’ve been upset and frustrated. There are days that I’ve said, ‘I wish it was cancer.’”

Coming to Know That RRMS Can Be Scary

Changes that seem taken in stride by many young adults become scary for those diagnosed with RRMS. As a nurse, when first diagnosed, Ms. T said, “I felt that feeling, that fear of, ‘Oh, my gosh.’ I’m going to be, the patient in the bed with MS, and they were kind of scary.” Before the actual diagnosis, Ms. C said that she felt her life was about to change. She said, “It was scary, but you have to know what’s going on.” She also dreaded the injections associated with her medicine and said, “They’re scary.” However, Ms. C expressed the same thought about not being able to take the injections, in the event she would lose her insurance. “It is scary. It’s very scary.”

Ms. H was facing an exciting future as a teacher after making minimum wage as a para-professional for several years. However, she said, “And with having change, I know I’ll have to go to another school, and it’s the fear. This school spoils me, and to know that

I will be driving by myself; that's another thing that scares me. I mean, I'm just a big scarty cat now. I'm nervous about it, and it's just a fear of the unknown." Even the children of young adults with RRMS are not immune to the scary feeling. Ms. C shared a story of her daughter visiting the neurologist because she wanted to know if she could get MS. Ms. C said, "When you're seven years old, that's scary."

Discovering That RRMS Is In the Backdrop of My Life

Four of the women explained how they discovered that RRMS is a backdrop in their life. Ms. L said, "It's always there. You just, you go and you do and you look out for things, but you can't let it rule." Ms. H chose to ". . . keep it in the background rather than bringing it to the forefront." She used the analogy of her wheelchair and said, "It's like my two little tires in the back, way back. These [points to large front tires] big tires, these you can almost consider my life. I depend on these. These are my drive tires. These are the ones that I see. These little bitty ones [the back tires], I forget all about them. I really do! I know that people see those and so these are the ones that we deal with."

When discovering that RRMS is the backdrop of life, Ms. T said, "With the MS, there are times when it's JUST not even on the radar. . . . And then there are other times when you know it's at the forefront and suddenly you're struggling to function or to keep things." Ms. C said that when symptoms occur that remind her of the RRMS, she thinks, "It's just rearing its ugly head to say, 'Hello, I'm here,' and 'I'm just going to deal with it.' A lot of times I tend to just live without . . . It's not something you think about constantly. It's there, and you're aware, but you just do whatever it is you have to do."

General Context

Seeing Life through a New Lens

Individuals respond to life changes in many ways. These young women expressed seeing life through a new lens after life changes related to RRMS. Ms. H said, “Would I rather be walking? No. I fell too much. I’d rather be in my chair. If they told me they’d found a cure, or they could make me walk tomorrow, I’d rather be in my chair.” She continued to say, “You know my sister called me and said, ‘You’re not disabled, you’re differently ‘abled.’” When talking about what the diagnosis meant for life, Ms. L said, “It meant not to live everyday as a sick person. It meant to get up and thank the good Lord for every day I have when I get out of bed.” In a follow-up interview, she said, “The good Lord’s giving you another day when you’ve gotten up and gotten out of bed.”

The participants pointed out that they were aware of “the small things in life” and were not taking those things for granted. For instance, Ms. L said, “You know, just little stuff. It’s just or seeing people that are worse off than you. I’m still functioning, and I am very blessed to be as well as I am. I have a limp sometimes or I’m tired sometimes but I’m still home and I’m still able to do.” Ms. J said, “I haven’t given up on any of my dreams and I haven’t given up on the hope of someday having another child. The hope of some day being able to get up and play with my kids, teach her how to play soccer or something like that, but for right now I can’t and I understand that.”

Wanting to Know More about RRMS While Not Wanting to Know Too Much

Each woman identified a period after the RRMS diagnosis when she wanted to know more and searched for more information about the illness. At the same time, they

were concerned about knowing too much. The two participants who were nurses were surprised about how little they knew about RRMS, although they had practiced for years.

Ms. C wanted to know what she was dealing with prior to the actual diagnosis. She said, “I’m either going to know what I’m dealing with, or I am going to be so thankful that’s not it.” As she strived to learn more, she said, “I mean, I knew enough, but yet I still didn’t.” She felt the information was difficult to find. “There are a lot of people with it, but at the same time they don’t really put it out there.” Ms. H said, “I wanted to know what I’m up against, because you don’t put a boxer in the ring when he don’t know how to box. I’ve gotta know answers.” Ms. M said, “I mean being a nurse, I kind of had the inner edge on it. Then I realized I certainly didn’t know squat about it.” She said, “I got on the Internet and looked up a bunch of stuff. I haven’t read a whole lot. It says it’s [MS] not really that hereditary, so I just think about that.” Ms. L said, “I didn’t really know a lot. I didn’t go home and get on the internet and drive myself crazy over it by any means.” She continued and said, “I feel that if I know too much, I mean, I need to know what I need to know. But I’ve got to find the positive in it, too. If I just read about every patient and everything they have, it’s too much.”

Learning When to Ask For Help and How to Let Things Go

Young adults with RRMS have many changes after the diagnosis. One change is realizing that they may not be able to do everything independently. Ms. T said, “You can’t do it by yourself. I’ve learned that.” Ms. J said, “You have to adapt to what you can do now and what you can’t do, and if you need help, you have to ask for it. I never used to ask for help.” Ms. J said, “When there are days when I can’t get out of bed, my mom will have to come pick up my daughter, because I just hurt so bad.” Family helpers

included the very youngest members. Ms. J, who has a two-year-old, said: “I can change her diaper, I can get her dressed, we take baths in the evenings, brush her teeth, comb her hair. Last night, she was rubbing my shoulder, she goes, ‘Feel good, Mom’? Then she goes, ‘Well, then, rub my back.’ So it’s just kind of a pull-give kind of thing.” Several women had learned to let things go until they had more energy or time. Ms. L said, “Before [the diagnosis] I was a total neat-freak. If one thing was out of line, I had to pick that up right away. Now, I’m just kind of laid back.”

Specific Context

Learning to Move Past the Moment of the Diagnosis

The women described their initial shock about the RRMS diagnosis. Ms. H said, “I had to get past that to even begin to think, I mean what’s next, what do I do if.” Ms. C describes the moment as, “You’re just ‘kinda’ out on this little cloud and there’s just no end. It’s just kind of an up and down. It’s definitely an up and down. I guess the getting on point was when I was diagnosed and it’s still just going and going.” Ms. M said initially she thought, “Well, am I going to be able to work? I need to be able to work. I don’t want to end up in a wheelchair and be disabled, and I can’t take care of my kids. I expected the doctor to be able to prescribe something or do something that would take care of it, and then I’d be done with it. I’d be on my way. Instead I’m with something that’s lifelong.” Ms. L described learning to move past the moment of being diagnosed with RRMS. “I would say, just like going down a road or going in a direction. That would be a good comparison. Just going and dealing with what comes up, the hills and the valleys. You just jump in and do it. Let’s deal with it and go through each step.”

Choosing Who to Include In My RRMS World

Choosing who to include in the world of RRMS became a big decision. Each woman made decisions about who to include in the RRMS world that was smaller and different from her social world. Ms. T said, “It’s not something that I am wearing on my sleeve. I’m not just out there with it. I’m willing to talk about it with a select few people. There are NOT a lot of people that know that I’m really comfortable sharing the diagnosis that I bring into it. I work pretty hard to not show any outward signs of anything.” Ms. C said, “I just don’t discuss it all the time.” Ms. L said, “Very few people knew. It’s probably out more than what it was in the beginning. I mean, my family knows. Some very good friends know.” Ms. T said, “I’ve also observed other people with the diagnosis be a lot more open with it. I’ve not really seen a real positive response to that so maybe, through that, I’ve decided to take the other path.” Ms. M had received an MRI result at work; a nurse with whom she worked said, ““What does that mean? Does that mean you’re going to be in a wheelchair?”” Ms. M looked sad as she said, “I think about that. She doesn’t know much about it, and she’s a nurse. That’s how most people are. I mean, they don’t know anything about it.”

The participants found it very difficult to know who to tell and continued to ponder the reactions of persons they told. Ms. J said, “I really do want them to know what I have [rather] than to sit there and stare and wonder. It hurts being so young and walking into a store and having to use a wheelchair and everything. And then you got people saying, ‘Why are you using a wheelchair?’” Even women who were more open about the diagnosis had stipulations. Ms. C said, “I don’t have a problem talking with anyone but,

my thing is, don't come to me for a pity-party either. I mean, you can have your 15 minutes of cry time, but get over it, because life goes on. Thank God: I've got my kids."

Although most examples of letting people in to the RRMS world pertained to friends, colleagues at work, or strangers, some women continued to struggle with the degree to which they should open up to significant others about their day-to-day experiences with RRMS. Ms. T said, "If my husband will ask, 'how are you doing today?' Sometimes that answer is easy, and other times, it is not. 'Well, today I'm kind of numb.' Or 'Today I'm kind of this or I'm kind of that.' Or, 'I don't want to talk about it today.' Sometimes that's even my response."

Deciding To Fight the Disease While Wishing the Medicine Was Not So Hard to Take

The young women described how they decided to fight the disease while wishing the medicine available for treatment was not so hard to take. Decisions related to RRMS were made in a variety of ways. One way to fight the illness is by taking daily injections. Ms. C said, "That Copaxone hurt me so bad, it was horrible. So at least the Avonex is easier. I don't have the reactions like the other ones. Oh, it was horrible, horrible." Ms. J was talking about the different medications she had taken and said, "He went ahead and moved me to Copaxone which is once a day, and it's not working hardly at all. I have my good days, and I have my bad days, but my bad days are really bad." Ms. T reflects on how she takes her medicine and said, "I mean, you have to, it takes maybe five minutes, and sometimes you just don't have five minutes!" Ms. H initially tried the injections and said, "I was on Betaseron and I had a terrible, terrible time with it, and I told him [her physician] 'I just can't do it anymore'. I had real flu like symptoms. I hurt so bad, and I told him, 'I can't do it anymore!'" She said, "You can fall down with it, or you can get up

and you can fight it.” Ms. M said, “I don’t forget my shots. I’ve purposefully not done them a few times. I kind of think about sometimes. I come up with reasons why I shouldn’t do it, because I think it might affect me the next morning or day. Then I kind of argue with myself. I think it’s more of an attitude.” Ms. L said, “I am not going to let this disease get me down. I’m going to do what I want to do, when I want to do it. You’ve got to not let it get a-hold of you and take you down. Let’s deal with the cards that I’ve been dealt and go.”

Seeing the Economic Impact of the Cost of RRMS on My Family

The economic impact of RRMS on family was a theme that was described by the young women as scary, frustrating, and even embarrassing. Ms. J said, “I got denied for my disability, and I cried. It was frustrating. They said you could still work. Even though I can’t write, I can’t type, I can’t talk well on the phone. So now, I have to go through the whole appeal and everything. It gets frustrating. Like I said, there are some bad days!”

Ms. C was concerned about what would happen in the future with her life insurance. She did not have the RRMS diagnosis when she took out the policy. “Now I am on medication. What’s that going to do? Are they going to say, ‘Well, sorry.’ We have actually qualified for the medical card, which actually bothers me to no end.” When she went to a clinic for a suspected urinary tract infection, the receptionist told her that they did not accept medical cards. Ms. C offered to pay cash and the receptionist responded, “Oh no, we can’t do that for people like you” [persons on Medicaid].

For somewhat different reasons, Ms. H was very upset about having to use Medicaid. She cried as she said, “I hate being on Medicaid. The state controls you. I feel like I live a lie. I know if I start taking this Tysabri, the state has a bigger hold on me.

That's why I've waited a month to get my medicine, because I don't want the state to do anything with me. I want the state to leave me alone. But I don't have a choice, because I can't get insurance. That's it – their regulations, the rules. Being regulated with the state is worse than having the disease. Health care reform scares me.”

Ms. T said, “I think we pretty much put ourselves on a track where right now we are a family with two incomes living on one income. We haven't been doing it necessarily for the 10 or 11 years that I've had MS. For quite a bit of it we have really been planning for the future, not necessarily planning for when the RRMS gets so bad that I can't work. I think that's what I see it as being, and I think that's what he [husband] sees it as being, although we haven't really named it.” Like other aspects of RRMS, the financial security of these families also evoked uncertainty.

Coming to Know That Wondering is Part of Thinking about the Future

When thinking about the future Ms. C said, “I'm hoping that this pain injection is doing what it's supposed to do and that the disease doesn't really go anywhere else, so that the weird stuff that I get from time to time, and just each day [does not get worse].” Ms. M said, “Well, it's back to that whole factor of crippling, the wheelchair business. I wonder if years down the road if I'm going to be able to still work and have a job and do things that I'm doing now. And I worry if my kids are going to end up having it.” Ms. J said, “It's just the fact that I don't know what I'll be in five, ten years.” Ms. J said, “We've just been doing a lot more pictures and stuff like that, 'cause' I hope there's not a day that comes that I don't remember. But worse, I want a back-up plan, just in case, so that way at least; I do have things to remember.” Ms. L added, “I think well, am I going to end up in a wheelchair? Am I going to be really bad off like some of the people I've

seen? Am I going to end up in a nursing home at a young age? That's always in the back of my mind." Ms. H summed up her thoughts about the uncertainties of the future when she said, "I look forward to that day, but I don't know."

Learning to Take the Disease Day by Day

Ms. C described learning to take the disease day by day. "You just move along, one day at a time." Ms. J was following advice from her mother, who also has RRMS. She said, "My mom tells me, 'Take one day at a time', because she's been there and done that. That's all you can do. We may have to do certain things different, your routines, but it just becomes a day-to-day thing." Ms. T expressed a similar thought. "It's just one-day-at-a-time kind of attitude. I look at it as getting through one day at a time, one moment at a time, one activity at a time. I mean it depends." Ms. H struggled with having to live day-by-day. "I don't want to have to just live day-to-day, today. I mean day-by-day is a big thing. I live in the now, in the moment." Ms. M said that through her participation in this study, she would hope to share this message with others: "Instead of trying to look at the long-run picture, just try to look at the day today." Likewise, Ms. L said, "Once I'm up in the morning and I'm going, well, we're 'gonna' face the day."

Ms. M thought initially that her RRMS would progress rapidly. "I'm learning that no, it's kind of a slow progression. I was surprised after only a year on the medicine that the MRI said I'd been worse. It's not a new disease, but there's new medicines out and new research going on. I don't know that we'll ever truly understand everything."

