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A Narrative Analysis of Resilience and Coping in Persons Diagnosed with Multiple Sclerosis

Mildred Christian Alford
Walden University

Walden University

College of Social and Behavioral Sciences

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Mildred Alford

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Review Committee
Dr. Susan Marcus, Committee Chairperson, Psychology Faculty
Dr. Grant Rich, Committee Member, Psychology Faculty
Dr. Debra Wilson, University Reviewer, Psychology Faculty

Chief Academic Officer
Eric Riedel, Ph.D.

Walden University
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Mildred C. Alford

Ph.D., Ed., Berne International Graduate University, 1998

M.S. Ed., Texas A & M University, Commerce, 1989

B.S., Psychology, University of Houston, 1976

Dissertation Submitted in Partial Fulfillment

of the Requirements for the Degree of

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Health Psychology

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Abstract

Multiple sclerosis (MS) is an autoimmune disease that affects millions of people.

Approximately 85% are diagnosed with progressive-relapsing MS, and most are women.

This illness is characterized by clearly defined attacks of worsening neurological

function, followed by partial or complete remissions. While there is considerable

quantitative literature documenting the progressive symptoms and consequential impact

on quality of life, little research has been done to explore the illness narratives of women

with MS as they cope with the demands of everyday life. Therefore, the purpose of this

narrative analysis was to explore the experience of resilience and coping in women with

MS. Using the conceptual framework of positive psychology, seven women diagnosed

with MS at least two years prior were interviewed. Riessman's thematic analysis was

used, and the fully formed narratives revealed these themes: life before diagnosis,

process of diagnosis, after diagnosis, role of family and caregivers, health challenges,

resilience and coping strategies, and presence and effect of positive emotions. Findings

are discussed in light of the research on positive psychology strategies that enhance

quality of life; and on research with persons who have MS and other chronic illnesses

who experience depression, fatigue, pain, the loss of social support and poor self-

efficacy. Future studies are encouraged to include longitudinal data to understand how

coping and resilience emerge and change over time. These results can contribute to

efforts to advocate for quality of life while living with this condition, and will be shared

with those who are diagnosed with MS, with their families through local and national MS

societies, and with professional audiences in scholarly and applied forums.

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Dedication

This work is dedicated to my family: my husband, Rick, our three children, Major Brandon Alford and wife, Cara-Lee, Brian Alford and wife, Nori-Lyn, and Ashley Alford Brodie and husband, S.Sgt. Steven Brodie, and Grandchildren, Caleb, Madison, Gabriel, Matthew, Liam, James, and Baby Alford # 7. It is also dedicated to my parents, Whit and Dee Christian, and other special members of my family: Brother, Sisters, Nieces and Nephews who encourage me and give me great support.

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My sincere appreciation to my Committee Members: Advisor, Dr. Susan Marcus, Committee Member, Dr. Grant Rich, and URR Member, Dr. Debra Wilson. I'd also like to thank my family members, and friends who have helped me reach this goal.

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Chapter 1: Introduction to the Study

With an estimated 2,500,000 persons affected with multiple sclerosis (MS)

worldwide, there continues to be a concentrated effort to increase awareness about the

disease and its ramifications (Mackenzie, 2013; McGuigan, 2004; Visser, 2012). Studies

are being conducted in the United States and other countries on the biology of the disease

process, treatments for the disease conditions, and prevention of future occurrences

(Trisolini, Honeycutt, Wiener, & Lesesne, 2010).

One area of research that has grown in recent years concerns how persons with

debilitating diseases can find contentment and happiness while dealing with the disease

process and associated challenges (Kirchner & Lara, 2011). According to Albert

Schweitzer (nd), happiness is "nothing more than good health and a bad memory."

However, even if good health is not part of a person's current state, mental health

practitioners and scholars have suggested that afflicted individuals can find a pathway to

happiness in spite of physical limitations (Forbes, While, Mathes, & Griffiths, 2006;

Grytten, & Maeseide, 2006; Pakenham, 2006; Pawelski & Gupta, 2009).

For example, Seligman (2002) suggested that all lives can be enhanced through

strategies based in positive psychology. Coping strategies can be formal (like stress

management techniques, mindfulness meditation, positive visualization) or self-designed

from personal experience with challenge or trauma (Fredrickson, 2000; Roberts, 2010).

However, the question of how people living with MS come to find these strategies, and

find life satisfaction in the midst of their personal challenges has not been fully explored.

This qualitative study of resilience and coping in persons with MS will add to the body of scientific and practical literature available to individuals with MS, and to the caretakers and professionals who aim to offer a better quality of life. The results of this research can be shared with MS patients and caregivers through local and national MS organizations and communicated to healthcare professionals in presentations and journals. While my intent in the study was not to demonstrate "cause and effect," the qualitative approach I took in the study can offer the opportunity for transferability – knowledge sharing across comparable settings and experiences – such that persons who experience MS, care for individuals with MS, or study MS can find meaning and value in the results (Patton, 2002; Shenton, 2004). Of special interest is how persons with MS cope with the debilitations of the disease and how resilience to life's circumstances adds to the overall health and well-being of individuals who suffer from it.

This chapter includes a discussion of the study's background, the purpose statement, and the research questions and definition of terms. It also includes discussions of my assumptions in the study, and its limitations and significance.

Background of the Study

MS is a debilitating disease, and the affected person is challenged not only by the physical consequences, but also with the mental, emotional, social, and spiritual consequences of the disease process. Meta-analytic studies and literature reviews have reported that major depression is common in persons with MS, with estimates of lifetime prevalence of major depression in MS as high as 50%, which is considerably higher than the general population (Hind et al., 2014; Siegert & Abernethy, 2005). When there is a

peripheral infection, such as cancer or autoimmune diseases, innate immune cells interact

with the brain and produce pro-inflammatory cytokines that cause sickness in the patient.

When this interaction occurs, inflammation causes the brain to signal a continued or

exacerbation of the disease and symptoms of depression often occur in patients who are

vulnerable. It is likely that this action might account for the increased number of

clinically depressed patients who are physically ill. This biological occurrence might be

responsible for the increase in major depressive episodes in the physically ill, mimicking

the more psychosocial factors such as loss of a loved one, shock, trauma, extended

incapacitation, etcetera (Dantzer, O'Connor, Freud, Johnson, & Kelley, 2008).

Anxiety and other affective symptoms have also been identified as more

frequently occurring in MS patients (Kirchner & Lara, 2011), as well as in other persons

with chronic, debilitating conditions (Fredrickson, 2000; Moskowitz, Folkman, Collette,

& Vittinghoff, 1966). Researchers have also described cognitive impairments

(Pakenham, 2006), as well as fatigue, stress, and declining social functioning (Kirchner &

Lara, 2011). Most of this research has focused on quantitative studies, including both

large and small cross-sectional studies, as well as longitudinal observations of the

changes in physical and mental abilities over time (Edmons, Vivat, Burman, Silber, &

Higginson, 2007).

In recent years, research on how people experience and recover from trauma has

indicated that certain qualities and strategies can be cultivated to improve depression,

cognitive function, and produce happiness and hopefulness even under adverse

conditions (Lobentanz, Asenbaum, & Vass, 2004; Masten, 2001; Seligman ,1990).

Research and theory from positive psychology suggests that cultivating resilience and positive coping strategies can lead to a more meaningful life (Amato, Ponziaini, Rossi, Liedl, Stafanile, & Rossi, 2001; Lobentanz, Asenbaum, & Vass, 2004; Rao, 1995).

Resilience is currently defined as the ability of a person to endure and recover from difficulty, and in recent years researchers have focused on examining the internal characteristics of determination, endurance, adaptability, and recovery (Comas-Diaz et al., 2000; Masten, 2001; Taormina, 2015; Tugade et al., 2004; Vatali, 2011). There is considerable literature on the resilience of children recovering from trauma (Reivich & Schatte, 2002; Froh et al., 2011), as well as quantitative examinations of the construct of resilience as a mediator of adult recovery from natural and man-made disasters and other traumatic life events (Taormina, 2015).

Coping is traditionally identified as cognitive processes and behaviors that people use in response to stress to reduce or manage distressing emotional states (Menninger, 1963; Valliant, 1977). Earlier research on coping has indicated that it may mediate between stressful events and psychological and behavioral outcomes (Coyne, Aldwin, & Lazarus, 1981; Felton, Revenson, & Hinrichsen, 1984; Lazarus & Folkman, 1984). While there have been some quantitative efforts to examine how coping with diseases like MS influences quality of life (Motl & McAuley, 2009), there is limited qualitative literature that provides rich, thick descriptions of these experiences (Schneider & Young, 2012). The quantitative studies enhance understanding of "what" is happening, but have missed the intensive explorations of "how," "when," and "what for" (Patton, 2002; Riessman, 2008). In this research, I addressed the gap in knowledge and literature on

how persons with the debilitating disease of MS can experience positive coping and resilience in daily life.