Immediate Context

Knowing I Need Rest When I Feel the Fatigue

For these young women with RRMS, failure to recognize that they needed rest when they were fatigued had major consequences. Ms. C said, “I do have to be careful not to over-exert, because I know what I can and can’t do. There are points that I have to say no. I won’t do it, or I have to stop. If I put in too long of a day, I’ll pay for it for three days afterward, for wearing myself out. I’ve adapted things so I know that I have to do things early on in the day before I get tired. It’s changed the way things are done in my life and the order of things being done.” Ms. J said, “I used to cook huge meals. I cooked and cleaned every day. Now I can do a load of dishes, and I have to sit down for half an hour so.” Ms. T said, “I’m pretty clear about I need to sleep or I need to rest.” Ms. M became tearful as she explained how she tried to hide her fatigue from her children. “I’ve tried to take the rest periods, and all that, but I’m just set in my ways. I don’t like to change a lot. I like to get stuff done. I still like doing it the other way.” Ms. A said, “I do have some times throughout the day, not really a certain time or a certain thing. I just can tell that I probably did a little too much yesterday or last night. But after awhile, you don’t fight against it, but go with it, and deal with it, and know your limits.”

Realizing That Planning Is Important To Help Maintain a Sense of Control

The six young women explained how important it was to them to maintain a sense of control and that to do so, planning ahead was critical. As Ms. C said, “It’s just adapting and modifying things and planning. Now I am just the ultimate planner. I plan. I have to; that’s part of life now. I need to plan and make sure things are accommodated in order to do stuff.” Ms. T said, “I think that I’m a lot more careful with the commitments I

make – the things that I agree to be involved in.” Ms. M reflected, “I’m one of those people that like to know in advance what’s going on in my routine. If it changes at the last minute, and I don’t know about it, I get very frustrated and stressed out.” Ms. L was very matter of fact and facing new challenges. “Okay, let’s put this in perspective. I think you come to realize you’re going to get tired. So [as if speaking to herself], ‘Let’s plan this out and figure it out, how you can still do what you want to do.’”

Making Decisions about Telling Others Who Are Not In My RRMS World

The participants shared the difficult decisions they faced about what to tell others who were not part of the RRMS world. Ms. C struggled about the possibility of being labeled as a person with RRMS. “You look at me: I’m healthy. I try to do just as much as anyone else. Because they don’t know, they don’t realize that I do have a disease and that I do have to be careful with not to over-exert.” Ms. C observed that other persons view her relationship with her husband as perfect. “It’s the way our lives have always been. That’s how it is, so when you know you feel like you’re losing control of things, it’s tough. It’s really tough.” Several women decided to include someone in the RRMS world right on the spot. With sadness, Ms. J described such a situation. “It’s like today; we went to Walmart. I had to use one of those little riding carts. This lady said, ‘You need to save those for people who are disabled’. I said, ‘Well I’m 27, and I have a debilitating disease. Why don’t you ask before you say something?’ They all laugh and say stuff. You see older women talking and stuff like that. I’d rather they would come up and ask me than just sit there and make fun, because it’s not my fault.”

Ms. T talked about her decision not to go to a support group for persons with RRMS. “I’m not really sure I want anybody in my hometown to walk in, to see

somebody I know that I didn't know was [diagnosed with RRMS] and that they didn't know that [she had it, too.]. I'm more open to . . . if there is someone that has a new diagnosis, and I know about it, I am willing to talk about it to them or be more open to them." She said, "I don't know how I decide who to include or when to tell people. I know that you know definitely when something's going on, that's either visible or going to affect that certain group of people." She said this about the decision to participate in the research study. "It was not an easy decision. I had seen your notices. I had seen stuff on the bulletin boards, and I think it was even something in the paper, and I thought, 'Nope. I'm not goin' there.'" Ms. H admitted to hiding symptoms at work even though she was in a wheelchair. Ms. M said she did not mind telling people, but she was uncertain about their reactions. "I don't want them to pity me or anything like that." In the beginning, Ms. L said she was much more selective about whom she included in the RRMS world. "Very few people knew in the beginning. I think that was more because I didn't want the special treatment. I didn't want a pity-party. I appreciate care and concern, but I didn't want sympathy as far as 'Oh, I'm so sorry,' I didn't want to thrive on that."

Knowing the Importance of Listening To My Body

Listening to one's body was a critical facet of the experience of living with RRMS. Ms. C said, "I don't know if you want to say 'sensitive', but you're more aware of your body as a whole. It's a new awareness of things. You become totally in tune with your body. I guess it's just like being pregnant, when you notice things, and now because these changes happen, you pay more attention." Ms. H said, "You have to start listening to your body. Especially with [RRMS], you realize: '[I] can't feel my legs'. My new

symptom is my thumb. You have to learn your body. You have to learn to listen to your body, and that's something you really can't put off. Because you put it off and you're in the hospital, and to me that's almost like a prison sentence. I hate being in the hospital. You just, you have to learn to listen to your body. Don't and you cannot ignore it, because it don't go away." Ms. L connected the importance of knowing her body with knowing how much she could do. "You're going to get down and your walk is going to start being off.' I just keep that in the back of my mind." Ms. L said that since her diagnosis, she cannot tolerate extreme temperatures. "I'm an outside person. I love to be outside, so that can be pretty difficult at times."

Findings Related to the Second Research Question

The second research question was: How do young adults make meaning of the expectations that others have of them while living with RRMS? In one sentence, the answer can be phrased like this: They were trying to understand and deal with the expectations that they believed others had of them as persons with RRMS, even as they made efforts to shape and reshape those expectations.

Findings are presented within three, nested, interactive layers (Hinds et al.). Young adults discussed how they recognized expectations others had of them and make meaning of the expectations. Two themes were related to general context, because this layer includes the ways in which individuals find meaning in events that have evolved from personal interactions (Hinds et al.). They were: (a) *Trying to stay in control and make it all right for everyone* and (b) *Knowing how other people respond to other people with RRMS*. Two themes (*Realizing that health-care providers are a strong support* and *Considering the ways in which my family supports me*) were associated with specific

context, because it can be directly influenced by others in the more recent past (Hinds et al., 1992). Finally, there were three themes related to immediate context, as evidenced by relevant aspects of the current situation (Hinds et al.). These three themes were: (a) *Wishing for an opportunity to talk to others like me*, (b) *Finding that nobody really understands what it is like*, and (c) *Finding that it takes planning to look normal*.

General Context

Trying To Stay in Control and Make It All Right for Everyone

Identifying what can be controlled to maintain a sense of normalcy for others was a strategy that helped these young women manage their disease. Ms. J said, “I am NOT a sit-down-watch-other-people-do-stuff [type of person], it drives me crazy. I’m one of those who has to get right in the middle of helping. And then watching my daughter in there with her grandma – it’s really hard for me because I can’t do what I want to do with her.” When Ms. T was initially diagnosed, she reminisced about feeling completely numb. “But I continued to do everything that I was supposed to do, as a good supervisor.” Ms. M said, “I need to be able to work to support . . . , because I’m the primary supporter of my family. And I didn’t know, as I thought, ‘I need to work full-time.’” As Ms. L reflected on the past year, she said, “I’m going to get teary-eyed. I’m sorry. My mother was really ill a couple of years ago, and I was doing a lot of running back and forth, and I just got worn down. This year, I had a vehicle catch on fire, and then four days later my grandma passed away. Then you just go through the motions. That kind of stuff really wears me down. Some things happen in life that you just don’t have any control over.” Ms. C said, “I’ve always been the one that takes care of everyone, friends, my children, whatever. I’m the rock. Like a year or so ago, even, when

my knee had gone numb, it was just very frustrating. I'm the rock. I'm the one they come to, and I was losing control." She continued, "It's what it [RRMS] does, but I think at the same time, I have to explain to my kids. And I believe, God forbid, if something did happen, that I was in some way that I couldn't do what I do, they would do it. They would, when push comes to shove, they do know enough, and they could deal with it."

Knowing How Other People Respond to Other People with RRMS

Knowing how other people respond to other people with RRMS was a frightening facet of the experience for these young adults. Several women spoke about expectations of employers or co-workers. Ms. J said, "My employer was very interesting. Once she found out [about the diagnosis], I was fired. It really hurt, as I'd worked overtime for free for them. As much as I'd done for them, for her to treat me like that, it really hurt. Why not give me a job that is less demanding? Instead, they just fired me." Ms. T said, "I think there are some people that have had somewhat lower expectations either physically or whether or not I would be able to do that. One co-worker in particular, she was being very honest, and I appreciate that. She said, 'You don't know how long you're going to work.'" Ms. T went on to talk about a supervisor. "[She] actually put on an evaluation at work, 'I need to get my health under control.' I think those were the exact words in my evaluation. I did change jobs after that. I felt that supervisor had no concept of what I was dealing or going through, so I kind of felt that was maybe not an environment that I wanted to be in." She went on to say. "There's a lot of ways that I'm vulnerable, too. Certainly my work, my career identity depends on me being able to function." Ms. H said, "They don't expect much out of me, because they know they are going to get it anyway, whether they ask for it or not. So, no, they don't ask a lot of me, but I just do it."

Ms. M said, “I think that most people expect the same amount out of young people. Whereas the older people that are diagnosed with it, I don’t think people, I don’t really want to say ‘care,’ because who knows how much longer they’ll live? But younger people, they haven’t lived all their lives.” Ms. L said, “I feel at work sometimes I don’t want them to see me getting down. I mean, I can still do this. I can. I’m okay. I can.”

Specific Context

Realizing that Health-Care Providers are a Strong Support

Even though these women viewed their health-care providers as a strong support, they made decisions about when to let them know about symptoms or other issues they were facing. Ms. C illustrated this. “If it came to the point that my leg was unbelievably weak or something weird, I know to call. But at this point, I know I can write it down and that I can make them aware. But otherwise, I’m like, ‘It’s a long –holiday week-end and we’re just not going to worry about it.’” When talking about her support system she said, “I guess you would say, Dr. H and his nurse, are really, because they’re there. I know that I could call them whenever I do need to. I really can. I can say, ‘This is what’s going on.’ And I know that they are there.” Ms. J said, “Dr. H told me, ‘Anytime you need me, call me.’ He’s always there for me if I have a question or if I have a worry, and so is Dr. S, my primary.” When talking about her neurologist, Ms. T said, “I know that he would stop me, and say, ‘You’re going down the wrong path,’ if I truly was out of line. Yes, maybe we should go back the other way or turn around. I think that he also gives me a little bit of credit for knowing some about [it]. I rely on him to be up on the latest research.” Ms. H spoke of having a teamwork relationship with her neurologist. “I’m nowhere near a neurologist, but my neurologist, we work together. We don’t work: I’m the patient, and

‘I’ll do as you say.’ We work together. We are a team.” Ms. L identified physicians to whom she could go for answers. “There’s a couple at the clinic that I know if I need to, I can go to and ask a question. If I really need something, I can get in touch with them.”

Considering the Ways in Which My Family Supports Me

Several women emphasized various ways in which their husbands were key sources of support for them. Ms. J said, “My husband, we talk about anything that I’m upset about. He helps me so much. He walks with me to help me exercise, and he knows that I can’t walk far. For me now, it’s just a normal thing. I can’t go outside unless I have him there with me. He’s never told me, ‘You might as well give up.’ He keeps telling me, ‘Just try a little more every day.’” Ms. T said, “My husband will protect me a lot of times to make sure that I get plenty of sleep. I think that’s a protective thing on his part. I can’t remember how much I really talked about my husband being kind of a stabilizing force in a lot of this and bringing me down and bringing me into a plane where I can deal with stuff. But anyway, he has certainly been a very solid person that I rely on a lot.”

Other women referred to ways in which they drew on support from their parents, as well as their husbands and children. Ms. H commented, “How many men would stand beside you and have a wife like me? How many kids would say, ‘My mom would never know and go on and do what you can.’ I have the most devoted kids.” She continued, “My family is what has kept me strong.” Ms. L said, “My husband, he’s there for me even though he’s gone on the road. He’s my rock, one of them. My mom and dad just worry about me horribly. I mean they, just every time I talk to my mom, ‘Are you okay?’ The love and the care and concern I do get from my husband and family and friends, that means the world. For somebody to say, ‘How are you doing’? And mean it.”

Ms. C described RRMS as a family process. She said, “They’re [family] just as much a part of it as I am, because they do understand how things go and what I can and can’t do. They expect me to do things as normal. And there are times when I’m like, ‘Okay, remember, Mommy does have a disease, give me a little help.’” She said that her seven-year-old was “a good little care-giver.” Ms. J considered her two-year-old a big support. She said, “My daughter is really good about helping too. She’ll grab my hand and walk with me everywhere. So it’s just whenever you have that kind of support. I mean even though little, a two-year-old can really lighten your life a lot.”

Immediate Context

Wishing for an Opportunity to Talk to Others Like Me

The participants wanted to talk to others who had experienced similar symptoms and had a similar lifestyle. Ms. C said, “I wish there were more people that you could call and talk to. I wish you could get on-line and there’s this group of people, someone to lean on, somebody that understands. I want, I think, for someone to talk to, that they are going through something similar or how they deal with something.”

Finding that Nobody Really Understands what it is Like

Ms. L was talking about chronic diseases other than RRMS when she said, “My sister-in-law, we’re pretty on the same page, because we both have chronic illnesses. But I still don’t understand what it’s like to live with what she is living with, just like she doesn’t understand. I think the person has to be in that situation to really truly understand. Everybody’s different.” She said, “I mean my husband can be understanding and caring and loving, and he can be right there for me, but he does not understand what it’s like to have MS.” Ms. C said, “My husband is my very best friend in the world, but it’s different

because he doesn't know that [what it is like to live with RRMS]. You have your close family members and your close friends, and they try to understand, but they truly don't have a clue when it comes down to it." Ms. M shared this about her husband. She said, "I think he considers me normal because he can't see a physical disability. And so I think he has trouble understanding it, still, unless I'm really complaining about something."

Finding that it Takes Planning to Look Normal

Although persons often plan to prepare for events, the young women were undertaking a planning process to look normal. Ms. C said, "This is what a person with an invisible disability looks like." Ms. T said, "I work pretty hard not to show any outward signs of anything, that I look somehow positive or negative. I don't know, because there is going to come a time when they are going to be obvious symptoms or obvious things that people are going to see and wonder, 'What's up with that?'" Ms. H said, "You have to live such a secret, double-life, and that's not me. I'm not a liar. I'm not." Ms. M said, "I think I do compensate. My body compensates for it sometimes, and so I may not display a lot."

Findings Related to the Third Research Question

The third research question of this study was: How do young adults learn new ways of being during periods of exacerbations? In one sentence, the answer can be characterized in this way. Through contemplation of their lives and conversations with selected others in the RRMS world, they were learning new ways of being, not only during exacerbations of RRMS, but during their daily lives with RRMS.

Findings are related in this section. Of the five themes, two themes relate to metacontext, because they were viewed as having an indirect influence on the young

adult's behavior (Hinds et al.). Those themes are: *reliving what it was like to have the initial symptoms* and *deciding where you fit in a world that wants perfect people*.

Rationalizing my way into an understanding of how I ended up with RRMS was viewed as a general theme, because it captured context that could change over time (Hinds et al.).

The theme relating to specific context (the influence of personal factors) (Hinds et al.), was *seeing the importance of charting my own course*. Finally, one theme, *redefining who I am*, pertained to the present, exemplifying immediate context.

Metacontext

Reliving What it Was Like to Have the Initial Symptoms

The participants continued to find it difficult to relive what it was like to have the initial symptoms of RRMS. Ms. C recalled, "Then I got labeled with MS and that was difficult. It did change our world to a point, because you don't know what to expect down the road. I immediately thought 'wheelchair' when diagnosed." Ms. J said, "When I was first diagnosed, I thought my life was over. I really did, because I didn't think I was going to get better. I didn't know, you're 17, you think, 'woe is me.' But now I'm older, I see it as it's just a little bump in a long life." She said, "I had a little bit of weakness in my legs during a week. Then I woke up one morning and I couldn't walk, couldn't talk. My left foot drags really bad, and that's when I thought something was kind of wrong."

Ms. T said, "I started noticing that I was numb on one side and it was just numb up to my knee, and then I was numb up to my hip. I'm thinking, 'Oh, that must be sciatica, that must be a disc, or something that's just in my leg. It's just that. It's in my hip. It'll be fine.'" Ms. H reflected, "I remember lying on the floor. I was on my side. and the next thing I knew – Thunk [lifts leg to let it fall]. I thought, 'What's going on?' I

would trip over my toes.” Ms. M said, “I didn’t have any clue that it was ‘gonna’ be MS. I thought it was like a pinched nerve in my back.” As she thought about the diagnosis period, she said, “Oh, that diagnosis can’t be right. I’m fine! How can that be what’s going on?”” Ms. L said, “For a couple of weeks I had this in my eye, like if you look into a light bulb and your eye gets that fuzziness to it. I had that for a few weeks, and it just gradually got worse. I really thought it was just a sinus thing.”

Deciding Where You Fit in a World That Wants Perfect People

Ms. J used an electric wheelchair to do her shopping. She had to deal with perceptions of others who expected her, as a young person, to look healthy. “It’s really embarrassing for me. It’s even embarrassing to go get on one; that’s not me. Your heart just falls into your gut. You walk in. You see people staring at you. You ‘want to turn around and walk out, but you can’t, because you’ve got to do grocery shopping.’ It hurts. When this first started, I would cry all the way through Walmart, just cry, because you got people pointing and smirking and saying stuff to you, and it’s not your fault.” She said, “There’s frustration every day, when you call somebody and say, ‘Hey, you want to come over?’ It’s heartbreaking when they say, ‘No, I’ve got something else to do.’”

When Ms. T went to an educational seminar, “I looked around the room and saw these people that obviously had disabilities; I didn’t feel a part of that. I wasn’t ready to say, ‘I’m going to join that group.’ I’m not ready.” When Ms. H was hospitalized during an exacerbation, commercials about losing bladder control played continually on the television. She thought, “That could be me! That’s when I’m like, possibly a 40-year-old stuck in an 80-year-old body.” Ms. C often referred to her body as “broke.” Ms. M said, “I even had my mother-in-law make the comment, ‘We’ll make sure that you get in and

out of the boat okay,' pretty much diagnosing me as going to be wheelchair-bound." Ms. T said, "I know my father-in-law initially didn't know what to think of the diagnosis, if that meant I was going to be crippled in a wheelchair in a month, or a year, or ten. I don't know he really understood." She was hurt by a remark he made to one of her employees. "He told her that he just didn't know how long that I would be able to continue working."

Ms. H, who was in a wheelchair, said, "I think of me as a whole chair, me with the chair. I'm always like, 'Guys, I'm 400 pounds, and you don't want to mess with me!' [She weighs about 120 pounds; the wheelchair weighs 280 pounds]. I am very protective of it. We went to Silver Dollar City, and I wanted to ride the train. My husband said, 'We can leave your chair.' I said, 'Oh no, the chair don't go. I don't go.' I was able to ride in my chair. The chair, I am almost like a kid with a teddy bear. It's my security." She was getting new tires for it. "I'm going to get my tires! I'm so excited! It's almost like getting a new set of shoes." Some persons with RRMS are apprehensive about losing mobility, but Ms. H had embraced this change and made the wheelchair part of her identity.

General Context: Rationalizing My Way into Understanding How I Ended up with RRMS

The young women related various ideas they had created to understand how they came to have RRMS. Ms. C said, "Of course, you have to bring God into the whole thing, because, that's not fair [teary]. It's not fair. It's not fair to my kids. They're wonderful. Why is it us? Why isn't it someone else? What did we do? We're not supposed to question." Ms. J said, "You have to get your mind off of the 'what-ifs', the 'why me.' There are times I think, 'Why me?' Why did this have to happen to me?' I used to be so, I played volleyball, I played basketball, I played sports. I can't do that anymore. I know that there are things that I can do. So, I just don't live in that place as bad as I used to."

Several women explained their initial questions about how they “got” RRMS. Ms. H said, “I’m so analytical. I’m like, ‘Well, how did I get it?’ I wanted to know, and they said they don’t know. I was like, ‘Why can’t you tell me?’ I didn’t understand where it came from. I was thinking, ‘Is this like the flu? Can I give this to my husband?’” Ms. T thought her mother felt guilty about the diagnosis. “She was really [doing] a lot of self-blame. Every time she looked at me, every time I did something that wasn’t my normal coordination, she would see it. You could just see the tenseness in her shoulders and in her face. I think she blames herself somehow. I don’t really know why, but for something we were exposed to as kids, for something that she could have protected me from. I got too much sunshine, or I swam in the river. I don’t really know that anybody knows if there’s any relation to anything you do in childhood that has a trigger for MS.”

Specific Context: Seeing the Importance of Charting My Own Course

The six young women emphasized how important it was to them to chart their own course as persons with RRMS. Ms. C said, “Everybody’s got to find their own way of doing stuff.” Ms. J said, “I’m not going to quit doing my life for an illness. I may catch the flu easier than half the population; I don’t care. I still want to live my life and have fun. I don’t want to stay here in my bedroom or in a house with all the doors shut. It’s just not me. I made the decision a long time ago that I wasn’t going to do that, no matter how bad it got. You’ve got to do it your own way. You’ve got to make your own plan.” Ms. T said, “I want to be in the driver’s seat. I mean, it’s my body.”

Immediate Context: Redefining Who I Am

Identity is an important concept for young adults. To redefine oneself without losing the essence of one's being is difficult. Ms. C said, "My body's not perfect as it should be. It's not perfect. There are obviously broken pieces that we can't fix currently. If it was broke[n] on your car, whatever, you could fix it." Ms. J shared, "We were avid campers, fishermen, riding horses. Now, I can't even get up on a horse. I don't go to dance clubs. I just can't. Me and my husband, we used to play pool every Saturday. Friday, Saturday nights we used to go and just hang out with our friends. But now, I'm usually in bed by 10:00 or so. It's just the fact that your old norm is not your new norm anymore." Ms. H referred to herself obliquely as a person who has a handicap. "I don't get to many people's houses, because they are not all handicapped-accessible."

Ms. T was redefining herself as a practicing nurse. She gave a very interesting example of how she had done this, redefining herself from a nurse who could use any pen available to one who needed to use a particular pen that worked for her. "It's choosing the right tools. As a nurse, nurses are kind of into pens and things, but I have pens with the gripper. It's not a big fat chubby pen; it's not a real skinny pen. It has to be my pen. I don't want to use your pen, because it slips in my hand. So I choose to have my pen."

CHAPTER FIVE

CONTRIBUTIONS, SIGNIFICANCE, AND LIMITATIONS

I have presented the framework, method, and findings of an interpretive phenomenological study of young adults living with relapsing-remitting multiple sclerosis (RRMS). The purposes of this final chapter are to address the contributions to the literature pertaining to young adults living with RRMS, to consider the significance of the study to nursing science and to public policy, and to explain limitations of the study.

The primary focus of this study was to interpret the meaning of the experience of living with RRMS for young adults within contextual layers of that experience. This will be a basis for proposing education and support for young adults after receiving a diagnosis of RRMS. “A lack of context in research becomes a threat to the accurate interpretation and application of findings” (Hinds et al., p. 62). To show the nature of the knowledge developed, contextual layers of the experience were shown in Chapter Four. Context will also become a source of data to aid in understanding as themes are compared to relevant literature (Hinds et al.).

Understanding the Meaning of the Young Adult’s Experience of Living with RRMS

This section has two parts. In the synopsis of the study, the results pertaining to the primary research questions and the three subsidiary research questions are reviewed; in answer to those questions, the themes most pertinent to each research question are summarized. In the second part, themes are presented and compared to literature. Finally, implications for research, rehabilitation, and public policy are discussed.

A Synopsis of the Study

Because limited attention had been given to the young adults' experience of living with RRMS, the purpose of this phenomenological study was to explore and interpret that experience. The primary research question was: "What is the meaning of the experience of living with RRMS for the young adult?" During interviews with six young adults living with RRMS, pertinent data were gathered. A phenomenological method, based on the Heideggerian approach (Heidegger, 1996) was used as a guide to interpret how young adults with RRMS make sense of being in their world. The goal of the analysis was to uncover meaning in data (Miles & Huberman, 1994).

Themes Compared to Relevant Literature

Having presented findings in the last chapter, I turn to comparing the themes to relevant literature pertaining to the experience of young adults living with RRMS. In the second chapter, I used the work of Hinds et al. as the organizing framework for analysis of selected literature, in part because it was consistent in several ways with the philosophy of Heidegger (1993). "Time is the allotment of presencing for what presences in each case" (Heidegger, 1993, p. 104). Context was conceptualized by Hinds et al (1992) as layers distinguished by: "(a) the extent to which meaning is shared, (b) the dominant time focus, and (c) the speed with which change within the layer can occur and be perceived" (p. 65). The themes presented in contextual layers in Chapter Four will now be compared to relevant literature.

Overview: Discussion Related to the First Research Question

The first research question was: For young adults, what is the meaning of changes that might have occurred since the RRMS diagnosis? Few researchers have addressed this

question in prior research with the population of young adults. The findings from the 20 themes related to this question will be discussed in this section. Answers to the first research question are rich in meaning, adding depth and understanding to previous knowledge. The broad scope of data pertaining to this question indicates the relevance of data for other young adults with RRMS, health-care providers, and the public.

Metacontext Themes from the First Research Question

Realizing that Living with RRMS Involves Uncertainty

Living with certainty and predictability has been reported as having significant value in Western culture (McNulty, Livneh, & Wilson, 2004). The young adults in this study were *realizing that living with RRMS involves uncertainty*, and they identified this uncertainty (“that little gray area”) as one of the worst aspects of the illness. Concerns about uncertainty have emerged for persons with MS in studies stemming from various research traditions. For instance, in a study involving 50 persons with MS there was a significant correlation between perceived uncertainty and lower levels of psychosocial adjustment (McNulty et al.). “The uncertain illness trajectory in MS may compromise the individual’s coping resources and ultimately the capacity to adjust successfully to the condition” (McNulty et al., p. 96). Furthermore, in a study with 78 persons (55 women and 23 men) with MS, Mullins et al. found an association between higher levels of perceived uncertainty and increased psychological distress. Likewise, the theme of uncertainty has arisen in qualitative studies with persons with MS. Boeije and Janssens (2004) emphasized the uncertainty for persons with MS due to prognostic risk of wheelchair dependence. In a phenomenological study with 10 persons, Miller (1997) noted that participants found MS to be “so unpredictable that they did not know what

their level of function would be when they woke up” (p. 299). Furthermore, women with MS have expressed concerns about the implications of discontinuing medications (Prunty, Sharpe, Butow, & Fulcher, 2008).

Thus, findings of this work are generally consistent with prior literature relative to the preeminence of uncertainty in the lives of persons with RRMS. However, the findings extend understanding about uncertainty in particular and important ways. One of the most important ways that this study contributed to understanding uncertainty created by RRMS is by capturing the meaning of uncertainty for a young adult. For the six young women, uncertainty began with RRMS symptoms prior to the diagnosis. The uncertainty they expressed related primarily to symptoms. Their stories were riveting. One young adult shared that when first diagnosed her vision was affected. She initially thought she had a sinus infection and then thought it must be related to her stress in her life. She described the waxing and waning of the symptom and then it gradually began to get worse. She feared a brain tumor; she considered the worst possible scenarios, as she saw several health-care providers over a course of several weeks before an optometrist suggested that the cause might be MS.

Stuifbergen, Becker, Blozis, and Beal (2008) described development of an Acceptance of Chronic Health Conditions Scale, with “acceptance being defined in terms of the lived experience of those with chronic illness” (p. 111). When testing the scale they found that those individuals who had a higher level of acceptance regarding their illness believed the disease had less of an impact on their life.

When the diagnosis is made, if young adults had a clearer understanding of the underlying reason they experience various symptoms, they would have the opportunity to

make sense of the source of the uncertainty leading to a higher level of understanding and acceptance. Additionally, knowledge gained from this study included the desire to have projections for the future. Currently, there is no way to outline a trajectory based on clinical presentation. However, this should be kept in mind as a need young adults have expressed when diagnosed with RRMS.

Discovering that RRMS is Frustrating

Young adults with RRMS in this study expressed frustration when they were outside, such as difficulty walking in the grass without tripping. One young adult expressed frustration about playing with her child. She had found that her child would run away when they were outside because she knew her mother could not chase her. This was frustrating for the mother to have to catch the child. Another participant expressed frustration about the things necessary to manage the disease such as taking injections, scheduling MRI's, working with insurance forms, and making frequent doctor visits.

Frustration related to RRMS has been identified in earlier studies related to symptoms experienced with the disease (Pakenham, 2001). Development of a measure to evaluate how individuals cope with MS led to the finding that 44% of the 414 participants identified emotional problems such as anger and frustration as their main MS-related problem (Pakenham, 2001). Results of a quantitative study involving 1,882 patients identified that the majority of patients with MS have genitourinary (GU) symptoms. Whereas the GU symptoms are typically not life threatening, they often cause a great deal of frustration (Litwiller, Frohman, & Zimmern, 1999). Whereas most studies about MS pertain to frustrations associated with physical symptoms, some scholars have addressed frustrations pertaining to social concerns. Holland and Madonna (2005)

observed that for persons with MS, “The energy required to maintain a social network despite increasing disability can be daunting” (p. 18).