Statement of the Problem

Depression, anxiety, and other affective symptoms often accompany the physical challenges for persons with MS (Wynia, Middel, van Dijk, De Keyser, & Reijneveld, 2008). These may be a reaction to the life circumstances, a consequence of the neurological changes, or a side effect of medications like corticosteroids (Feinstein, 2001; Kirchner & Lara, 2011; Patton, 2002). These negative emotions and a narrowing of expectations about the quality of life make living with the disease even more detrimental. Research and theory from positive psychology has indicated that cultivating resilience and positive coping strategies can lead to a more meaningful life (Amato et al., 2001; Lobentanz et al., 2004; Rao, 1995). There is a gap in the literature regarding the understanding of how persons with MS experience a meaningful life and the coping strategies they have developed to cope with their illness in daily life.

Purpose of the Study

The purpose of this qualitative study was to explore the experience of resilience and coping in women with MS using a narrative analysis approach (see Delpit, 1995; Mishler, 1991; Riessman, 2008). Using the theoretical framework of positive psychology (Emmons & McCullough, 2003; Kitano & Lewis, 2005; Seligman, 2011), I examined the accounts of participants' experience of MS from just prior to diagnosis to their current life circumstances in order to gain insight about the meaning of resilience and coping.

Research Questions

I used narrative analysis to explore the following research questions:

1. What is the meaning of resilience to individuals living with MS?

2. What is the meaning of coping to individuals living with MS?

3. How do the themes of positive psychology illuminate the experience of a "meaningful life" in individuals living with MS?

Using the positive psychology model (Seligman, 2011), I examined how individuals with MS are enabled or constrained by their disease, and what their stories say about resilience and coping. This included an exploration of the five elements of well-being: positive emotion, engagement, relationships, meaning and purpose, and accomplishment.

Nature of the Study

I conducted in-depth interviews in order to gain access to the narrative arc of the participants' experiences of living with this disease (see Riessman, 2008). This type of narrative analysis allows for more in-depth considerations of what is said, and includes the influence of the interviewer, the setting, and social context. Using the framework of positive psychology I examined participants' narrative styles and language to make meaning of their experiences. Specifically, I explored the concepts of resilience and coping, and listened for issues such as depression, anxiety, and lack of mobility that have been reported as common experiences for persons with MS. Patel (2005) considered personal narratives as important tools in assessing problematic areas as well as providing insight for clinical applications like treatment planning.

I collected interview data from women with MS who are in the Lone Star Chapter of the National Multiple Sclerosis Society. The target population included women who have been diagnosed with MS over the age of 18 years. I posted an invitation for participation on the MS website and via Facebook. After initial contact, an informed consent was sent to each participant. The interviews with each participant took place via telephone and lasted about an hour, and I budgeted for additional time if needed for completion or clarification. I deliberately chose telephone over face-to-face interviews because persons with this condition deal with mobility, stamina, and scheduling challenges that are likely to make face-to-face interviews difficult. The data were analyzed using Riessman's thematic approach to identify themes and narrative elements within and across cases.

Conceptual Framework

The theory of positive psychology (Emmons, 2008; Fredrickson, 2001; Grimm, Kolts & Watkins, 2004; Seligman, 2011) served as the conceptual framework I used to understand and explore how persons with chronic, debilitating diseases like MS can experience meaning their lives. Positive psychology is an all-encompassing theoretical framework, philosophical position, directive for therapeutic applications, and guideline for self-help and social support groups. It is best summarized by Seligman's (2012) presentation of the "five pillars" or elements of well-being (PERMA):

- **P**ositive emotion (of which happiness and life satisfaction are all aspects)
- **E**ngagement
- **R**elationships

- **M**eaning and purpose

- **A**ccomplishment

The theory of positive psychology proposes that "positive emotions" have benefits beyond the experience of happiness. "Positive emotions," according to Frederickson (2001), include joy, gratitude, serenity, interest, hope, pride, amusement, and inspiration, and impact attitudes and actions. Further, this model indicates that actively cultivating "positive emotions" has direct and indirect mental and physical health benefits, including relief from depression (Seligman, Steen, Park, & Peterson, 2005) and increased resilience against physical illness (Fredrickson, 2001).

Engagement refers to the participation in activities and interests that create the experience of what theorists call "flow," the absorption in activities and events that are useful, fulfilling, and challenging. The construct of engagement has been examined in great detail as a factor in work satisfaction, academic success, and therapeutic outcomes (Maddux & Gosselin, 2003; Tetley, Jinks, Huband & Howells, 2011; Wimpenny & Savin-Baden, 2013).

Relationships include being connected to persons in meaningful ways for mutual support, friendship, and cooperation. Considerable research has indicated that relationships are a key factor in health, well-being, and longevity (Holt-Lunstad, Smith, & Layton, 2010).

Meaning refers to the experience of belonging to and participating in an event, group, or organization that serves a purpose greater than one's own personal needs. Wong (2012) described meaning as the means for integrating human needs and functions,

and cited extensive literature documenting the relationship between meaning and well-being in both personality and social psychology research.

Accomplishment includes the cultivation of mastery or achievement of a skill or goal through focusing on the satisfaction of incremental steps. Accomplishment has been examined thoroughly as a factor in work and academic performance, as well as in the therapeutic outcomes for those with disabilities and mental illness (Luthans, Avolio, Avey, & Norman, 2007; Tetly, Jinks et al., 2011; Wimpenny & Savin-Baden, 2013).

Researchers have shown that these pillars cultivate resilience—the ability to buffer adversity and alleviate stress and depression in persons who were suffering from illnesses (Masten, 2001: Snyder, Feldman, Taylor, Schroeder, & Adams, 2000). Revich and Shatte (2002) identified factors they considered obstacles in life which tend to hamper one's well-being by studying the lives of persons who were not performing to their capacity, persons who experienced set-backs in their lives, persons with illnesses, and those who were not able to handle their problems effectively. In their book, they describe work with corporate executives, parents, children, teachers, and athletes to develop skills to counteract negative reactions and build positive resilience in their lives. Their findings showed the importance of resilience as a primary factor to success and happiness.

These skills are also called positive psychology strategies, and include treatment or self-designed interventions that build the emotional strengths of persons who suffer either emotionally, physically, or spiritually. These skills act as a buffer against adversity and psychological disorders. Researchers have suggested that these skills may be the key

to resilience, which may guide people to experience fewer setbacks and a more meaningful and fulfilling life (Masten, 2001; Seligman, 2002).

For the purposes of this study, I used the concepts identified in the positive psychology literature (e.g., resilience, meaning, and engagement) to formulate the interview questions and the thematic analysis of interview responses.

Definition of Terms

Anhedonia: The inability to enjoy experiences or activities that would normally be pleasurable. It is a key diagnostic criterion for a major depressive episode (APA Dictionary, 2007).

Autonomic nervous system (ANS): One of two primary divisions of the central nervous system. The ANS is largely responsible for the maintenance of involuntary body functions such as heart rate, blood pressure, body temperature, and respiration.

Multiple sclerosis (MS): A potentially debilitating disease in which the body's immune system eats away at the protective sheath that covers the nerves. This interferes with the communication between the brain and the rest of the body. Ultimately, this may result in deterioration of the nerves themselves, a process that is not reversible (Mayo Clinic, 2012).

Myelin sheath: The covering of the nerves which is lost as MS progresses. Myelin is a white fatty substance that surrounds some of the axons of the nervous system, which accounts for some of the whiteness of the white matter of the brain (Sternberg, 2009). In MS, the protective coating on nerve fibers (myelin) is damaged and may eventually be destroyed. Depending on where the nerve damage occurs, MS can affect

vision, sensation, coordination, movement, balance, cognitive reasoning, bladder and bowel control, and numerous other functions of the body.

Positive psychology: The study of three concerns: positive emotions, positive individual traits, and positive institutions (Seligman, 2002). To understand positive emotions, one must study contentment with the past, happiness in the present, and hope for the future. To understand positive individual traits, one must study the strengths and virtues (e.g., the capacity for love and work, compassion, courage, creativity, integrity, moderation, self-control, self-knowledge, and wisdom). To understand positive institutions, one must study the meaning and purpose as well as the strengths that create better communities. These include civility, justice, leadership, nurturance, parenting, purpose, teamwork, and tolerance (Seligman, 2002).

Positive psychology strategy: A treatment or intervention which serves to build the strengths of persons who suffer either emotionally, physically, or spiritually that acts as a buffer against adversity and psychological disorders. It may be the key to resilience, which may guide people to a more meaningful and fulfilling life (Masten, 2001; Seligman, 2002).

Relapsing-remitting MS: The term given to the primary form of MS which affects the largest number of people (MS Society, 2012). Most people with MS, particularly in the beginning stages of the disease, experience relapses of symptoms, which are followed by periods of complete or partial remission. Signs and symptoms of MS often are triggered or worsened by an increase in body temperature.