Whereas those studies each addressed frustration that individuals with MS experience, the studies were not specific to RRMS. The current study included only participants diagnosed with RRMS. The frustration experienced by participants related to change, loss of employment, and loss of mobility. Indeed, they identified change as the major source of frustration, not only for themselves, but also for their families. The disease led to many changes in the management of routine life events, including frequency of planned outings with friends. One distinguishing characteristic of RRMS is its changing nature (Holland & Madonna, 2005). Thus, it is important to clarify types of frustrations that affect persons with different types of MS, rather than assuming that persons with all types of MS experience similar frustrations.

Coming to Know that RRMS Can Be Scary

This work is consistent with the finding of an earlier qualitative study that RRMS can be scary. In contrast to the focus on fear in prior literature about MS, findings of this study shed new light on experiences of persons with RRMS. I suggest that the phenomenon of *coming to know that RRMS can be scary* is different from the state of being fearful. That phenomenon is an existential experience. The young women in this study did not focus on a specific thing about which they were afraid. Instead, they expressed a troubling emotional state associated with situations they had experienced due to the RRMS. They also viewed situations that their children had experienced, relative to their own diagnosis of RRMS, as “scary.”

A general theme of fear emerged in a focus group study with 13 persons who had MS (Malcomson, Lowe-Strong, & Dunwood, 2008, p. 664). The six persons who had the RRMS type of MS did not “elaborate on their feelings regarding their ability to cope” (Malcomson et al., p. 664). Fears were centered on relapses, work, and progression of MS (Malcomson et al.).

Discovering that RRMS Is In the Backdrop of My Life

In a qualitative study with 27 women, of whom 22 were older than 40 years of age, including persons with RRMS and progressive forms of MS, Reynolds and Prior (2003) concluded that participants were placing fatigue in the background of life to increase quality of life. In contrast, data shared by the young women in this study suggested that the backdrop of life should be viewed much more broadly than in terms of fatigue. The participants viewed the entire scope of RRMS as the curtain or backdrop of their lives. It was there. Sometimes they were more aware of it. Although the level of conscious awareness of the RRMS varied, it became part of the landscape of their lives. They spoke of sometimes forgetting they have MS and then something happens to remind them. For example, one young woman was sharing a story of watching television with her family and the dialog included a person with MS. She said as she was engrossed in the documentary she realized that she too had MS. It was as if she had forgotten that she lived with the disease herself.

This is an important and complex finding related to how young adults incorporate RRMS into their lives without letting it consume their identity. Each of the young women explained, in her own way, that she was not allowing the RRMS to rule her life. Instead, she was placing it in background and dealing with the issues related to RRMS only as

needed. This permitted the young adult women to carry out activities typically associated with young adulthood, such as child rearing, building careers, and maintaining family relationships (Levinson, 1996). Yet, they were cognizant of the importance of doing their best to keep the disease under control by taking medications and resting.

General Context Themes from the First Research Question

Seeing Life through a New Lens

Literature has not reported this theme for young adults diagnosed with RRMS. For participants in this study, *seeing life through a new lens* involved viewing the world differently than persons who did not have RRMS. For instance, they did not take things for granted such as being able to walk when they arose in the morning. One individual who has a wheelchair to assist with mobility says she is thankful for her chair because it prevents her from falling. This is a different view from many individuals. This idea might be unique to persons in the young adult age group who have been diagnosed with RRMS. The ability to see life from a different perspective requires critical thinking about life circumstances. RRMS requires young adults to reevaluate ways of viewing life. One young person spoke of her work environment and an accommodation of having her own bathroom in a public school. She was extremely thankful that she did not have to share facilities with others because it took her so much longer to transfer from her chair to the stool that she did not want to be an inconvenience to others waiting. She defined this as a way in which the administration treated her well and a reason why she would never want to leave the school as an employee. This is an additional way that young adults with RRMS *see life through a different lens*. They look for different things from their

employers, they find joy in being able to walk, and they reported recognizing what is important in life.

Wanting to Know More about RRMS While Not Wanting to Know Too Much

Few studies on patient knowledge of MS are available. Having found only two studies that revealed information on knowledge of MS patients about the disease, Giordano et al. (2010) sought to develop and validate a MS Knowledge Questionnaire (MSKQ), a self-appraisal for use upon initial diagnosis. Of the 156 persons with MS involved in instrument development studies, more than 90% had RRMS. The researchers assumed that the person with longest duration of MS would be the most knowledgeable about it. However, they found an inverse association between knowledge and duration of the disease. No explanation was given for the finding (Giordano et al.).

Johnson (2003) learned about the importance of knowledge about MS for persons newly diagnosed with the disease. In a qualitative study with 24 participants (aged 37 to 67 years, $M = 50.6$ years), a participant spoke of finding out information by accident. Another expressed frustration at the lack of knowledge displayed by health professionals. Additional information about MS at the time of diagnosis and for years thereafter was recognized as a need (Johnson). In a focus group study involving 28 persons with MS, Solari et al. explored the types of information that were most useful, rather than identifying problems related to knowledge deficiencies. Participants explained that during the period of the initial diagnosis, they preferred simple, direct language, followed thereafter with additional information. Solari et al. concluded that, "Information given should be tailored to the situation and needs of the individual" (p. 766).

Whereas findings of the current study are consistent with the literature, there is one important, new finding from this study. That revolves around the idea of young adults wanting to learn at their own pace. These young women emphasized that they want the information available to them on-demand, rather than at a scheduled time in a scheduled place. They asked for information to be “put out there” for their use. They could then decide how much information was enough to have at a given point in time; this speaks to their need to control this particular facet of their experience.

Learning When to Ask for Help and How to Let Things Go

In a quantitative study, Lode et al. (2009) compared coping in 86 patients recently diagnosed with MS to 93 healthy controls. The persons with MS employed fewer problem-focused strategies while utilizing a passive coping style. Rolland (1987) provided a conceptual framework that included the family life cycle as it was affected by chronic illness. He identified periods associated with the illness, one of which was the transition of recognizing the changes necessary in “living with chronic illness” (p. 208). Although that study was not disease-specific, the examples did include patients with MS.

In a descriptive study with 38 participants, Isaksson and Ahlstrom (2008) found that some participants had particular trouble asking for help. It was difficult to maintain their personal integrity when they had to explain why they needed help. They had to offer such explanations because in most cases, they did not talk about the disease with the family. Some participants said that their children did not know about the disease issues.

In contrast to these prior findings, participants in my study were actively engaged in problem recognition and problem solving. They recognized the importance of communicating with family members about the disease. Although they struggled with

that in some cases, the member affected with RRMS had to begin *learning when to ask for help and how to let things go*. By talking to family members about their situations, the six young women had experienced that it was not only necessary to ask for help but possible to do so. They sought and accepted involvement of other family members, working together to take a collaborative approach to managing the illness.

Specific Context Themes from the First Research Question

Learning to Move Past the Moment of the Diagnosis

In a four-year longitudinal study with 45 persons after diagnosis with MS, the greatest emotional impact occurred upon diagnosis and waned over the course of the disease (Hopman, Coo, Brunet, Edgar, & Singer, 2000). After monitoring the trajectory of MS with 101 persons, Janssens et al. (2004) suggested that anxiety of young adults upon diagnosis could be reduced by emphasizing the low probability of becoming wheelchair-dependent within the short term. In a phenomenological study with 20 middle-aged persons with RRMS, Miller and Jezewski (2006) studied experiences with glatiramer acetate treatment. The adjustment process that followed diagnosis was very complex. Part of ensuring a healthy future is learning to move past the moment of the diagnosis and make decisions about how to live a full productive life with RRMS. This decision may involve life-long medications. Johnson (2003) observed that perceptions formed at the time of initial diagnosis could have a lasting impact on coping.

With one exception, findings of this study are consistent with the prior literature. The key contribution of this study is the idea that *learning to move past the moment of the diagnosis* involves more than an emotional feeling at the time of diagnosis, more than decreasing anxiety, and more than learning about medications. For young adults, *learning*

to move past means making the RRMS a part of the future, making it a life journey, and learning to take the moments as they come. The young adults in this study describe how initially they think they are going to die, or they think they will be in a nursing home quickly needing total care. They find after a brief interlude that the disease progresses slowly and they incorporate the changes into their daily lives.

Choosing Who to Include In My RRMS World

For the participants in this study, it was a challenge to choose whom to include in the RRMS world. The RRMS world was a smaller, personal world created by young adults in this study to separate the disease from their social life. Generally, only close family and close friends were initially included in this RRMS world. They did not always choose to tell their employers. The process was highly selective and they reported testing people to get a sense if they could be trusted. They tested individuals by mentioning the disease state to get a reaction. From the type of reaction they observed, they would make further decisions about what to disclose. For young adults with RRMS, this is a very meaningful finding.

Boyd and MacMillan (2005) used a phenomenological approach to learn more about the experience of 12 children and adolescents (aged 7 – 18 years) living with MS. One theme that emerged was “disclosing the diagnosis” (p. 338). Young people in the study (Boyd & MacMillan) were very selective about to whom they would disclose their diagnosis. A motive identified by Grytten and Maseide (2005) for concealing the disease was to prevent being discredited or deprived of dignity. Concealing MS at work is “an instrumental strategy to maintain work and income” (p. 237).

Phillips and Stuijbergen (2006a) conducted a longitudinal quantitative study to examine “predictors of continued employment among persons with multiple sclerosis (p. 35). Their findings included “years of education, functional limitations related to MS, and health-promoting behaviors were factors contributing to 10.2% of the variance in employment over time” (p. 35). Functional limitations included ambulation, vision, bowel, bladder, and cognition. Participants in the current study identified masking their symptoms to prevent others in the workplace from recognizing they were having an exacerbation. They reported pretending they were reading when they stumbled or testing themselves to see if they were as ‘sharp’ mentally as they expected themselves to be.

Whereas findings of this work are generally consistent with prior literature relative to choosing whom to tell about RRMS, the findings extend understanding in additional ways surrounding the creation of a smaller RRMS world that includes only individuals deemed trustworthy of personal information related to RRMS.

Deciding to Fight the Disease While Wishing the Medicine Was Not So Hard to Take

Medications available for the treatment of MS are taken to alter the course of the disease, not as curative agents (Nortvedt, Riise, Myhr, Nyland, & Hanestad, 1999b; Schapiro, 2009). Thus, when the side effects are painful, compliance is difficult. “No discernable benefit is visible, relapses may still occur, which is discouraging to the individual who is self-injecting” (Holland & Northrop, 2006, p. 188). In an attempt to understand one patient’s perspective, Fawcett and Lucas conducted a study to “illuminate the primacy of the journey as perceived and presented by the traveler” (p. 47). They concluded, “For the individual seeking hope and normality the potential benefits are offset by the challenge of regular intramuscular or subcutaneous injections” (p. 50).

This work differs from earlier literature primarily due to context. Instead of reporting facts about medications (including their benefits and outcomes) or focusing solely on the experience of one person, this work revealed ways in which six young adults were *deciding to fight the disease*. For them, the experience involved pain, planning, and time associated with medication administration. One participant made choices about when or if to take her medication based on what she planned to do the following day. This may have meaning in evaluating compliance of medication, as well as for a deeper understanding of how young adults make choices about fighting the disease.

Seeing the Economic Impact of the Cost of RRMS on My Family

The story told by one young person in this study was powerful. She shared the concern that she might have to obtain a divorce after 22 years of marriage to continue qualifying for assistance with her medication. She had contacted her state representative early in the disease state and was advised to become the head-of-house to qualify for additional assistance. She told the story with tears steaming down her face. She wanted to work, her husband wanted to work, they had a modest home and a modest life style from observation. She took her medication every other day rather than every day as was prescribed to make it last longer. She described waiting to have prescriptions filled so she could prolong the cost. I walked away with a sense of sadness for this young adult who had such difficult decisions to make related to her family and her disease.

The impact that financial costs of MS have on quality of life was the focus of a qualitative study with “16 health professionals, 26 people with MS, and 11 family members of people with MS” (DeJudicibus & McCabe, 2007, p. 3). The researchers

concluded that as MS progresses; the paid level of employment might decrease, having a substantial impact on family finances and quality of life. Another research team used semi-structured telephone interviews to assess experiences of 15 partners of people in the early stages of MS (Bogosian, Moss-Morris, Yardley, & Dennison, 2009). They found that financial difficulties were a common theme, even in the early stages of the illness.

Iezzoni and Ngo (2007) developed a telephone interview questionnaire for use with MS patients, exploring topics such as MS history, medication use, insurance, and employment status. Of the sample of 983 persons, 15% were young adults under the age of 40 and 72.7% had the RRMS form of MS. Although 96.3% of the sample reported having health insurance, participants reported concerns about postponing care and skimping on medications, while 25% were very worried about paying for basic needs.

In this study, similar data about the economic impact of MS emerged. However, one new and somewhat surprising finding emerged – the belief that additional economic burdens result from public assistance programs such as Medicaid and Social Security Disability. Participants in this study described the economic burden as scary, frustrating, and even embarrassing.

Coming to Know that Wondering is Part of Thinking about the Future

Ambiguity surrounds the diagnosis of MS. The diagnosis is also recognized as having no cure. This combination leads individuals with MS to live and cope with an uncertain future (McNulty et al.). Zwibel reported that maintaining the ability to walk was the major concern of patients with MS, “whatever their level of disability and whatever the disease duration” (p. 12). In a qualitative study with eight persons with MS and other diseases designed to explore the experience of chronic pain, uncertainty

associated with disease symptoms affected overall perceptions, including making plans about the future (Richardson, Ong, & Sim, 2006). Along with the day-to-day uncertainties associated with MS, persons with MS, including participants in this study, wonder about what the future will hold with advances in treatment.

Findings of this study complement existing literature. However, data revealed more of a sense of wondering, rather than labeling the thought as uncertainty. The young women wondered if their medicine would continue to work, they wondered if they would be able to work, and they wondered if they would end up in a nursing home at a young age. They looked to the future with a sense of wonder.