Resilience: The degree to which a system continuously prevents, detects, mitigates, or ameliorates hazards or incidents. Resilience allows persons to "bounce back" to their original ability to provide core functions as soon as possible after incurring damage (Tugade, Fredrickson, & Feldman-Barrett, 2004).

Assumptions

I assumed that participants would understand the interview questions, and that participants would be honest and forthright with their replies, which was the case in each interview. I also assumed that I would accurately interpret the participants' information and, after member checking, found this to be true. It was also assumed that the information gained in the study would reflect the actual improvements or lack of improvements to the lives of the participants, that the study would reveal realistic, historical information, and that each interview would meet those assumptions.

Further, I assumed that the timeframe would be adequate for the narratives. Only one interview ran beyond 1 hour. The average time was around 60 minutes. I assumed that an adequate number of participants would volunteer to participate in the study. Seven participants volunteered for the interview. It was also assumed that the participants could articulate experiences that were transferable to a broader understanding of the phenomena of life satisfaction in individuals with MS. This assumption was also met. Finally, I assumed that my personal experience would not bias the design of the questions, the quality of the interview, or the data analysis given my previous professional employment and the high ethical standards.

Delimitations, Scope, and Limitations

Delimitations. There were several delimitations specific to this study that could have posed limitations on the transferability of the findings. The participants could have experienced time and stamina constraints in arranging and participating in the interviews. However, they did not. I scheduled interviews to coincide with the participants' time availability, physical stamina, and mental clarity. I provided a comfortable, safe atmosphere in which the participants felt assured. The requirements were fully explained to eliminate any frustration or imposition for the participant.

The overall health of the participant could have been a limitation in the interview itself. The participants were fully cooperative and desired to complete the interviews, though the very unstable nature of MS might cause the person to have days that may not allow her to dedicate time to the study because of any number of health issues.

My personal experience with MS did not pose risks to research credibility, but rather positioned me as an empathic but neutral researcher. Nonetheless, I employed several strategies (as described in Chapter 3) to mitigate this potential delimitation. These included releasing the need for control over the narrative, using member checking to verify that I am summarizing and interpreting from the experience of the participants, and audit trails and journaling to track the interview and data analysis process.

Scope. The boundaries of the study included how I defined the accessible population of persons with MS. I invited participants from the Lone Star Chapter of The National MS Society. Founded in 1955, it now includes members from Texas, New Mexico, Oklahoma, Louisiana, and Arkansas. The Lone Star Chapter provides quality

programs and services to 24,000+ persons living with the daily challenges (MS Society, 2010). It is not known how similar or different members of other MS chapters are from these members, but I assumed that there are common experiences that transcend geographic locations. Trochim (2012) observed that transferability is primarily the responsibility of the one doing the generalizing. The qualitative researcher can enhance transferability by doing a thorough job of describing the research participants, context, and procedure. Details are presented in Chapter 3.

Limitations. Narrative research starts from the premise that there are two stories being told—the story of the participant and the story as told by the researcher (Riessman, 2008). Maxwell (1992) has noted that these two "stories" mark two levels of validity in a narrative study. Since I conducted all the interviews, demonstrating the validity of the study methods and results is of great importance. As Neill (2007) observed, that a researcher's personality/thinking style and/or an organizations'culture is under-recognized as a key factor in preferred choice of methods. Therefore, a limitation is my personal relationship to the organization. To address this limitation, I refrained from comments about personal involvement with the organization until the completion of the interview, if at all.

In addition, I attempted to pose the same questions to all participants to ensure consistent results, although these may not have been posed in the same order. This did not limit me from discovering unexpected data (see Fisk, nd). To address this limitation, at the end of the interview, I asked a direct question to the participant, such as, "Do you

have anything you'd like to add to your comments?" This allowed the participant to include issues which may not have been covered in the interview.

Qualitative research is often misunderstood (Madill & Gough, 2008). A common misunderstanding is that small, purposeful samples do not produce definitive conclusions. Madill and Gough (2008) stated that qualitative methods can be clustered in ways that make typology difficult to identify. They also recognized the criticism that qualitative research may be termed *biased*. Research that is qualitative may reveal the attitudes toward a problem or issue (living with MS in this study), but may not allow for adjusted feelings with time. Results of small sample studies of persons with illness are also difficult to replicate, since the personal opinions of participants may change in relation to the illness. Madill and Gough cautioned against deeming it biased by presenting different frameworks where qualitative research can be conducted. I provided sufficient details about the selection of cases and the data collection procedures and analysis plan so that others may attempt to replicate the methodology and share similar or disparate findings. Further, I attempted to achieve saturation with a small sample size by purposefully sampling for homogeneity of the phenomena of interest (Guest, Bunce, & Johnson, 2006).

Researcher bias can present problems, especially if the researcher is personally involved in the issue being studied. Riessman (2008) warned about emotions in interviews, from both the participants and the researchers. This could have presented a problem with authenticity of the participants' comments, and could have led to exaggeration or embellishment of the actual experiences. However, it did not. Likewise,

comments made based on my personal experience could have encouraged the participants to add or subtract from their answers, so I used careful wording and clarification to prevent this. Mattingly (1998) reminded interviewers that narratives do not merely refer to past experiences, but also create experiences for their audiences. The narratives may offer the audience an opportunity to associate the details of their hardships with the listener/reader's own life experiences. To address these limitations and enhancements, I redirected questions, and clarified answers to avoid misunderstanding by either the researcher or the participant. More time was given, when needed, on emotionally charged questions and comments, and clarifications on issues were made when needed. I also gave participants an opportunity to clarify questions to reduce any misgivings about the topics and issues. More specific question/answer information is given in Chapter 3.

Significance of the Study

Bregman and Thiermann (1995) stated that chronicling the distress, pain, and anguish associated with illness and sharing it with anonymous others is considered a worthwhile venture for the narrator. Sharing the stories of living with MS may be helpful for others who suffer from MS, while providing a window through which others may view and understand individuals' thoughts and emotions. By eliciting participants' narratives, the study provided insight into the day-to-day obstacles that people with MS experience. An in-depth evaluation of facets such as depression, resilience, and adversities may provide insight about coping mechanisms on a broader social basis, which may alleviate some of the stress and anxiety that accompany MS.

In studying the *illness narrative*, researchers have used thematic methods to analyze interviews about illness (Riessman, 2008). For example, Williams (1984) developed the idea of narrative reconstruction. This refers to the narratives of individuals for whom chronic illness has disrupted the expected life course. Williams conducted and audio-recorded interviews of persons who had been diagnosed with rheumatoid arthritis. One question he asked was why they thought they got the disease, and he allowed them to expand on their stories in order to make sense of the genesis of disability. By doing so, he developed a theoretical argument which attempts to give meaning to the occurrence of the disease. Williams (1984) explained that through the use of narratives, the participants were trying (a) to establish points of reference between body, self, and society; and (b) to reconstruct a sense of order from the fragmentation produced by chronic illness. He referred to this categorization as telos, or the self has a purpose. To attain this impression of life's course, the interview material was quoted, and Williams found that if the disease can be related to some other point in the individual's life, it can be interpreted as an attempt to reconstitute and repair ruptures between body, self, and world (Riessman, 2008). Furthermore, this interpretation repeats a past theory of Mills (1959), who suggested that a person might link his own illness with others and view it on a grander scale, such as a public issue. Williams's definition of the narrative, adopted by many subsequent researchers, included the whole narrative as it unfolds in the interview. He sought to map the interpretive process that occurs in biographical disruption. Thematic analysts place their primary focus on what is being said—which is similar to grounded theory—instead of dwelling on how, to whom, or for what purpose (Riessman, 2008).

By using these techniques, I hoped to produce a broader, more inclusive interview process in order to reveal a more in-depth look into the acceptance and/or rejection of the disease in the individual's life while highlighting which coping mechanisms, if any, are employed.

The paradigm of positive psychology suggests that positive emotions and the cultivation and well-being increases happiness and reduces obstacles like depression and anxiety (Seligman et al., 2005). Information offered by individuals with MS and their experience with coping, resilience, when compared to the themes that are consistent with Seligman's five elements of well-being (positive emotion, engagement, relationships, meaning and purpose, and accomplishment), may offer another avenue to eliminate some of the suffering and distress (Seligman, 2011).

By addressing these obstacles directly in the narrative portion of the study, I have added insight into the hurdles that have been faced by persons with MS. The participants shared innovative ideas that they have found helpful, which are now available to others who face the same challenges. In addition, the caregivers of persons with disabilities have access to this information, which may help them provide more competent care.