Learning to Take the Disease Day-by-Day

Physical and psychological challenges often confront individuals with RRMS. These challenges vary “not only from year-to-year but also from day-to-day” (Somerset, Peters, Sharp, & Campbell, 2003, p. 21). “Getting on with day-to-day life” was a theme identified in a qualitative study involving 13 participants (Malcomson et al., p. 669), one of whom emphasized the importance of living one day at a time. The major conclusion was the need for a “holistic patient-centered package of care” (Malcomson et al., p. 673). Rolland (1987) described the experience of learning to take the disease day-by-day as the chronic phase of an illness. “It is a phase when the individual and family recognize the permanent changes presented by the illness and it is referred to as a phase of ‘day-to-day’ living” (p. 207).

Findings are congruent with previous research but move the knowledge base forward with a clearer understanding of what constitutes day-to-day life for a young adult with RRMS. Living life day-to-day may include changing routines, adapting the days’

activities based on how you feel, or being willing to set things aside that could be done later. An important finding for young adults is that taking the disease day-to-day assists in overall understanding and management of RRMS.

Immediate Context Themes from the First Research Question

Knowing I Need Rest When I Feel the Fatigue

Although symptoms of fatigue are influenced by environment and physical conditions in MS, fatigue has been reported by 75-90% of patients (Forwell, Brunham, Tremlett, Morrison, & Oger, 2008; Holland & Madonna; Penner et al., 2009). In a descriptive study with 120 people diagnosed with MS, all participants verbalized complaints of fatigue (Mollaoglu & Ustun, 2009). In a phenomenological study with nine persons with MS, fatigue was perceived as a time-consuming symptom, typically defined in relation to energy loss, emotional afflictions, and life restrictions. However, they viewed it as also “constructively perceived, involving a desire to accept life and strive for a better situation” (Flensner et al., p. 707). Reynolds and Prior found that women with MS were “pacing” (p. 1232). The challenge of coping with daily activities was managed through rest periods.

Mollaoglu and Ustun urged health-care providers to evaluate carefully factors that contribute to fatigue. In this study, in contrast to prior literature, participants voiced that they were evaluating such factors during their daily lives. They learned from experience, quickly identifying when they needed rest. Further, they indicated that they were aware of their limits in undertaking specific daily activities. In this small sample, different women voiced different scenarios that gave them pause – situations that they had to

handle in new ways to avoid over-exertion. The individualized nature of fatigue emerged in this study, and it is a new finding in the literature about RRMS.

Realizing that Planning is Important to Help Maintain a Sense of Control

Planning and goal setting have been associated with better adaptation to MS (Mohr & Cox, 2001). For instance, planning, which was defined as “planful problem solving” (Aikens et al., p.437), was significantly correlated with less psychological distress in a sample of 22 persons with MS. Although from a different research tradition, the findings of this study emphasize the importance of planning for young adult women with MS. The participants indicated that planning was essential for maintaining a sense of control over this very unpredictable disease.

Making Decisions about Telling Others who Are Not in My RRMS World

There are few other studies pertaining to this theme, primarily because the notion of the RRMS world was discerned and expressed in this study for the first time. However, there is tangential pertinent evidence in a phenomenological study that was designed to understand the experiences of caregivers of persons with MS. McKeown et al. found that caregivers often rejected outside support in an effort to shield the person. Persons with MS wanted to maintain independence and did not want outsiders involved in their care

The notion that young adults with RRMS are very selective about informing others about their situations has critical implications for their health and well-being, especially since those others can include health professionals. Their decisions to tell or not to tell certain people about certain facets of their experience could directly influence

the understanding others have of their needs for social and psychological support and health care.

Knowing the Importance of Listening to My Body

I did not find any literature reporting a theme similar to that of *knowing the importance of listening to my body*, as related by participants of the current study. The young adults in this study realized they could identify early warning signals of an imminent exacerbation by paying attention to changes in their body. These changes were identified as subtle, things such as your thumb going to sleep, your gait being slightly weak, or an odd sensation in your extremities. These became cues for them to watch and report if they progressed. One participant compared it to being pregnant and paying more attention to changes. They also have learned to walk a fine line between being paranoid about changes and being cognizant of changes that are significant. They learned this through experience of waiting too long to call the physician and taking a longer time to recover from the symptoms that progressed. This is a meaningful finding not only to those affected with RRMS, but also to caregivers and health-care providers.

Overview: Discussion Related to the Second Research Question

The second research question was: How do young adults make meaning of the expectations that others have of them while living with RRMS? The focus of earlier studies has been the disease of MS, not specifically RRMS. Few researchers have sought to explore meaning in studies related to MS. Findings of this study complement existing literature and add to the body of knowledge related to the work of young adults within their families and communities. The knowledge gleaned from these data will enable

family members, employers, and young adults living with RRMS to more fully understand what the experience is like from an insider's perspective.

General Context Themes from the Second Research Question

Trying to Stay in Control and Make it All Right for Everyone

Blank and Finlayson conducted three semi-structured interviews with two couples living with MS. Two coping strategies used, 'taking time for self' and 'having a positive attitude,' were similar phrases reported by participants in this study. Walsh recognized families needed to accomplish family tasks to ensure optimal functioning within the family. One participant identified that staying in control enabled her to continue to care for her family, as she desired. She recognized the importance of making time for herself to accomplish the bigger goal of caring for her family.

A rite of passage for young adults is leaving the birth home and creating a new home with their own family (McGoldrick & Carter). One participant in the current study said that it bothered her if she was not in control and could not take care of those around her. She felt her role as a mother was one that she did not want to relinquish to others. Young adults establish careers, become productive members of society, and accept social responsibility (Falvo). Those who worked full-time wanted to ensure they were viewed as good employees. Their goal of staying in control was to take the load off others they worked with when they could.

Knowing How Other People Respond to Other People with RRMS

Each of the participants spoke of how their work was affected by their RRMS. One participant was dismissed from her job when she could not perform all of the duties within her job description. Her wish was to stay with the company. She had hoped she

would be offered a position that did not include lifting or other physical skills, but she was dismissed when she experienced an exacerbation that was obvious to those around her. Another changed jobs when her supervisor made remarks on her evaluation related to her disease prognosis. Each identified their employers as individuals who first taught them about *knowing how other people respond to other people with RRMS*.

Langgartner, Langgartner, and Drliceck (2005) told the story of one person's experience with MS. "In our society, success and output are all that count. Either someone can fulfill his or her tasks or that someone has to leave" (p. 887).

Researchers conducted a retrospective analysis of disability data from 17 U.S. companies. Compared to employees without MS, employees with MS had significantly higher absenteeism cost, as well as disability costs (Ivanova et al.). That finding was reported as a significant workplace burden on employers. In contrast, the participants in this study related a variety of workplace burdens on employees with MS.

Young adults in this study made choices about what type of employer to work with and looked for individuals who would be willing to work with them if they needed accommodations. It is important for employers to realize persons with MS recognize and appreciate needed accommodations provided in the workplace. Additional education is needed for employers to understand more about the challenges young adults face who live with RRMS.

Specific Context Themes from the Second Research Question

Realizing that Health-Care Providers are a Strong Support

The participants found themselves *realizing that health-care providers are a strong support*. The six young adults with RRMS recognized neurologists, primary care

physicians, office nurses, and clinic staff as team members. They referred to themselves as part of the team. One participant planned to postpone starting a new medication until she was ready. She said it would not make her physician happy, but they would discuss it and come to a mutual understanding. Another said she felt valued by her health-care team and believed they respected her knowledge. Yet another spoke of making lists to talk to her physician about when she had her appointment. All believed they could reach their providers when needed and did not hesitate to contact them for significant problems.

In contrast to the findings from the present study, earlier studies have reported that persons with MS did not believe they had received psychosocial support from health professionals (Isaksson & Ahlstrom, 2008; Malcomson et al.). The participants in the study conducted by Isaksson and Ahlstrom (2008) were selected from a local MS register in Sweden drawn from an earlier study (Isaksson & Ahlstrom, 2006). A general lack of professional support was a theme in one qualitative study (Malcomson et al.). The thirteen individuals in this study were drawn from two regions of the MS society in Northern Ireland (Malcomson et al.). The participants identified poor communication and a lack of individual care as problematic for their overall experience. In another study involving semi-structured interviews with 23 persons with MS in the U.K. and 17 of their caregivers, participants felt that they had to fight for the services they needed (Edmonds et al.). However, the nature of the services needed was not described.

Considering the Ways in Which My Family Supports Me

In their study of one person's experience of MS, Langgartner, Langgartner, and Drlicek (2005) concluded, "the most important companions for a patient with multiple sclerosis are probably family members and friends" (p. 888). Family was especially

important at the time of diagnosis. Initially, the family tends to see the disease in a clear, rationale manner. Grytten and Maseide (2006) explored the stigma of MS in social relationships with 8 persons with MS (including 6 persons with RRMS) and 6 of their relatives. A key theme identified was that of over-emphasizing MS, which participants reported as more common with friends, acquaintances, and strangers than among family members. Families were identified as key in helping the person define MS and contribute to a positive coping system. In fact, one participant referred to family support as an “anchor” (Grytten & Maseide, 2006, p. 202) of the supportive emotional network.

In this study, participants viewed family support in a way that has not been reported elsewhere. The participants recognized that family support occurs when someone is present, but that it can also occur in the absence of a family member. It was articulated as a protective mechanism, a helping relationship, and type of devotion.

Immediate Context Themes from the Second Research Question

Wishing for an Opportunity to Talk to Others Like Me

Emotional support was described as “feeling that there is someone to confide in who will be empathetic, someone with whom to share private thoughts and fears” (Hilari & Northcott, 2006, p. 18). With a sample of 132 people diagnosed with MS, Schwartz and Sendor (1999) studied the effect of how helping others with the same chronic disease would help oneself. Participants showed significant improvement in levels of confidence, self-awareness, self-esteem, depression, and role functioning. Freeman and Allison (2004) explored the effectiveness of a weekly group exercise class on mobility, balance, fatigue and well-being in ambulant people with MS. Psychological aspects improved, but

the researchers were unsure if improvement was due to the exercise or to the support session led by participants after the class.

Findings of those studies are akin to the theme of *wishing for an opportunity to talk to others like me*. This is an unmet need in the young adult population with RRMS. Other researchers have detailed the importance of emotional support for persons with RRMS, but others have not emphasized the perceived need to talk to someone else who has had the same experience.

Finding that Nobody Really Understands What it is Like

This theme evokes a feeling of loneliness. Compared to persons with cancer, persons with MS expressed less loneliness related to their disease in a study that focused on the qualitative aspect of the loneliness experience. This was attributed to MS patients having time to identify their resources and utilize the resources in dealing with the disease (Rokach, 2004). In a descriptive study conducted to describe how patients with MS manage chronic sorrow, Isaksson and Ahlstrom (2008) identified a theme of “deficient affirmation” (p. 183). This theme related to a lack of understanding by family members as evidenced by the spouse forgetting that the patient was having problems or not acknowledging symptoms. Grytten and Maseide (2006) also wrote about the experience individuals with MS have had with a lack of understanding. “You look so good, so MS must be insignificant” (p. 200).

Such findings are comparable to key findings of this study. Many individuals with RRMS look “normal,” and it is sometimes difficult to understand that they are experiencing symptoms that are invisible to others who are observing. They can go for months or even years without any symptoms or any problems related to the disease, and

then suddenly they might be incontinent or unable to walk. It is difficult for persons who have had such experiences to explain it to others. Attempts at explanation might not be successful. Thus, young adults who live with RRMS can indeed feel like nobody really understands, including persons who are closest to them. Thus, it is critically important for family, friends, and health providers to invite young adults with RRMS to talk about what it is like to live with the disease.

Finding that it Takes Planning to Look Normal

Self-managing was the topic of a qualitative study with persons who had chronic illnesses including MS. Participants reported that they would endure discomfort in attempts to appear normal, such as keeping up appearances by taking the stairs rather than using stair lifts (Townsend et al.). In addition, participants made decisions not to attend support meetings because it clashed with their self-identity. Grytten and Maseide (2005) found that concealing MS was strategic to maintaining the appearance of an ability to work, thereby avoiding the stigma of an incompetent label.

The theme of looking normal around others as a planned activity is consistent with prior literature. An important finding is that it takes effort to look normal. It is not a comfortable process. It is a process that led one young participant to feel like a liar or a fraud. Other scholars have reported this as a positive mechanism (Townsend et al.); I would suggest that this view needs to be reconsidered, because conservation of energy is important for young adults living with RRMS. These young adults recognize that looking normal takes energy. They realize that they could be using that energy in a more productive way, such as taking part in activities that would contribute to a rewarding quality of life or would enhance their over-all health and well-being.

Overview: Discussion Related to the Third Research Question

The third research question was: How do young adults learn new ways of being during periods of exacerbations? Five themes were identified that related to answers for this question. Young adults went beyond the scope of this question to include how they had found new ways of being while living daily with RRMS. This gave depth to the answers surrounding the question. The question had not been answered for young adults living with RRMS in earlier research. The relevance of these findings is important to health care providers who are considered by the young adult as part of their team when initially diagnosed. Furthermore, these findings are relevant to family members as they support the young adult. Certain findings from this research question are relevant to policy related to disability and continued employment for young adults with RRMS. For other young adults with RRMS, these findings also have meaning with regard to understanding how life can be redefined after a diagnosis with RRMS.

Metacontext Themes from the Third Research Question

Reliving What it was Like to Have the Initial Symptoms

Johnson (2003) conducted in-depth interviews with 24 persons regarding the meaning of the MS diagnosis period. Participants in the study described devastation, shock, and dissatisfaction with management of the diagnostic phase, such that one participant could clearly recall the event 26 years later. Several participants said that as persons, they felt like puzzles; once the physician had solved the puzzle as to the nature of the diagnosis, they were no longer interesting to the physician (Johnson).

Langgartner, Langgartner, and Drlicek (2005) reported on one person's experience during the phase of diagnosis with MS. The individual, a medical

professional, said that when waiting for the diagnosis, he felt “as if the doctor was talking about someone else” (p. 885). He did not think of himself as a person who could possibly have MS (Langgartner et al.).

There is a marked element of surprise when a young adult is diagnosed with RRMS. It is important to give the person time to absorb the information and then ensure that they are given an opportunity to express their thoughts about what they might expect. Because the experience seems so bizarre to the young person at the moment, they could benefit from having a patient navigator to assist with the initial transition and to guide them through the maze of questions they have when the shock subsides. Several participants in this study identified the concern that they would be a wheelchair within a year of the diagnosis. They were not told initially that RRMS progresses slowly, and indeed, some still did not know this was the case. Individuals who maintain their mobility for 10 years after the time of diagnosis have a very good prognosis related to mobility (personal communication, Dr. Anne Cross, March, 2008). This fact does not change the diagnosis, but offering information of that type could enable young adults with RRMS to prepare mentally and emotionally for what they might or might not face in later stages.