Implications of Positive Social Change

The results of this study will be shared with the members and representatives of the MS Society, Lone Star Chapter. I have had many opportunities to join group meetings to advocate for legislative changes on a state and national level. I participated in such activities as recently as 2012, and will continue to be involved on local, state, and national levels. The results of this study will also be shared with the organizers of the

annual MS Walks throughout the five-state area. The information will not be limited to

local events, but will be provided to the National MS Society. Specifically, I will offer

the findings in a presentation for the National MS Society. I will also be willing to make

presentations to college programs, medical programs such as the Maxine Messinger

Clinic in Houston, and will post my availability on social media. A local Houston

educational organization, disAbility 101, which gives presentations on all issues that

concern persons with MS, will be provided the information in the study, and I will offer

to present the materials in a program for the organization.

Publication of the findings of this study will offer insightful information for those

suffering with MS, and those who treat the disease and care for the patients. The

information will be available to the MS Society and American Association of MS, in

addition to interested parties with local associations. Psychology professionals and other

medical professionals will have access to the information which will offer insight into the

lives of those who are suffering from MS, and those who care for them. Caregivers and

family members of those with MS will also have access to the information, giving them

more tools to combat the stages of MS. All will be better prepared to assess and cope

with the symptoms that present from the onset of the disease.

Summary and Transition

In this chapter I introduced narrative research, positive psychology, and its

implications in physical and mental health. The problem statement, purpose of the study,

and research questions were presented. I also offered the operational definitions, and

addressed the assumptions, scope and limitations, and the significance of the study.

In Chapter 2, I present the body of research on positive psychology and the strategies that have been developed over the years including theories of related studies and material currently in use. It includes discussions of ongoing studies and possible future studies. It also includes information on narratives regarding how they contribute to the understanding of attitudes and feelings of persons with disabilities, and how interpretations of these narratives add to the overall information needed to assist persons with disabilities in their day-to-day living.

In Chapter 3 I describe the methods and procedures for selecting participants and collecting data. The guidelines for ethical protection for the participants are listed, and I provide justification for the number and selection of the participants.

Chapter 4 consists of the data I gathered, including the personal narratives of persons with MS, with an emphasis on historical background relating to the onset, progress, and projected diagnosis of MS. Narratives include elaboration into personal feelings and opinions of the narrators.

In Chapter 5, I explain why I undertook this study, discuss its implications for positive social change, offer recommendations for actions upon the findings, make suggestions for further studies, and close with a thorough summary explaining the findings and their impact.

Chapter 2: Literature Review

The purpose of this study was to collect and examine the narratives of persons with MS in order to understand their sources of life satisfaction and gain insight into the positive coping strategies they use to maintain psychological well-being.

The current literature on MS provides information on the disease itself, but there is not enough information regarding individuals' methods of coping with MS. There have also been few studies in which persons with MS have been given the opportunity to express their own feelings, fears, and questions (see MS Society, 2013). The shortcomings of MS research have been highlighted by advocacy programs, but the information currently available is insufficient to meet the needs of the thousands who must deal with MS on a day-to-day basis.

In this chapter, I define MS and discuss its symptoms and disease process. I also describe the diagnosed population and environmental factors that play a role in the development of MS. It includes the impact of quality of life for those who have MS and those who are caregivers. Changes in lifestyles as a consequence of MS are explained as psychological effects such as depression, anxiety, cognitive impairments, and fatigue. In this chapter, I also define the role of the support system, which includes personal support, educational and professional support, and both local and national medical resources. This chapter includes a discussion of the informational support that is provided to those with MS, and I explain the positive psychological affects that enhance quality of life. Finally, I discuss the types of research methods I used in the study, and provide an overall summary.

Literature Search Strategy

The method I used for researching the literature involved searching the following: PsycINFO, PsycARTICLES, SocINDEX with Full Text, Psyc EXTRA, PsycBooks, Psychology: A SAGE Full-Text Collection, Walden Dissertations, Academic Search Premier, the Multiple Sclerosis Society website, *Narrative Methods for the Human Sciences* by Catherine Kohler Riessman, and articles published by *Breathe London* which includes studies and publications in positive psychology. Terms used in the searches were: *positive psychology, disabilities, positive strategies,* and *narratives*. Other sources include psychology textbooks such as *Statistics for the Behavioral Sciences* (Gravetter, 2007) publications by the National MS Society, and online psychology articles by medical doctors and psychologists. Most articles I used were published from 1990 to present, with the exception of one Greek reference and a few original publications.

Although MS treatments have been ongoing for decades, the overall scholarly knowledge of the details of MS victims' lives has been limited. There is limited current research, but more dissertations and studies of MS on a personal basis are being done to bolster the information. This study adds relevant information to what exists to allow others to profit from the findings (see Ascherio & Munger, 2007; Compston & Coles, 2002).

Conceptual Framework: Positive Psychology

Much research on the life experience of MS patients has focused on the disease as the phenomenon of interest (Christenbery, 2011). In this study, I focused on "a meaningful life" to better understand how people with this debilitating condition create

their lives as "worth living." Noted psychologists such as Seligman, Emmons, and Layard have published extensively on positive psychology, but the definition given by Peterson (2006) highlighted some of the attributes most relevant to this study. He defined positive psychology as the scientific study of what makes life most worth living; that is, positive psychology is the study of a "meaningful life." He noted that researchers in psychology need to be concerned about strength as well as the weakness, and foster positive human potential.

He stated that even persons with serious and debilitating conditions can be a source for understanding the meaning of emotional well-being, which contributes to one's coping ability and may be joined with self-esteem, performance and productivity at work, and even longevity (Fredrickson & Joiner, 2002).

Seligman's Five Elements of Well-Being

In his most recent contribution to positive psychology, Seligman (2011) broadened the conceptual framework from happiness and positive emotions to five elements of well-being (referred to by the acronym PERMA): positive emotion, engagement, relationships, meaning and purpose, and accomplishment. Positive emotions refer to feelings like joy, gratitude, hope, love, and inspiration. Engagement is described as being absorbed in activities and events that are useful, fulfilling, and challenging. Relationships include being connected to persons in meaningful ways for mutual support, friendship, and cooperation. Meaning refers to the experience of belonging to and participating in an event, group, or organization that serves a purpose greater than one's own personal needs. Accomplishment includes the cultivation of

mastery or achievement of a skill or goal through focusing on the satisfaction of incremental steps.

Research on PERMA

In addition to business training, therapeutic interventions, and personal development books, the PERMA concept has been examined more systematically in several arenas. For example, Waters (2011) reviewed 12 studies of positive psychology strategies implemented in schools and found that student well-being and academic performance are positively impacted by programs that employ the tools of positive psychology. These tools combat depression, anxiety, and low self-esteem, and address substance abuse behaviors as well as environmental and social issues. Waters noted that these programs are "aimed at cultivating positive feelings, positive behaviors, or positive cognitions" (Sin & Lyubomirsky, 2009, p. 467). A study by Durlak, Weissberg, Dymnicki, Taylor, & Schellinger (2011) showed students who were enrolled in a program involving social and environmental issues scored higher on achievement tests than other students who did not participate. Considering students' goals, other researchers found that cultivating hope in students proved to "anchor purposive behavior" (Marques, Lopez, & Pais-Ribeiro, 2009). Other researchers like Kern, Waters, Adler, and White (2014) have developed psychometrically rigorous measures of PERMA and found support for this multidimensional approach. Using a questionnaire, they tested cross-sectional associations between well-being and self-reported measures of overall life satisfaction of 153 employees from a large private school in Australia. Kern et al., sought to compare the use of positive strategies with current theories. They assessed the

associations among well-being, physical vitality, physical activity, school engagement, hope, somatic symptoms, and stressful life events, and found that Seligman's (2011) PERMA model could be used to measure well-being in a practical manner. Kern et al.'s study offers more information for teachers to help them meet the well-being needs of entire classes and individual students. Some of the activities included buddy-peer programs and senior-junior mentoring opportunities. Multidimensional well-being assessments appeared to be very helpful in analyzing the needs of students and staff, and would be beneficial to any organization in addition to an educational system.

Studies on well-being are being made to determine progress for our societies. In reviewing his original theory on well-being, Seligman added that well-being includes the nurturing of one or more of the original elements. The current theory of inclusion is known as "doing the right thing." Forgeard, Jayawickreme, Kern, and Seligman (2011) recognized the many advances in measuring well-being in societies. In their research, Forgeard et al. reviewed past and ongoing studies of well-being measurement, and the theories which support them. They combined terms of happiness, positive emotion, engagement, meaning/purpose, life satisfaction, relationships/social support, and accomplishment/competence with subjective and objective measures of well-being to "best capture human flourishing." From their analysis of many models of assessment, they created a tool that measures both objective standards of living and subjective personal data to create what they refer to as a "dashboard approach" to measurement. It does not merely measure well-being by a number rating, but provides tools for researchers to include both types of data. The results of this assessment will help

organizations arrive at an educated avenue to assess well-being and encourage its development.

Dr. John Barletta, a noted Australian psychologist, used PERMA as one of his primary references when creating a survey to aid patients in his practice. For over 30 years, he has trained in many countries and used his expertise to provide programs for well-being. In a recent publication, Barletta (nd) stated that PERMA is "more than a to-do list." He added that the five pillars of PERMA are pillars of wellbeing from positive psychology, and by embracing and appreciating life more fully, one can focus attention and energy on what's important in life. He added that users build resilience when they create "an environment of positiveness."

Multiple Sclerosis: Definition, Symptoms, and Disease Process

MS is a potentially debilitating disease in which the body's immune system eats away at the protective sheath that covers the nerves. This interferes with the communication between the brain and the rest of the body. Ultimately, this may result in deterioration of the nerves themselves, a process that is not reversible (Mayo Clinic, 2012). MS is caused by damage to the myelin sheath, the protective covering that surrounds nerve cells. The nerve damage is caused by inflammation, which occurs when the body's own immune cells attack the nervous systems located in areas of the brain, the optic nerve, and spinal cord. This damage can cause an interruption of the nerve signals, which results in loss of balance and coordination, cognitive ability, and other functions; in time, these intermittent losses may become permanent (Abumaree, AlJumah, Pace, & Kalionis, 2012). Symptoms of MS are unpredictable and vary from person to person

depending on the location of affected nerve fibers. MS signs and symptoms may include

all or some of the following: numbness or weakness in one or more limbs, which

typically occurs on one side of the body at a time or the bottom half of the body; partial

or complete loss of vision, usually in one eye at a time, often with pain during eye

movement (optic neuritis); double vision or blurring of vision; tingling or pain in parts of

the body; electric-shock sensations that occur with certain head movements; tremors; lack

of coordination or unsteady gait; fatigue; and dizziness (Mayo Clinic, 2012).

Most people with MS, particularly in the beginning stages of the disease,

experience relapses of symptoms, which are followed by periods of complete or partial

remission. Signs and symptoms of MS often are triggered or worsened by an increase in

body temperature. The disorder is most commonly diagnosed between ages 20 and 50,

but can be seen at any age (Miller, 2010). As in other autoimmune diseases, MS is

significantly more common (at least 2-3 times) in women than men. This gender

difference has stimulated important research initiatives looking at the role of hormones in

MS (Mayo Clinic 2014; MS Society, 2012).

Although MS is not directly inherited, genetics do play an important role in who

gets the disease. In the general population, the risk of developing MS is one in 750;

however; the risk rises to one in 40 in someone who has a close relative (parent, sibling,

and child) with the disease. In families in which several people have been diagnosed

with MS, the risk may be even higher. Although identical twins share the same genetic

makeup, the risk for an identical twin is only one in four—which means that some

factor(s) other than genetics are involved (MS Society, 2012).

Although usually diagnosed between the ages of 20 and 50, during the past few years, young children and teens are being diagnosed. Studying the disease in different age groups may help scientists determine the cause of MS and explain why the disease course differs from one person to another. Important questions include why the disease onsets so early in some children and why people who are diagnosed after age 50 tend to have a more steadily progressive course that primarily affects their ability to walk (MS Society, 2012). When this nerve covering is damaged, nerve signals slow down or stop. The nerve damage is caused by inflammation which occurs when the body's immune cells attack the nervous system. This can occur along any area of the brain, optic nerve, and spinal cord. It is unknown what causes this to happen. The most common thought is MS occurs as a result of a virus or gene defect, or both. Environmental factors may also play a role (Calabresi, 2007). MS is more common at northern latitudes that are further from the equator and less common in areas closer to the equator. Researchers are now investigating whether increased exposure to sunlight and the vitamin D it provides may have a protective effect on those living nearer the equator.

MS occurs in most ethnic groups, including African-Americans, Asians and Hispanics/Latinos, but is more common in Caucasians of northern European ancestry. The exact prevalence among minority populations is unclear (MS, 2015). Recent evidence submitted by nursing home admissions revealed that the illness is diagnosed at an earlier age with African Americans, and is likely to be more disabling than in non-African Americans (Buchanan, Martin, Zuniga, Wang, & Kim, 2004). Some ethnic groups have few, if any, documented cases of MS regardless of where they live. These

variations that occur even within geographic areas with the same climate, suggest that geography, ethnicity, and other factors interact in some complex way (MS Society, 2013). There have been no known diagnoses from the people of Inuit, Yakutes, Hutterites, Hungarian Romani, Norwegian Lapps, Australian Aborigines and New Zealand Maoris —supporting that notion (MS Society, 2013).

Impact of MS on Quality of Life

When determining the state of well-being, researchers such as Rosenberg (1998) proposed there are three hierarchical levels of analysis: affective traits, moods, and emotions. He shared that all three levels must be considered when determining a person's quality of life. Affective traits interact with the moods and emotions of every person to create the make-up of the quality of life a person experiences. When the lives of persons with disabilities are examined, research revealed that some of the most common issues include the quality of living conditions. They affect physical abilities, desires to accomplish, and the emotions which they feel as they attempt to overcome the barriers in their lives.

Pennington (2010) believed that peace of mind achieved with little or no help from others is a primary goal of those who are disabled. He added that finding a new normal in their lives is a key to changing the impact that stress has on one's sense of well-being. Using Maslow's Hierarchy of Needs model, Chapman (2001) highlighted the importance of what he labels Belongingness and Love needs. The need to fit in the world they live in is a major concern for those who are forced to live in less than accommodating circumstances.

Studies on the limitations of physical abilities indicate that physical activity is indirectly associated with quality of life in persons managing MS, especially when considering symptoms of depression, fatigue, pain, social support, and self-efficacy (Motl, McAuley, Snook, & Gliottoni, 2009). Motl et al. conducted a longitudinal study (six months) to determine whether physical activities affected the well-being of MS patients (n=299). The study also looked at factors such as pain, fatigue, social support and self-efficacy. The results indicated that improved quality of life is directly related to physical activity, and is affected by pain, fatigue and social support. Thus, the more a person is able to perform physical tasks, the higher life satisfaction.

von Steinbüchel (2010) conducted a study of almost 800 participants from the ages of 13 to 65 who were assessed using a quality of life scale - Glasgow Outcome Scale. The outcome of the study revealed that the patients with disabilities reported anxiety and depression at a rate of two to three times higher than those who did not have a disability.

Lifestyle Change as a Consequence of MS

When persons are diagnosed with debilitating diseases such as MS, they are forced out of a world in which they have become accustomed and into a world of limitations and barriers. Lifestyles must change, sometimes within weeks of a diagnosis. Barriers such as weather become issues which must be addressed. For example, the warmer the weather, the more difficult it is for persons with MS to learn, remember, or process information (Leavitt, 2013). Consequently, someone who may have enjoyed the

outdoors and warm, sunny weather may have to adjust to a completely new lifestyle which prohibits staying outdoors for a prolonged period.

MS is caused by damage to the myelin sheath, the protective covering that surrounds nerve cells. As previously stated, the nerve damage is caused by inflammation, which occurs when the body's own immune cells attack the nervous systems located in areas of the brain, the optic nerve, and spinal cord. This damage can cause an interruption of the nerve signals, which results in loss of balance and coordination, cognitive ability, as well as other functions, and in time, these intermittent losses may become permanent (Abumaree, AlJumah, Pace, & Kalionis, 2012).

Disabilities have a major impact and long-term effects on the patients. Hughes (2006) reported that experiences of high affect, along with impoverished meanings, produce low quality of life. When lifestyles are so severely altered, many seek motivation to improve their circumstances by unorthodox methods. For example, when becoming disabled in the military, Staff Sgt. Heath Calhoun was faced with the task of learning to be mobile without the use of his legs. He chose to make *disabled* a relative term which pitted his own abilities with those who were still able. This attitude allowed him to enter competitions he may have not entered prior to his traumatic experience (Miller, 2010).

One of the most debilitating lifestyle changes associated with MS is the lack of normal mobility. Getting out of a chair and walking or moving freely about one's own home or surroundings are taken for granted by most outside the realm of disabilities. Since MS is an autoimmune disease which affects the central nervous system, commands

from the brain are ignored by the body and the inability to move freely is common.

(Kirchner & Lara, 2011; Leavitt, 2013; Paturel, 2011). Consequently, for those suffering

with chronic disabilities, mobility is relevant. Although walking at a normal gait is

difficult or impossible for most with disabilities, the opportunity to be mobile is achieved

by other means such as walkers and motorized scooters.

Personal freedom, according to Layard (2006), is one of the factors to which

almost everyone in the West has become accustomed, and the loss of that personal

freedom through illnesses such as MS is noted as one of the most frustrating issues.

Paturel (2011) reported that irregular gait and balance are common problems with

persons with MS. There are five strategies used by the leading MS mobility researchers

which rehab specialists believe to be the most helpful to persons with MS. The first is

balance measurement; evaluation of a person's balance to provide targeted therapy.