Deciding Where You Fit in a World that Wants Perfect People

The participants in this study emphasized that the imperfections they perceived due to having RRMS were not acceptable to others, particularly strangers who did not care to see persons with disabilities. Such a theme has emerged in prior qualitative research as well. In an exploratory study of concerns of 20 women with MS who were considering motherhood, one major concern was frustration with societal attitudes (Prunty et al.). These attitudes can extend to the workplace. Understanding benefits and

barriers faced by employees with MS was the purpose of a qualitative study with 16 people (aged 27-58, $M = 43.7$) conducted by Johnson et al. (2004). The MS type was not presented. One of the participants said, "It's nice to think that people don't discriminate, but they do. I always used to be ashamed of it, or scared to tell somebody, because it is very much my problem" (p. 206). Another participant felt stereotyped and believed that they saw only her disability and not her as a person.

One participant shared a captivating story about her wheelchair. She has incorporated her chair as part of her identity, referring to getting new wheels as getting new shoes. She compared it to a teddy bear being one's security blanket; she does not like to have it out of her sight and she views herself as weighing 400 pounds when she actually weighs approximately 120 pounds. Sakalys (2006) reported on the construct of embodiment and caring science, observing that, "The body-self relationship is complex, deeply entrenched in philosophical debate" (p. 17). The discussion of the body included viewing the body as a third person might view it, versus "the subject body" or the phenomenological body (p. 17). The phenomenological body is the body that the individual knows intimately. It is the body with which you live, the body you experience and see as the "me" (p. 17) of existence. The young adult who referred to the wheelchair as part of her identity was referring to the phenomenological body. It was the comfort that comes with liking who you are even if it does not conform to societal views of who you should be as a young adult. It is in this body that the young adult with RRMS lives.

The findings extend our understanding about *deciding where you fit in a world that wants perfect people*. Findings about ways in which young adults made meaning of the attitudes of other persons about perfection are important additions to the existing

body of knowledge. Perfection is an unreachable goal for any human. Nonetheless, young adults with RRMS face the expectation of perfection (or the absence of visible hallmarks of disability) when they are out in public, in the workplace, and in some cases, at home.

General Context Theme from the Third Research Question

One theme of general context emerged: *Rationalizing my way into an understanding of how I ended up with RRMS*. Data offered multiple examples of rationalizing the cause of RRMS. Although there are no definitive associations between RRMS and environmental causes (Cook, 2006), participants speculated about the whether specific activities or foods could have caused the disease. Although participants questioned why they were ill when others were not, they did not assign blame. Nonetheless, they wished for answers to their “why” questions. An additional instance of rationalization involved incorporating MS into one’s physical status, while electing not to view it as affecting the mind.

There are few other research findings related to the theme of rationalizing an understanding of how a person got RRMS. However, the literature available is consistent with this finding. Pakenham (2007), who used a quantitative method in a study with 408 persons with MS, referred to a similar notion as “making sense” (p. 380). A multi-item measure was tested to examine sense-making. One item related to spiritual perspective was entitled, “My MS is part of God’s plan for me” (p. 384). Other items measured life purpose, causal attributions, values and priorities, acceptance, and luck. Life purpose included the thoughts that having MS offers new opportunities that can aid in creating new purposes. The notion of acceptance incorporated several topics, including the

importance of getting on with life and the idea that managing the disease helps one to make sense of it (Pakenham).

The phenomenon of creating a rationalization about the personal origin of MS was an important facet of the experience of these participants, as sense-making was for persons involved in another recent study (Pakenham, 2007). Researchers should explore such unique interpretations about the possible origins of the illness and examine ways in which those interpretations might influence coping with the disease over time.

Specific Context Theme from the Third Research Question

The remarks of one young adult in this study clearly exemplified the phenomenon of *seeing the importance of charting my own course*, when she said she would “try anything.” Although she realized that she might have to make adaptations, she planned to continue doing things she enjoys and not stop living because of her diagnosis. Similar remarks by other participants evoked comparisons with the construct of self-efficacy. Stuijbergen (1995) identified the importance of self-efficacy as an influence upon health-promoting behaviors for the 61 individuals with MS who participated in this study.

In a factor analysis of a self-efficacy measure for people with RRMS, key concepts were personal control, independence, and activity (Rigby, Domenech, Thornton, Tedman, & Young, 2003). In a recent study, the positive relationship between managing MS and quality of life for 292 persons was mediated by self-efficacy, as measured by The Multiple Sclerosis Self-Efficacy Scale (Motl, McAuley, Snook, & Gliottoni, 2009). Similarly, autonomy and self-reliance were associated with improved psychosocial well-being in an investigation of factors associated with depression and social function for 318 persons with MS (Somerset et al.).

Plow, Mathiowetz, and Resnik (2008) studied the impact physical activity has on self-efficacy, self-identity, and social support with 50 participants diagnosed with MS. A finding that self-efficacy decreased, led the researchers to conclude the construct may have initially been overestimated by participants. Self-identity improved and social support as defined by the scholars decreased. A greater awareness during the study of a lack of social support was reported as a rationale for the decrease in this construct.

Although the phenomenon identified in this study might have similarities to constructs such as self-efficacy and concepts such as autonomy, *charting your own course* might also involve being self-reliant and finding alternative support mechanisms if significant others are not available. In this study, this phenomenon exemplified personal control over life, independence of thought, and a refusal to stop living after the diagnosis of RRMS. The gist of those data is reminiscent of these words about courageous behaviors. “Individuals who are courageous make a concerted effort to get on with their lives in spite of difficulties” (Finfgeld, 1995, Courageous Behaviors section, para. 4). The young women in this study made the decision very early in the disease process that they would make their own plans and live their own lives.

Immediate Context Theme from the Third Research Question

The theme of *redefining who I am* had not been previously addressed in the literature pertaining to persons with MS. The fact that it surfaced in such a pronounced way in this study is important, because it suggests that young persons with RRMS must persevere to redefine personal identity while not losing the essence of being. It is more than one construct, and indeed perhaps a combination of many. For these participants, it was important to understand that the body had changed. Some participants focused on

physical limitations, whereas others focused on observable physical differences post-diagnosis. Redefinition of the self also involved the amount of rest they needed and the types of activities they chose. This all became part of who they were. They did not make apologies for the changes. Although they did not necessarily embrace those changes, they recognized them as part of their lives. Thereby, they created a new norm for their lives.

Personal identify includes one's occupation. *Redefining who I am* might involve changing occupations as described by two participants in the study. As one young woman contemplated what she might be able to do, she became emotional. The person she wanted to be was not the person that she could be. She had aspirations of becoming an environmental biologist when she was diagnosed at the age of 17. She realized that occupation would include travel, living in extreme conditions, and other aspects that she would not physically be able to manage. Next, she considered being a nurse. Through multiple exacerbations, she realized that a nursing career was also physically challenging. She is at a point now that she is once again contemplating what her occupation should be and how she can redefine herself within the parameters that her RRMS permits.

Lexell, Lund, and Iwarsson (2009) conducted a grounded theory study with 10 persons with MS, including two persons with RRMS. The aim was to deepen the understanding of how people with MS become engaged in their occupations. Although some participants in that study could no longer perform their pre-diagnosis occupations, they reflected positively upon their prior occupational experiences. Others felt limited in the number of occupations available to them, and they struggled with balancing duties at work and home. Some participants reported that they were "living life differently" (p. 777), in that their lives were more structured post-diagnosis.

Transition has been defined as movement, conversion, happening, modulation, or a connection to what follows. The definition has also included adaptation to change. This adaptation includes letting go of “familiar ways of being in the world that defines who they are” (Kralik, Visentin, & vanLoon, 2006, p. 326). This study contributes to the literature by pointing out that young adults diagnosed with RRMS might have to relinquish an anticipated definition of the self – one not associated with familiar ways of being but rather with goals that did not come to fruition due to the disease, while reconstructing a new definition of self.

The Significance of the Study

The results of this interpretive phenomenological study can be used to guide the development of interventions and support services for individuals and families with RRMS. The results of this study could also contribute to nursing research, rehabilitation, and development in public policy.

The Significance for Nursing Research

This study helped to highlight the importance of seeking to find meaning for young adults living with RRMS. The study helped to expand knowledge with many different themes including transitions that occur at the time of diagnosis and the meaning of that experience to the young adult. When a young adult receives a diagnosis of RRMS, whatever the nature of a family’s relationships, all members are affected. They will be affected during their day-to-day life. If the person diagnosed is a parent, roles may shift and the child may find themselves as a caregiver at a very young age. This role shift then affects the community in which the young family resides. Resources should be available to assist the person diagnosed, the family, and the community in which they

reside. They should not feel they have to bear the burdens of this disease alone. Instead, they should feel they can find and access the necessary resources and support to live a full and rewarding life.

When dealing with a disease trajectory filled with a great deal of uncertainty, it is important to identify what that uncertainty means to young adults living with RRMS. Whereas the trajectory of the disease cannot be eliminated, nurses can make a difference by listening to the lived experience of young adults and by providing answers to assist them to live with the uncertainty. The young adults in this study identified that their health-care providers can and do make a difference in their daily lives with RRMS. Through dissemination of these findings, other health-care providers will gain new insights about the meaning of that involvement to young adults with RRMS.

The Significance for Public Policy

Statistics concerning the extent of disability associated with RRMS have been useful in planning the scope of rehabilitation. The incidence, severity, and cost of RRMS cause enormous losses to individuals, family, and society (Bogosian et al.). This cost is more than economic; the cost includes loss of family relationships (Cheung & Hocking), and loss of individual contributions to society (Grytten & Maseide, 2005).

However, statistics cannot explain the emotions, the fear, the frustration, and the lived experience of young adults who have received a diagnosis of RRMS. Young adults who are in the midst of their highest lever of productivity deserve the assurance of public policy that is designed to provide assistance when the disease prevents them from continuing their employment (DeJudicibus & McCabe, 2007). Individuals diagnosed with RRMS need expensive medication to limit progression of the disease. Without insurance

or public assistance, the medication is cost-prohibitive. Young families should not be forced to choose between keeping the family together and qualifying for assistance by changing the head of household through divorce. The economic burden associated with RRMS was described as scary and embarrassing. Things they cannot control should not embarrass young adults facing a lifetime of living with RRMS. This issue must be addressed through public policies. Policy-makers should also reconsider employment practices for employees with chronic illnesses to prevent discrimination.

The Significance for Rehabilitation

Rehabilitation is considered only for conditions that have the potential to be cured; in fact, some insurance carriers base reimbursements on the cure rate for an illness (Iezzoni & Ngo). However, some states have waived that requirement for persons with traumatic brain injuries, allowing those individuals to be eligible for rehabilitation services although the condition is incurable (Dr. Margaret Williams, personal communication, December 2009). According to a conference report published in 2008, rehabilitation research in MS is open for a broad array of topics including “any factor that could help a person with MS achieve and maintain maximal physical, psychological, social, and vocational potential” (Kraft et al., 2008, p. 1292). Assistive technologies, for instance, could be specifically developed to assist persons with certain rehabilitative needs. Currently, the barriers to rehabilitation research are primarily cultural, structural, and societal in nature (Kraft et al.). The impact of outpatient rehabilitation on quality of life in MS was the focus of a quantitative study conducted with 111 persons in the progressive phase of disease (Patti, 2002). Rehabilitation was found to be an effective mechanism in improving quality of life with advanced MS (Patti). Without insurance

coverage for out-patient rehabilitation, that critical type of help remains an unavailable option for many young adults with RRMS.

Whereas participants in this study had not experienced a significant decline in cognitive function or bladder function, those concerns are real for many young adults living with RRMS (Fernandez, 2002; Koch, et al., 2001). Rehabilitation should be available for any young adult needing assistance with balance, cognitive issues, bladder training, or other concerns that are common for young adults living with RRMS.

Implications for Further Research

Based on the deeper understanding of the meaning of living with RRMS as a young adult gleaned from this study, further phenomenological research is now needed about a variety of facets of experience. Findings from this study were situated within the context of developmental milestones, thus, healthcare professionals can begin to appreciate that this is not an ordinary chronic disease affecting middle-age to older adults.

First, more work should be done about how the experience at the time of diagnosis affects living with the illness for a lifetime. The characteristic of RRMS that can be significant for young adults is the changing nature of the illness, that is, its relapsing-remitting nature. It is imperative for researchers to study how frustration is manifested and how it can be managed specifically with those who live with RRMS. Further consideration should be given to the idea that the scary feeling associated with RRMS for young adults is conceptually different from the construct of fear. Further research should be done to understand what it means for a young adult with RRMS to learn to listen to the body. There is a need to understand the meaning of how this occurs and what cues, if any, are available to guide this experience.

Further qualitative studies should be focused on the theme related to putting RRMS in the backdrop of life. It would be important to conduct a comparative study with young adults who have RRMS and young adults diagnosed with other chronic illnesses such as diabetes to determine if the theme is apparent with other chronic illnesses. The sensitive issue of sexuality and RRMS, potentially related to this theme, did not arise in the interviews, possibly for reasons discussed later in limitations of the work.

Due to the complex finding that participants wanted to know just enough about RRMS without knowing too much, researchers should further explore how young adults with RRMS wish to learn. The fact that they are adult learners is important, but obviously, their needs are unique, as suggested by the findings. Future research could also be done to explore the experiences of family members of young adults who have been diagnosed with RRMS, as well as their learning needs. Finally, because the sample in this study was comprised of rural persons, it would be important to conduct a comparative study with a sample of urban young women.

In addition, it is imperative that further research be undertaken to better understand how to reach the target populations of young adults living with RRMS. Several participants in this study were health professionals who knew the importance of research; yet they hesitated to participate because I was a stranger. With regard to recruiting participants for studies of RRMS, I will report in the literature that word-of-mouth was the most effective recruitment strategy in this study; it was friends who encouraged eligible volunteers to participate. This fascinating observation points to the need for health-care providers to inform persons with RRMS, both men and women, about the importance of becoming involved in research studies to help others living with

RRMS. This may have implications for young adults feeling part of a health team and not “distanced,” and, for those participating in research to affirm the possible benefit they have experienced.

In a qualitative interpretive study, participants’ responses can be influenced by a variety of factors. In this study, I learned that the interview environment could be influential. One participant preferred to have the first two interviews conducted at a private area at her worksite. Whereas she seemed open and forthright in the workplace, she was much more so during the third interview in her home. She was more relaxed and more willing to share very personal details of her life that she said she had wanted to mention at earlier interviews but hesitated to do so. The nature of the influence of the interview environment on data yielded in such studies would be an interesting research topic.