Wireless sensors which assess stability and mobility are used to measure balance and gait

(Horak, 2011). Next is resistance training: According to White (2011), resistance

training can enhance muscle strength and endurance and reduce fatigue without elevating

the body temperature. A third is progressive resistance training program. It is currently

being analyzed. Robot training (Giesser, 2011) is a mechanized way of providing

locomotor activity without exacerbations or fatigue. The fourth is boosting daily activity

which is an internet-based behavioral intervention which offers persons with MS an

opportunity to increase daily activities through skills and strategies. Last, goal-setting

and self-monitoring foster self-efficacy and provide the patients with approaches to help

improve symptoms, mobility, and quality of life (Motl, Dlugonski, Wojcicki, McCauley, & Mohr 2011).

Promoting health in persons with MS is being more widely researched than ever before, according to Motl et al. (2011). Taub (2004) has introduced a treatment called constraint-induced therapy (CIT) where the patient is urged to use the part of the body which has become problematic due to the diagnosis of MS. Currently, the efficacy of CIT therapy is being studied as a treatment of MS. For example, if a person's left arm has been affected more so than the right, the patient will wear a mitt on his right hand and will only use the left arm during the treatment. This CIT helps people with MS learn to use the neglected body part. These treatments are combined with complementary medical procedures such as massage, relaxation techniques, yoga, or aquatic therapy. The need to advance the technology to provide persons with MS more information and options in therapy has furthered the research in mobility for all persons who are disabled. A study by Chen, Wang, Lee, Tang, Chu, and Suen (2010) provides information on instrumental activities and basic activities of daily living for those who are disabled. The activities are categorized according to the importance and degree of difficulty, and are defined as to the treatment which is recommended. They exercise limbs and muscles to build or rebuild strength and mobility.

For most with disabilities, this challenge is possible if the tools are available. Positive strategies are tools needed and recommended by others. For example, Reeve (2005) reported that considerations which determine a positive reinforcer's effectiveness include the recipient's need and the recipient's perceived value of the reinforcer. The

need to attain goals is present in a majority of persons living with MS as evidenced in the number of participants in the programs offered by various associations (MS Association, 2012).

Psychological Effects of MS

Disturbing psychological effects of MS occur in various stages of the disease. Confusion, frustration, personal doubt, and inability to explain oneself, not only to others, but personally, are some of the maladies which present themselves (Shebib, 2012). For example, when asked about the hardest part of dealing with the disease, Shebib stated that people struggle with defining MS and explaining how it is manifested in their lives. Shebib's statement is common when dealing with MS. In addition to the physical limitations, a person with MS may face mental and emotional hurdles. MS is a progressive disease of the central nervous system. Motor, cognitive, and neuropsychiatric symptoms can occur independently or simultaneously, as a result of lesions in the brain and spinal cord (Chiaravalloti & DeLuca, 2008). A variety of psychological areas of concern may result due to these lesions. They include depression, anxiety, cognitive impairment, memory loss, vocal and optical impairment, along with any combination of dysfunction, as intimated in the name *multiple sclerosis* or *many scars*. Fatigue strikes about four out of five MS patients and has a biological basis (Kravitz, et al., 1996). This type of mental fatigue tends to come on slowly but stay for longer periods, sometimes throughout the day into the night. Some patients refer to the mental fatigue as fuzzy brain and when it occurs, they cannot think clearly or focus. Those with MS get

emotionally frustrated by the things they would like to do, but are physically unable to do; MS is both demanding and unpredictable (MS Society, 2011).

Depression

Depression is defined as sadness or irritability. It may include all or some of the following symptoms: loss of interest, loss of or increase in appetite, sleep disturbances (either insomnia or excessive sleeping), restlessness or sluggishness, problems thinking or concentrating, or persistent thoughts of death or suicide (Feinstein, 2011; MS Society, 2004) Depression affects about 50% of people with MS. In its most severe forms, depression appears to be a chemical imbalance that may occur at any time, even when life is going well.

Morais et al. (2014) confirmed an association between inflammation and depression. They presented a 12-year study which documented the elevation of C-reactive proteins and inflammation which preceded depression, followed by an affective illness where relapses were more common. It was determined that patients with major depressive disorders have elevated levels of pro-inflammatory cytokines. A condition called abnormal cell-mediated immunity and lymphocyte proliferation are also present in patients with a major depressive disorder (MDD). The study stated that inflammatory disorders as seen in association with persons with MS have a higher vulnerability and reveal the most common psychiatric condition.

One puzzling aspect of MS for clinicians and researchers alike is the nature of the relation between depression and fatigue in MS. Fatigue is a common symptom in both depression and MS. Mohr et al. concluded that a relationship between fatigue and

depression has long been suspected in MS, but why or how has been generally

unarticulated (Mohr, Hart, & Goldberg, 2003). Thorsen and Clausen (2008) conducted a

study to determine if loneliness influences the experience of depression among persons

with disabilities. They found that loneliness is the most important factor which

influences depression when considering age, gender, status, income, education, and

disability. Their method of investigation used a multiple regression analysis involving

over 4000 participants. It concluded that persons with disabilities are more lonely and

depressed than persons without disabilities. The results of the study suggested that social

integration of persons with disabilities is important to offset the effects of loneliness and

depression. von Steinbüchel (2010) considered depression and anxiety to be two of the

most relevant issues for persons who live with disabilities. She offered five primary

variables when assessing quality of life of persons with disabilities. They include

emotional state (depression and anxiety), functional status (person's physical ability and

help required), outcome of an ability test, and comorbid health conditions. Weighing the

variables, she reported the outcome as 58% of the variance of the assessment.

Low grade depression can lead to clinical depression (Sanford & Petajan, 2003)

and around half of all people with MS are faced with clinical depression during some

point of their illness. Persons whose families have been plagued with depression are

particularly susceptible. Some researchers believe that MS causes the depression because

of the damage to the central nervous system, but others believe it may be medication side

effect (Sanford & Petajan, 2003). Oftentimes, the depression lasts for weeks at a time,

and is compounded when a lack of interest in usual activities pervades their lives. Other

problems include loss or gain of appetite, fatigue/lower energy, trouble sleeping,

concentration problems, or indecisiveness, relentlessness, low self-worth, low self-

esteem, and thoughts of death, violence, or suicide (Sanford & Petajan, 2003). Santos'

(2011) research suggested that half of the patients who suffer from disabilities such as

Parkinson's, M S, chronic pain, fatigue and brain injuries experience rates of depression

as high as 50% or more.

Anxiety

Although most people experience anxious feelings from time to time, a recurring

feeling of being out-of-control, nervous, and panic-ridden may signal severe anxiety.

The Mayo Clinic describes severe, ongoing anxiety that interferes with day-to-day

activities as a sign of generalized anxiety disorder. Anxiety may cause the imbalance of

neurotransmitters such as serotonin, dopamine and norepinephrine which are elements in

the diagnosis of MS. With the onset of mental and/or physical conditions, anxiety often

manifests. It may lead to depression, substance abuse, trouble sleeping, digestive or

bowel problems, headaches, teeth grinding (bruxism), and substance use disorder (Mayo

Clinic, 2012). The diagnosis of MS interjects an unpredictable lifelong condition with

adjustments in all facets of a person's life. Anxiety is rampant and reasonable when it

comes to fear of pain, disability, changes, adjustments, and the unknown (Sanford &

Petajan, 2003). Persons with disabilities often face anxiety when simple tasks need to be

performed. For example, tying a tennis shoe can be a major undertaking when an MS

patient suffers from a tremor in either hand. Likewise, getting dressed for a formal event

can be a major undertaking if there are buttons or ties in the wardrobe. Daily tasks

sometimes become so difficult that patients dread beginning their days for fear of inabilities. These fears are compounded with the anxiety which accompanies the tasks. LaRocca (2003) noted that emotions such as depression, grief, and anxiety commonly fluctuate as MS symptoms move up and down the intensity spectrum. Recognizing the disease is so unpredictable, Sanford and Petajan (2003) submitted that the fear of losing control over their lives subjects patients to emotional stress and anxiety which may also cause loss of self-esteem and self-worth. Layard (2005) reported that people with chronic pain and mental illnesses never adapt to their situations since these feelings of anxiety come from inside themselves instead of external sources. He added that control of the suffering must be made a top priority if day-to-day function is possible.

Deacon and Valentiner (2001) highlighted the importance of monitoring anxiety especially as it occurs as a result of a lifestyle change. Persons with MS have abnormalities in the circuitry of their brain activity, and research by Ressler and Nemeroff (2000) revealed that disrupted cortical regulation may impair concentration and memory and promote uncontrollable worry. Furthermore, altered sleep and arousal states are often present, along with hypersensitive stress and fear responses leading to anxiety, anhedonia, (the inability to gain pleasure from normally pleasurable experiences, APA Dictionary of Psychology, 2007) and aggression.

Cognitive Impairments

Cognitive dysfunction is a common feature of MS, affecting approximately 40/60% at some time in their disease course (Rao et al., 1991). Cognitive impairment often manifests as deficits in recent memory, attention, information-processing speed,

executive functions, and visuospatial perception (Rao, 1995). What would seem a minor cognitive dysfunction to a healthy person may be troubling and impair working conditions and daily living (Amato et al., 1995). Severe disability usually does not occur until late in the disease course when additional neurological impairments become evident (Rao et al., 1991).

MS often hosts a combination of other debilitating problems such as disability in motor, sensory or cerebellar function. It is referred to as cortical or cerebral-type MS (Krupp, et al., 2004). It is difficult to differentiate primary neurodegenerative dementias, infectious, or metabolic disorders. Treatment is challenging in these patients as symptomatic therapies aimed at MS cognitive impairment is of limited benefit (Krupp et al., 2004). Earlier case studies (Franklin, Nelson, Filley, & Heaton, 1989) described some of the characteristics of cognitive dysfunction, but phenotype remains inadequately described (Zarei, Chandran, Compston, & Hodges, 2003). Furthermore, risk factors that may predispose patients to primary cognitive forms of MS need further explanation. Along with MS come motor, cognitive, and neuropsychiatric symptoms, all of which can occur independently of one another. Most common symptoms include deficits in complex attention, efficiency of information processing, executive functioning, processing speed, and long-term memory (Staff, Lucchinetti, & Keegan, 2009). These deficits may affect the ability to carry out normal day-to-day routines (such as running a household, participating in social functions) and maintaining a career, which can affect the overall quality of life of the patient. The increased use of neuro-imaging techniques in patients with MS continues to advance the understanding of structural and functional changes in

the brain that are characteristic of the disease. Treating the cognitive deficits in MS depends on research and trials (Staff et al., 2009).

Fatigue

Fatigue is generally defined as a weary or tired feeling brought about by day-to-day activities. However, MS fatigue is abnormally severe and tends to occur daily, even after sufficient rest and sleep. It is caused by frayed nerve fibers wearing out easily. It is the nerve damage that is present in the "vast computer system of the brain and causes misfires and split-second delays in impulse transmission," says George Kraft, M.D. University of Washington Medical Center in Seattle (Adelson, 2012). According to Adelson (2012), there are three levels of fatigue which affect a person diagnosed with MS. They include: physical fatigue-tiredness in body in simple things such as walking from room to room; mental fatigue-lack of concentration, inability to think straight, and emotional fatigue-depression, combined with demanding and unpredictable events— patients become emotionally frustrated by things they would like to do but cannot physically complete. Johnson (2012) stated that fatigue is the most common symptom of MS, and occurs in 70-90% of patients. She stated that fatigue can be managed with proper treatment. Fatigue can stem from lack of sleep or quality sleep, depression, medication, stress, pain, being out of shape, and an increase in the amount of energy it takes to complete tasks (Kraft, 2009).

The Role of Support Systems in MS

In chronic diseases like MS, researchers have extensively documented the role of support systems to manage the medical and lifestyle issues. These include family support educational and professional support, medical resources, national non-profit organizations, and informational support.

Sanford and Petajan (2003) stated that MS is a chronic illness that includes fear and apprehension, denial, grieving, depression, guilt, in addition to physical limitations and other emotional upheavals. They cautioned the young mothers with growing families to be aware of vulnerability to guilt, and stressed that everyone in the family needs a basic understanding of the consequences of MS on ordinary activities and relationships. Friends and family members are affected by the stresses of MS. The support system for persons with MS is commonly made up of the immediate family, but can also include the extended family, close friends, and MS centers for help.

It is important for persons with MS and their family and friends to realize that there is no blame in MS. Research reveals that feelings of sadness, hopelessness and self-blame are indicative of possible depressive disorder that often comes as a consequence of an MS diagnosis (Ensari, Moti, & Pilutti, 2014). An MS study showed that after the initial adjustment phase, most persons with MS are able to regain and maintain a positive sense of self-worth (Sanford & Petajan, 2003).

Park and Gaffey (2007) reported that social support may be helpful in making adaptive changes, particularly in physical exercise and positive health behavior; changes are facilitated by internal *locus of control*. Locus of control is a personality construct

referring to an individual's perception of the locus of events as determined internally by his or her own behavior vs. fate, luck, or external circumstances (McCombs & Marzano, 1990). According to McCombs, the degree to which one chooses to be self-determining is a function of one's realization of the source of agency and personal control. McCombs suggested this explanation, "I choose to direct my thoughts and energies toward accomplishment. I choose not to be daunted by my anxieties or feelings of inadequacy." Directing their lives and self-determination are two tools which persons with disabilities could use to achieve their goals of balance.

Studies conducted at Baylor and Methodist Hospitals in Texas include stem cell transplantation and national trials testing current drugs for treatment of MS. International patients are treated at Mesinger Clinic. Staff members make travel arrangements and coordinate care with the patients' physicians. There are multilingual personnel and physicians and the clinic maintains contact with the MS Associations in Latin America as well as other countries. The neurology department of The Methodist Hospital continually ranks among the top in the nation as reported by *U.S. News and World Report.* The clinic has seven exam rooms with facilities for physical therapy, research, international patients, and social services. All of these services help to provide a holistic, caring environment for the patients and their families. The realm of needed care oftentimes extends much further than the normal medical care of a personal physician. The Mesinger Clinic provides support to the MS population through comprehensive patient care and assessments and maintains links with the MS Associations in other countries (Mesinger Clinic Report, Houston Methodist Hospital, 2014).

Family Support

The majority of MS patients have members of their families as the primary caregivers. There are many hurdles to face for both the patient and the caregiver. It is often easier for the patient to rely solely upon a family member due to the personal nature of many of the symptoms (MS Society, 2012). However, often, friends offer their time, relieving the primary caregivers for a period of rest. When this occurs, the value is immense. The gift of friendship through service is highly valued by those who suffer with MS.

The Greek philosopher Epicurus stated, "Of all the things that wisdom provides to help one live one's entire life in happiness, the greatest by far is friendship" (nd). He also stated, "Friendship goes dancing round the world, announcing to all of us to wake up to happiness" (Vatican Saying 52, Sedley, 2009). Furthermore, Epicurus wrote that a wise man would feel the torture of a friend no less than his own, and would die for a friend rather than betray him, for otherwise his own life would be confounded (Vatican Sayings 56 & 57, Sedley, 2009.) These ideas came from centuries ago, 341–270 B.C. Usener (1887) shared that humans may have originally been asocial and formed alliances and compacts as the necessity dictated. However, he added it is possible that Epicurus believed this capacity for friendship arose out of need, but that once the capacity for such feelings was acquired, feeling them came to be valued in itself.

Of course, the concept of friendship is described in the scriptures which date back over 2000 years, with examples of devoted friendships such as Jonathan and David, and Jesus and Lazarus (NIV). This is especially relevant in the lives of believers who are

diagnosed with MS. They rely on the foundational friendships they have already established to buoy their faith and attitudes regarding their illness. Layard (2005) stated that the quality of our community is crucial to making friends and feeling safe. In addition, Halpern (2004) described social capital as the quality of the community. Zak and Knack (2001) suggested that as we consider trust; we are able to determine if people can be trusted. The conclusion from research reveals trust does affect happiness (Layard (2006). If we apply this information to the lives of persons with disabilities, it is logical to ascertain what value is placed on friendship. The support which friendship offers goes far beyond lending a helping hand, psychologically and emotionally.

Radford (2005) explained that caring for a friend with a chronic illness such as MS can be deeply satisfying and has the potential to draw families and friends more closely together. She also suggested to the caregivers that the level of care required may fluctuate as the disease progresses or remits. An MS patient must be just as willing to accept support as a caregiver is to offer it. A network of caregivers is crucial to adequate care (Radford, 2005) and mutual respect and awareness must be the bond for successful healthy relationships.

When pursuing human strengths, Bolt (2004) reported that friends foster both psychological and physical well-being by providing social support. The features people regard as the most important in their closest friends are trust, honesty, and understanding and are mutually responsive to one another's needs (Bolt, 2004). In addition, these attributes contribute to hope in society and encourage survival of communities. Hopeful people have strong support systems and pursue collective well-being. The support

system of those who suffer with MS includes all ages of one's family and friends.

Durand (2011) wrote that active help generates positive emotions for both the caregiver

and the MS patient.

Educational and Professional Support

The National MS Society provides an abundance of publications and handbooks

to aid MS patients in controlling their lives. There are financial and life-planning

programs sponsored by the National MS Society, (Radford, 2005) and numerous

foundations which are easy to access on the internet or through local organizations. Most

moderate sized cities throughout the United States have organizations or branches of

national organizations which offer help and support to MS patients.

An organization such as disAbility 101 is an example of support for those who

live with disabilities, both patient and caregiver. DisAbility 101 is a Texas Non-Profit

Corporation in Houston with Internet Access and helpful programs on a regular basis.