Because different types of MS have different trajectories, researchers who undertake studies with persons who have MS should clearly distinguish the type of MS that participants have, rather than involving samples of persons with various forms of MS and viewing results as comparable across the entire sample (Johnson et al., 2004; Penner et al., 2009). Studies are needed that pertain to persons with one type of MS. Once similarities and differences in such experiences are established for persons with distinct types of MS, findings would be useful bases for intervention studies to directly influence various facets of experience that are troubling to these persons.

One issue requiring further research that is not directly related to the findings of this study, but nevertheless important, is a more definitive marker for the age when young adulthood ends. Three volunteers who approached me about participating in the study

were 43 years old. Each had children who were 8 to 16 years old. They fit the criteria for Levinson's (1996) definition of young adulthood, but they did not meet my inclusion criteria due to their age. As young adults delay having children, researchers should re-evaluate developmental levels and re-determine ages associated with each level.

Limitations of the Study

Ensuring generalizability is not an aim of qualitative research (Greene, 1998). In fact, to understand experiences that have not been fully explored, it can be useful to delimit the sample to persons with specific characteristics (Luborksy & Rubenstein, 1995; Porter, 1999). However, one potential limitation of the work is that the sample included only women, not young adults of both genders. In addition, all participants were married and had a spouse who was a wage-earner. Therefore, certain of the themes that emerged from this study are likely particular to women rather than to young adult men. For instance, issues associated with recognizing the need for and seeking help could vary not only among individuals but between genders. Furthermore, young adult women with RRMS who are single or do not have a partner in the home could well have different experiences with regard to availability of help in the home. Finally, married women with RRMS whose husbands are not employed might face even more troublesome financial issues than those reported by participants in this study.

Other limitations of the work also pertain to methodological aspects. First, because recruitment occurred in a rural region of northeast Missouri and central Illinois, data were necessarily obtained from persons living in that region. Whereas each participant related data different from those of all other participants in particular respects, persons in the sample might have been shared similarities due to residential location or

local culture that influenced the findings in unknown ways. The inclusion of urban persons in the sample might have led to discernment of themes other than those reported.

Second, the typical recruitment strategy of distributing flyers yielded a direct response from only one participant; fortunately, there were enough advertisements distributed in various sites that “friends told friends” about the study. The sampling plan had included the possibility of snowball sampling as a secondary strategy, not as the primary approach. Third, as noted earlier, participants did not mention issues of sexual functioning associated with RRMS; this might have been the case because specific questions about that matter were not included in the Interview Guide or could have been gender related. Because 85% of MS cases begin as RRMS, most studies of MS will by chance alone be comprised of persons with RRMS. Therefore, most other studies will also have participants with the same type of MS of this study. However, measures should continue to be taken ensuring studies pertain to persons with only one type of MS.

Conclusion

This study has been a beginning effort to contribute to the body of knowledge pertaining to young adults who live with RRMS. It is a personal and very emotional topic for the young adult. I was privileged to be included in the RRMS world of each of these six young women. They were struggling to make meaning of the changes that had occurred in their lives since the RRMS diagnosis. They were trying to understand and deal with the expectations that they believed others had of them as persons with RRMS, even as they made efforts to shape and reshape those expectations. Finally, they were learning new ways of being, not only during exacerbations of RRMS, but during their daily lives with RRMS.

As a researcher, I have learned a great deal about living with RRMS as a young adult. It was not an easy journey for any of the participants. The involvement of family was an integral part of the experience. The anticipatory guidance and interventions of health-care providers during exacerbations have marked impacts on the daily lives of young adults with RRMS. Despite the ongoing presence of supportive persons in the lives of these six young women, they raised troubling questions for which there are few definitive answers. With further study, the voices of young adult who live with RRMS continue to be heard and a deeper understanding will emerge that could inform interventions, which in turn, could positively affect quality of life for young adults with RRMS and their families.

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Appendix A



[Main Menu](#) | [IRB Forms](#) | [My Saved IRB Projects](#)
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Project Forms

IRB Project Number: 1135817

Project Title: The Experience of Young Adults Living with Relapsing-Remitting Multiple Sclerosis (RRMS)

Principal Investigator(s): Beshears, Brenda Kay

[View Complete Study Staff](#)

[Adverse Event Log](#)

[Cumulative AE Log](#)

Note: Please scroll down to see all project forms

Study Expiration Date: 05-21-2010

HS IRB Behavioral Sciences Application (Prior to 8/17/09)

Date Submitted	Status	Consent Type	Level Granted	Board Date	Approval Date	Mailed Date	Expiration Date
05-07-2009	Approved	Written	Expedited	05-27-2009	05-26-2009		05-21-2010

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Notes from IRB: No Notes Found

HS Continuing Review Report

Review #	Date Submitted	Review Status	Level Granted	Board Date	Approval Date	Mailed Date	Exp. Date
83220	04-21-2010	Pending					

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Notes from IRB: No Notes Found

APPENDIX B

Letter of Invitation to Participate in Research

Date: _____

Dear _____

I am a doctoral student at the University of Missouri - Sinclair School of Nursing. I am conducting a research study with young adults who have been diagnosed with relapsing-remitting multiple sclerosis (RRMS). If you are a young adult between the ages of 20 and 40 who has been diagnosed with RRMS by a physician at least six months before enrolling in the study, I invite you to take part in this research.

If you decide to participate in this study, you would take part in three recorded interviews in your home or in a private location of your choice. Each interview would last about an hour. I will conduct the interview and will ask you some questions about your experience of living with multiple sclerosis. At each interview and especially at the last interview, I will ask some questions to ensure that I understood your responses.

There are no known risks to you as a result of taking part in this study. The benefits include the opportunity to share your experiences of living with multiple sclerosis and the opportunity to make a contribution to knowledge in the field of multiple sclerosis. I hope that this knowledge will be of help to health care providers who care for young adults living with multiple sclerosis.

All information you share with me will remain confidential. I anticipate the results of this study will be published in a journal; no names or information that can be connected to you will be reported. After completion of the study, all raw data and recordings will be destroyed.

Your decision whether or not to participate will have no affect on your future health care. If you decide to participate, you can withdraw from the study at any time. If you have questions about this study or if you would like to volunteer to participate, please contact Brenda Beshears at 573-248-5017 or bkb539@mizzou.edu.

Sincerely,

Brenda K. Beshears

APPENDIX C

Pre-Addressed, Stamped Postcard Information



The Experience of Young Adults Living
with Relapsing-Remitting Multiple Sclerosis
Brenda K. Beshears, PhD(c), doctoral student
University of Missouri –Sinclair School of Nursing

Please fill out the following information below and mail this postcard to

Brenda K. Beshears.

Preferred Method of contact (Circle One): Home phone /Cell phone /Office Phone

Contact Information: (Phone)

I give permission for Brenda Beshears to contact me at the above number about the study
on young adults living with RRMS:



Signature

Print Name

APPENDIX D
Advertisement Flyer

**VOLUNTEERS NEEDED
for a Research Project
The Experience of Young Adults Living with RRMS**

This study will help health care professionals learn more about what it is like to live with relapsing-remitting multiple sclerosis as a young adult.

You are invited to consider taking part in this study if you:

- ❖ Have been diagnosed with relapsing-remitting multiple sclerosis by a physician at least six months before enrolling in the study
- ❖ Are between the ages of 20 to 40
- ❖ Are willing and able to relate your experiences

What is involved in the study?

- ❖ Having **3** interviews at a convenient location over one month

What benefits are there to participating?

- ❖ The chance to have a friendly, trustworthy visitor who will listen to your concerns about living as a young adult with RRMS
- ❖ The chance to indirectly help other young adults like yourself who are living with relapsing-remitting multiple sclerosis

We are inviting individuals to participate who live in:

- Adams County, IL
- Lewis County, MO
- Monroe County, MO
- Boone County, MO
- Marion County, MO
- Ralls County, MO

The researcher is Brenda Beshears, Doctoral Student
MU Sinclair School of Nursing.

If you or someone you know might be interested in participating, please call Ms. Beshears at 573 248-5017 for more information.

This study has been reviewed and approved by the Health Sciences Institutional Review Board of the University of Missouri-Columbia

APPENDIX E

Inclusion Criteria Telephone Interview Questions

Protocol for Telephone Screening Interview for Inclusion Criteria

Thank you for taking time to telephone me to contact me about the research study, “The Experience of Young Adults Living with Relapsing-Remitting Multiple Sclerosis.”

This is a research study about young adults who are living with relapsing-remitting multiple sclerosis (RRMS). I am trying to find out what it is like for them to live with RRMS. During this conversation, I will ask three brief questions to decide if you are eligible to participate in the study.

- 1) Are you between the ages of 20 and 40?
- 2) Have you been diagnosed with Relapsing-Remitting Multiple Sclerosis for six months or more?
- 3) Who diagnosed you with RRMS?

If the answers to Questions 1 and 2 are “Yes”, I will ask Question 3. If the answer to Question 3 is a “doctor,” I will explore as to whether the reference is to a medical doctor or not. If the volunteer was diagnosed with RRMS by a “medical doctor” or a “physician,”

I will explain that he or she is eligible to take part in the study. I will ask the following questions.

- 1) Would you like to meet with me to learn more about the study? (If yes...) The meeting will take approximately 60 – 90 minutes. What date and time would be good for you?
- 2) This first meeting and all interviews for the study need to be at a private location of your choice. Most people prefer to meet at the home. Where would you like to meet?
- 3) If at the home...Can you give me your home address?
- 4) Are there specific driving directions that I should know?

Thank you, and I look forward to seeing you on [day of week / date.]

APPENDIX F

CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

INVESTIGATOR'S NAME:

BRENDA K. BESHEARS, PhDc, RN

PROJECT #

DATE OF PROJECT APPROVAL:

FOR HS IRB USE ONLY	
APPROVED	
_____ HS IRB Authorized Representative	_____ Date
EXPIRATION DATE: _____	

Study Title: The Experience of Young Adults Living
with Relapsing-Remitting Multiple Sclerosis

INTRODUCTION

This consent may contain words that you do not understand. Please ask Brenda Beshears, the primary investigator (a doctoral student from the University of Missouri), to explain any words or information that you do not clearly understand.

This is a research study about young adults who are living with relapsing-remitting multiple sclerosis (RRMS). I am trying to find out what it is like for them to live with RRMS. Research studies include only people who choose to participate. As a study participant you have the right to know about the procedures that will be used in this research study so that you can make the decision whether or not to participate. The information presented here is simply an effort to make you better informed so that you may give or withhold your consent to participate in this research study.

Please take your time to make your decision about participating in this research study. I encourage you to discuss the study and your decision with your family and friends.

You are being asked to take part in this study because:

- You have been diagnosed with Relapsing-Remitting Multiple Sclerosis by a physician for at least six months before enrolling in the study.
- You are between the ages of 20 to 40

This study is not sponsored by any grants.

In order to participate in this study, it will be necessary to give your written consent.

WHY IS THIS STUDY BEING DONE?

The overall purpose of this phenomenological study is to explore and interpret the experience of young adults living with RRMS. The first aim of the research is to interpret the meaning of changes that might have occurred in the lives of young adults since the RRMS diagnosis. A second aim is to understand how young adults make meaning of the expectations that others such as family members, friends, and employers have of them as they live with RRMS. The final aim is to explore how young adults learn new ways of being during exacerbations of RRMS.

This research is being done because there is little research focused specifically on the meaning for young adults who are living with RRMS. The results might offer information for health professionals and young adults as they manage this chronic illness.

HOW MANY PEOPLE WILL TAKE PART IN THE STUDY?

At least six but no more than eight people will take part in this study

WHAT IS INVOLVED IN THE STUDY?

Over a period of 1 to 2 months, there will be

- an introductory meeting with Brenda Beshears and
- three interviews in your home or at a private location of your choice

After receiving an informational packet, you will have the option of contacting Mrs. Beshears by telephone. If you decide to make this contact, Mrs. Beshears will review the criteria for participation and decide whether you meet the criteria to participate.

In the introductory meeting at your home or a private location of your choice, Ms. Beshears will read an information sheet to you that will further explain the study. You will have a chance to ask questions about the study. If you decide to give your consent to participate, Ms. Beshears will ask you to sign the consent form. You are encouraged to ask someone you trust to join you with Ms. Beshears for this meeting.

If you decide to take part in the study, Ms. Beshears will meet with you in your home or at a private location of your choice for the interviews. Each interview will last between 60 and 90 minutes. During each interview, Ms. Beshears will ask questions to ensure that she understand your responses.

During the first interview, Ms. Beshears will ask you some questions about changes that might have occurred in your life since the diagnosis of RRMS.

During the second interview, the questions will be related to the expectations that you believe others have of you since the diagnosis.

During the third interview, Ms. Beshears will inquire about how you manage day-to-day life and if you have found new ways to accomplish everyday tasks. She will also ask questions about what it is like when the illness gets worse.

This is a general schedule for interviews at your home.

Interview #1: Immediately following or within two weeks after the introductory meeting

Interview #2: Within one week after Interview #1

Interview #3: Within one week after Interview #2

All of the interviews at your home or at a private location of your choice will be recorded. All of the information will remain strictly confidential. That is, Ms. Beshears will not tell anyone what you say during the interviews. You will be de-identified in any discussions or publications related to the project. However, you can tell Ms. Beshears that you want the recorder turned off at a particular time, and you can ask Ms. Beshears to erase something that you just said from the recording. Ms. Beshears will always call you the day before or the day of an interview to verify that it is still a good time for the interview. If you do not feel like having an interview, just say so, and Ms. Beshears will reschedule it at your convenience.

If you are ill or unable to participate when Ms. Beshears comes to your home for an interview, she will not proceed with the interview. Ms. Beshears will help you to contact someone who can assist you, such as a family member or a physician. In an emergency, Ms. Beshears will call 911 on your behalf.

If you suffer distress during an interview when discussing your situation as a young adult living with RRMS, Ms. Beshears will express caring concern for you, and will not ask further interview questions. If your distress is so apparent that Ms. Beshears believes that you need to have someone else with you, she will ask if there is someone that can be contacted on your behalf. Ms. Beshears will stay with you until someone else is there. Also, we will refer you to your physician for follow-up or to one of the social service agencies in your area that is available to assist persons in distress. If you become distressed, we will reschedule the rest of the interview.

HOW LONG WILL I BE IN THE STUDY?

You will be in the study for one to two months.

As mentioned above, there might be an occasion when either you or Ms. Beshears believes you are unable to participate in an interview. Within one month, Ms. Beshears will try to reschedule the interview, but if you are unable to participate then, Ms. Beshears will decide to take you off the study. If this occurs, Ms. Beshears will send you a letter about it to thank you for your assistance to that point. The data that we have from you thus far could be destroyed if you wish.

The reason mentioned above is the only reason that Ms. Beshears might decide to take you off this study. If you decide to start participating, we will consider you eligible to continue.

You can stop participating at any time. Your decision to withdraw from the study will not affect in any way your medical care and/or benefits.

WHAT ARE THE RISKS OF THE STUDY?

There are no obvious medical risks in this study. Some of the questions might make you uncomfortable. If this happens, please talk to the trained interviewer. You might choose not to answer any questions that make you feel uncomfortable. As stated earlier, if you suffer distress during an interview when discussing your situation as a young adult living with RRMS, Ms. Beshears will express caring concern for you, and Ms. Beshears will not ask further interview questions. If your distress is so apparent that Ms. Beshears believes that you need to have someone else with you, I will ask if there is someone that I can contact on your behalf. The interviewer will stay with you until someone else is there. Also, we will refer you to your physician for follow-up or to one of the social service agencies in your area that is available to assist persons in distress. If you become distressed, we will reschedule the rest of the interview.

Other minor risks related to this study of the experience of young adults living with RRMS include:

- Fatigue during the interviews
- An illness at the time of the interview
- Uncertainty or confusion about the nature of the study and your role
- The idea that once you are in the study, you have to continue until it is over, even if you would rather not continue
- Sadness at the thought that the research study is coming to an end
- A concern that someone other than the research staff will have access to one's personal information

I believe that if any of these risks should occur, it will be reversible. If the interviewer asks a question that brings up worries, concerns, or bad memories, you are free to say you do not wish to discuss the topic. You also are free to withdraw from participation in the study at any time. If any of our discussions causes you unusual emotional distress, Ms. Beshears can refer you to a professional counselor in your community.

For the reasons stated above Ms. Beshears will observe you closely during the interview. If you have any worrisome concerns about the study, including one of the concerns mentioned above or something that Ms. Beshears says to you, please tell me immediately. For more information about possible risks due to taking part in this study, ask Ms. Beshears or contact the Health Sciences Institutional Review Board at 573 882-3181.

ARE THERE BENEFITS TO TAKING PART IN THE STUDY?

If you decide to take part in this study, it might be helpful to you to have the chance to talk about living with RRMS as a young adult. Having the chance to discuss this important topic with an interested person may help you think about what it means to live day-to-day with RRMS. During the interview, you will be the center of another person's attention and most persons find that enjoyable.

If you decide to take part in this study, you can expect to be helping other young adults like yourself by contributing to the information we have about living with RRMS. I believe that in the future the information learned in this study will benefit other young adults living with RRMS and their families.

WHAT OTHER OPTIONS ARE THERE?

An alternative is not to participate in this research study.

WHAT ABOUT CONFIDENTIALITY?

Information produced by this study will be stored in the investigator's file and identified by a code number only. The code key connecting your name to specific information about you will be kept in a separate, secure location. Information contained in your records may not be given to anyone unaffiliated with the study in a form that could identify you without your written consent, except as required by law.

Without mentioning your name, Ms. Beshears and her doctoral committee will talk about the study in our meeting room at the university. I may also share information from the study at professional meetings, but your name will never be used. I will keep everything that you tell me confidential. I will not release or publish any information by which you could be directly identified. I will not use your name or other personal identifying information in reports or publications about the study.

If you decide to take part in the study, a recording will be made of each interview at your home. However, if you prefer that the interviewer not record something you are about to say, just say so. Ms. Beshears will turn off the recorder until you are ready to have it turned on again. Also, you might realize after you have said something that you would rather that remark were not on the recorder. If that happens, tell the interviewer right away. The interviewer will stop the interview and erase that part of the recording. Ms. Beshears will play the recording back to you so you can verify that the remark is no longer on the recording.

Each recording will be identified only with a number – not with your name. Ms. Beshears considers these recordings as the best record of what you said about your experience. This will be more accurate than if Ms. Beshears tried to remember everything you said or tried to take notes while you were talking. After the interview, Ms. Beshears will take the recording directly to her office, listen to the recording and type everything that was said into a computer. Ms. Beshears will then keep the recording in a locked file cabinet at her private office.

However, it is possible that someone who knew your voice could identify you if they listened to that recording. For this reason, you must give special written permission for Ms. Beshears to play part of one of your recordings when she talks about the study at professional meetings. If Ms. Beshears wishes to play part of one of your recordings in such a meeting, she will give you the opportunity to listen to the recording before asking you to give your permission to use it.

It is possible that your medical and/or research record, including sensitive information and/or identifying information, may be inspected and/or copied by the

study sponsor (and/or its agent), Food and Drug Administration (FDA), federal or state government agencies, or hospital accrediting agencies, in the course of carrying out their duties. If your record is inspected or copied by the study sponsor (and/or its agents), or by any of these agencies, the University of Missouri-Columbia, will use reasonable efforts to protect your privacy and the confidentiality of your medical information.

The results of this study may be published in a health-related book or journal or used for teaching purposes. However, your name or other identifying information will not be used in any publication or teaching materials without your specific permission.

WHAT ARE THE COSTS?

There are no costs to you associated with participating in this study.

WILL I BE PAID FOR PARTICIPATING IN THE STUDY?

Participants will not receive any inducement to participate or any compensation for participating.

WHAT IF I AM INJURED?

It is not the policy of the University of Missouri to compensate human subjects in the event the research results in injury. The University of Missouri, in fulfilling its public responsibility, has provided medical, professional and general liability insurance coverage for any injury in the event such injury is caused by the negligence of the University of Missouri, its faculty and staff. The University of Missouri also will provide, within the limitations of the laws of the State of Missouri, facilities and medical attention to subjects who suffer injuries while participating in the research projects of the University of Missouri. In the event you have suffered injury as the result of participation in this research program, you are to contact the Risk Management Officer, telephone number (573) 882-1181, at the Health Sciences Center, who can review the matter and provide further information. This statement is not to be construed as an admission of liability.

WHAT ARE MY RIGHTS AS A PARTICIPANT?

Participation in this study is voluntary. You do not have to participate in this study. If you decide not to participate, it will not involve any penalties or losses of any kind. Your present or future care will not be affected should you choose not to participate. If you decide to participate, you can change your mind and drop out of the study at any time without affecting your present or future care at the University of Missouri Hospitals and Clinics. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Brenda Beshears, the lead investigator of this study may decide to end your participation in this study at any time after she has explained the reasons for doing so and has helped arrange for your continued care by your own doctor, if needed.

You will be informed of any significant new findings discovered during the course of this study that might influence your health, welfare, or willingness to continue participation in this study.

WHOM DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?

If you

- have any questions regarding your rights as a participant in this research
- have any concerns about the study
- feel under any pressure to enroll in this study
- feel under any pressure to continue to participate in this study when you would rather not do so,

you may contact the University of Missouri Health Sciences Institutional Review Board at (573) 882-3181. The University of Missouri Health Sciences Institutional Review Board is a group of people who work to protect the rights of people who participate in research studies.

You may ask more questions about the study at any time. For questions about the study, contact the lead investigator, Brenda Beshears, at 573 248-5017, or her research adviser, Dr. Eileen Porter, Professor, School of Nursing, University of Missouri, at 573 884-7261.

A copy of this consent form will be given to you to keep.

WHAT ABOUT GIVING PERMISSION TO PARTICIPATE?

You have now heard the information about the study that we are doing to learn about young adults living with RRMS. Do you have any questions about the study?

You can make a decision today about participating. If you would like to participate, Ms. Beshears will show you the consent form for participating. She will review it with you and ask you to sign it. If you decide to participate in this study, Ms. Beshears will give you a copy of this consent form to keep. However, you do not need to make a decision today about taking part in this study. If you would like to think it over before you decide, it is your right to do so. If you would like to have a copy of this consent form to give to someone you trust before you decide whether you want to participate, please tell Ms. Beshears now. She will be glad to come back another day to review this information with you again so that you will have time to think about your decision.

SIGNATURE

I confirm that the purpose of the research, the study procedures, the possible risks and discomforts as well as potential benefits that I may experience have been explained to me. Alternatives to my participation in the study also have been discussed. I have read this consent form and my questions have been answered. My signature below indicates my willingness to participate in this study.

Participant

Date

*Witness (if required)**

Date

*The presence and signature of an impartial witness is required during the entire informed consent discussion if the patient or patient's legally authorized representative is unable to read.

SIGNATURE OF STUDY REPRESENTATIVE

I have explained the purpose of the research, the study procedures, identifying those that are investigational, the possible risks and discomforts as well as potential benefits and have answered questions regarding the study to the best of my ability.

Study Representative****

Date

*Witness (if required)***

Date

****Study Representative is a person authorized to obtain consent. Per the policies of the University of Missouri Health Care, for any 'significant risk/treatment' study, the Study Representative must be a physician who is either the Principal or Co-Investigator. If the study is deemed either 'significant risk/non-treatment' or 'minimal risk,' the Study Representative may be a non-physician study investigator.

**Regulations do not require the signature of a witness when the patient or patient's legally authorized representative is able to read and is capable of understanding the consent form document.

APPENDIX G
INTERVIEW GUIDE

Interview One

One of the things that I hope to do with this research is to understand what it means to be diagnosed with Relapsing-Remitting Multiple Sclerosis as a young adult. To help me with this, I will first ask you some questions about changes that might have occurred in your life since the diagnosis.

- 1) Would you mind sharing a little about your life?
 - a. What is your marital status?
 - b. What is your current age?
- 2) Can you tell me about your living arrangements?
- 3) What is your current employment status?

Example: Full-time outside the home
Part-time outside the home
Homemaker
Student
Unemployed or laid off
Disabled

- 4) Could you tell me about your diagnosis period?
- 5) When did you first think something was wrong?
 - a. How old were you?
- 6) I am wondering what your understanding was of the diagnosis at the time you were told you had MS?
- 7) Is there anything you wish you had been told about the diagnosis that you feel was missing?
- 8) Has your understanding of the diagnosis changed?

- 9) What did the diagnosis mean for your life?
- 10) What did you say to yourself early on about the diagnosis?
- 11) Are you hesitant to tell people about your diagnosis?
- 12) What changes have you experienced in your personal life since your diagnosis? (relationships, social life, work, living arrangements, relocation)
- 13) Was the RRMS a factor in bringing about that change? (If so), what other factors were involved?
- 14) How has that (specific change affected your day-to-day life since then?
- 15) What else should I ask about that would help me understand what it means to be diagnosed with Relapsing-Remitting Multiple Sclerosis as a young adult?

Interview Two

Before we get started with questions for today's interview, do you have any questions or concerns from our first conversation? [Any individualized follow-up probes from Interview One will then be asked.] In our interview today, I would like to ask about the expectations that you believe others have of you since the diagnosis of Relapsing-Remitting Multiple Sclerosis.

- 1) What expectations do you think family members have of you since the diagnosis?
- 2) How do you know that the family has these expectations of you?

- 3) How have these expectations changed since (a) the diagnosis and (b) any major changes in your life that have taken place since the diagnosis?
- 4) How do you deal with these expectations?
- 5) What expectations do you think others such as (friends, co-workers, employer) have of you since the diagnosis?
- 6) How do you know that others have these expectations of you? (person-specific)
- 7) I am interested in knowing how these expectations changed since (a) the diagnosis and (b) any major changes in your life that have taken place since the diagnosis? (person-specific)
- 8) How do you deal with these expectations?
- 9) Can you think of anything else that will help me understand the expectations that you believe others have of you since (a) your diagnosis with Relapsing-Remitting Multiple Sclerosis and (b) any major changes in your life since then?

Interview Three

In our interview today, I would like to ask you questions about what it is like when the illness gets worse. I will ask questions about how you manage day-to-day life and if you have found new ways to accomplish everyday tasks. Do you have any questions?

- 1) As a person who lives with RRMS, tell me about your usual day.
- 2) What is it like when the illness gets worse?

- 3) How often do you see a health care provider?
- 4) Have you chosen to use medical treatments for your illness?
- 5) Do you use any other therapies not prescribed by your doctor?
- 6) What are your sources of support?
- 7) What things in your daily life have changes since your diagnosis with RRMS?
- 8) I am interested in your thoughts about your future.
- 9) Have your thoughts about the future changed because of your illness?
- 10) Can you think of anything else that will help me understand what it is like to manage day-to-day life with RRMS as a young adult?
- 11) Is there anything else that you think I should know to have a better understanding of what it is like to live with RRMS as a young adult?

APPENDIX H

Initial Matrix with 38 Themes

Theme #1 How to tell/Who to tell	Theme #2 Meaning of diagnosis	Theme #3 Family reactions	Theme #4 Fatigue/Just Tired	Theme #5 It's just weird/strange
Theme #6 Symptoms when first diagnosed and later exacerbations	Theme #7 Faith	Theme #8 Disabilities or Different Abilities	Theme #9 Emotions	Theme #10 Uncertainty
Theme #11 Quest for Knowledge	Theme #12 It is a Disease that affects family/friends/co-workers	Theme #13 Wishing for opportunity to talk to others similar to herself.	Theme #14 Trying to make sense of the disease.	Theme #15 Diagnosis is associated with planning
Theme #16 Taking the disease day by day.	Theme #17 Pity	Theme #18	Theme #19 Background of life	Theme #20 It's not the same (Chronic Illness)
Theme #21	Theme #22 Fear	Theme #23	Theme #24 Health-Care Providers Influence	Theme #25
Theme #31 Guilt/Blame	Theme #32 Giving self permission to be sick.	Theme #33 Self-Esteem	Theme #34 Listen to your body	Theme #35 Medications
Theme #36 Expectations of family members	Theme #37 Work	Theme #38 Family Support		

VITA

Brenda Creek Beshears was born September 4, 1953 in Texas County, Missouri. After attending public schools in Licking, Missouri, she received the following degrees: A.D. (1985) and B.S. in nursing (1988) from Hannibal-LaGrange College in Hannibal, Missouri; M.S. in nursing from Southern Illinois University–Edwardsville, Illinois (1991); PhD in nursing from the University of Missouri-Columbia (2010). She has worked as a staff nurse, community health nurse, and a nurse educator. Dr. Beshears is currently an Associate Professor and Academic Dean at the Blessing-Rieman College of Nursing in Quincy, Illinois.

Brenda is married to George Beshears of Hannibal, Missouri and is the mother of two daughters, Angie Privett and Kathy Asbury; she is also the grandmother of two children, Lanie and Konnor. She is a member of Sigma Theta Tau - Pi Pi chapter and the Missouri Nurses Association. She is also active in her church and community.