The goal of disAbility 101 is improving the lives of individuals with disabling medical

conditions and to offer information to reduce the emotional, social and vocational impact

of the illness. It provides educational programs offering coping mechanisms and works

closely with other organizations to develop and train staff and volunteers. Its mission is

to raise the awareness of the social and emotional needs of persons with disabilities for

caregivers, physicians, nurses, allied health professionals, and mental health professionals

(disAbility, 2011).

Medical Resources

There are hundreds of clinics throughout the United States and worldwide. One of the most noted clinics in Texas is the Maxine Mesinger Multiple Sclerosis Clinic at Baylor College of Medicine and The Methodist Hospital in Houston, Texas. It opened in September 2003, and was designed to offer expanded medical staff and facilities, including neurologists, gynecologists, urologists, physical therapists and social workers and intends to bring a unique experience for the MS patients. These facilities and staff focus on clinical care, basic and clinical research, and patient outreach. The clinic is named in honor of the late *Houston Chronicle* society columnist Maxine Mesinger, who had the disease and was an active fundraiser for MS-related causes.

Another source of education and treatment is The Baylor College of Medicine Multiple Sclerosis Comprehensive Care Center (MSCCC). It is located in Houston and is composed of the Maxine Mesinger Multiple Sclerosis Clinic, Research Unit and Outreach Program (Baylor College of Medicine, 2011). The Outreach Program of the MSCCC is directed by Dr. Victor M. Rivera, founder of the Baylor International MS Center and is headquarters of the Latin American Committee for Treatment and Research in Multiple Sclerosis. The association represents more than 600 neurologists from 20 countries. In addition to monthly newsletters, published electronically and physically, the program hosts dozens of international observers and visitors. MS professionals, physicians and students all benefit from the programs presented (Baylor College of Medicine, 2011). Other participating organizations include the National MS Society, Lone Star Chapter, The Institute of Rehabilitation and Research Memorial Hermann (TIRR), and the

Methodist Hospital Rehabilitation Services. It is a full member of the Consortium of MS

Centers. These societies offer rehabilitation programs which are medical and social.

National Non-Profit Organizations

There are numerous MS Walks held each year all over the United States. Texas

holds about 20 campaigns throughout the state and many MS bike rides, involving

thousands of walkers, riders, and supporters. The major events involving the greatest

number of participants take place in Houston, Dallas, San Antonio, Austin, Waco, and El

Paso. Thousands of supporters participate in *Walk for a Cure* and raise funds for

research, education, and individual support (MS Society, 2011). Persons with MS are

there with the supporters, and it is not uncommon to have dozens of wheel chairs and

motorized chairs alongside the walkers. The MS Society also sponsors the *MS 150*, a

bicycle ride between cities throughout the United States. There are at least four in Texas.

Houston supporters participate in the Houston to Austin ride each year. In 2010, the

number of bikers reached around 13,000 cyclists for the two-day, 180-mile journey from

Houston to Austin as part of the 26th Annual BP MS 150, supporting the National

Multiple Sclerosis Society: Lone Star in its quest to create a world free of MS (The

Houston Chronicle, 4-12-2010). Due to storms in the area, the bikers did not make the

first leg of the journey from Houston to LaGrange, but as proof of their dedication, took

up the race in LaGrange on Saturday, and continued to Austin. This race has grown from

237 in 1985 when it raised $117,000 to over 13,000 riders who raised $18 million in 2010

with 11,000 riders who braved the uncertain Texas Spring weather. These are the results

of one chapter of MS, so it obvious that support for the persons with MS is growing with each year (MS Society, 2017).

Funds support research and programs, and services provided by The Lone Star Chapter of Texas benefit those affected by MS in 174 Texas counties (Hoffman, 2010). For 2011, the goal was $17 million and over 13,000 riders were expected to participate in the MS 150 in Houston. Combining five states increased service for the MS population. Now, there are 56, 000+ people affected by MS in the Lone Star Chapter, which now includes Texas, Louisiana, New Mexico, Arkansas, and Oklahoma.

The MS Society sponsors walks, bicycle rides, and luncheons. It also provides publications which help keep MS patients and caregivers abreast of new programs added each year and progress being made in research and medical provisions. Currently, the National MS Society prints *MS LifeLines Magazine*, which provides stories and information regarding individuals with MS, and program brochure details on upcoming featured speakers, where attendees can learn more about treatment options and in-depth discussions with healthcare professionals regarding treatment and support. *Momentum Magazine,* a quarterly magazine, is published to provide MS patients, their caregivers and supporters information which addresses all facets of life with MS. It is the largest MS-related publication in the world, and offers first-person stories by people living with MS, consumer report, expert opinions from specialists and MS activism and recent, life-changing advances in research (National MS Society, 2017). In the Spring, 2011 issue of *Momentum,* articles covered new drugs, family affairs, vision solutions, mobility, the public policy conference, meditation, and the FDA review on a new oral drug, to name

about half (Momentum, 2011). Current articles include myelin repair and in-depth

research information (Momentum, 2017). Also the *MSConnection* is the quarterly

newsmagazine of the National MS Society: Lone Star Chapter. Many brochures such as

Multiple Sclerosis Basic Facts Series contain information on specific symptoms and

frequent questions. The Basic Facts Series and all brochures can be downloaded online.

Keep S'myelin is a quarterly newsletter to give children and their parents tools to discuss

and learn about MS. All issues are colorful and have games, stories, and activities

regarding MS topics. They can also be downloaded or ordered to be received by regular

mail.

Informational Support

Another useful tool is the *FY09 Milestone Report: Moving Others toward a World*

Free of MS which can be downloaded on the Internet. It is a report on the progress of

FY09 and it highlights personal stories, and milestones in advocacy, research, programs,

wellness, scholarships, fundraising, volunteering, and other topics of interest. It includes

photos of individuals, families, and supporters. The FY10 Milestone Report will follow

with additional editions in the years ahead (MS Society, 2011). There are numerous

books which are helpful resources. Documentation of MS trials, both life and medical

are available.

One of the major sources for information is the Americans with Disabilities Act

(ADA) that provides protection to persons with disabilities in regard to housing,

transportation, recreation, and employment. The ADA provides a booklet which outlines

the basics of the ADA and the MS Society makes them available (Radford, 2005).

Financial and life planning are available to all who request it. The process of long-term

financial planning is wise, since there is no cure for MS and the probability of ongoing

care should be considered. MS provides a book entitled *Adapting: Financial Planning

for a Life with Multiple Sclerosis* and it is available online through the Society's website.

This booklet covers issues regarding income tax, assets, savings accounts for future

needs, and end-of-life plans. Other financial areas which need to be addressed are

insurance needs, employment rights, and state assistance. Other government programs

which address the needs of persons with disabilities are Medicare, Social Security

benefits, and private disabilities insurance companies also offer information. Some state

programs which are available to those who qualify are public assistance, food stamps,

and Medicaid. Resources for these programs are online websites and hospital and clinical

social workers. Securing a private attorney also addresses the needs of persons with

disabilities, along with private tax consultants (Radford, 2005). Funds sometimes come

directly from the family of persons with MS, or from friends who eagerly provide money

and services which would cost money if they had to hire someone to perform them.

Knowledge is a key to realizing well-being, so it is vital that every person with MS is

given every opportunity to gain knowledge about how to adjust to the demands.

Positive Psychological Affects and Enhancing the Quality of Life

The monetary cost of MS can be evaluated by charting the costs of medical

treatments, recording the costs of medications, and figuring the costs of time lost from

work coupled with charges for any care that must be hired. The emotional cost of MS is

not so easily calculated. Coming to terms with chronic illness, according to Radford

(2005), requires time and strength of mind, will, and emotions. Enhancing the quality of life for a person with MS through positive strategies is not an exact science and is time-consuming. Caregivers, friends, and support groups must partner with the person with the disability in recognizing the effects of the care. Some jobs are tedious, and traditionally are ones which the MS individual would prefer to complete alone. It is imperative to maintain a dialogue to keep lines of communication open (Radford, 2005).

Since Quality of Life is multifaceted, it is sometimes described as one's sense of well-being or satisfaction with life (Andrews & Withey, 1976; Campbell, 1981). Campbell describes satisfaction as the gap between what a person's expectations and aspirations for life are and the current situational reality is his other life.

Bolt (2004) stated that psychologists and researchers are no longer exclusively focusing on negative emotions as guidelines for treatments, but are now investigating positive emotions of joy, life satisfactions and happiness. He noted that when the predictors of happiness are being evaluated, one's sense of well-being is measured by how he is able to live gratefully.

Bolt assessed human strengths to understand how they are applied to personal growth. He used scientific method to assess, understand, and then build human strengths. He submitted that positive psychology balances the investigation of weakness and damage with a study of strength and virtue. He applied the virtues of love, empathy, self-control, wisdom, commitment, happiness, self-respect, and hope and their relations to friendship to obtain information which directly affects the well-being of those who possess these characteristics.

He summarized positive strategies using the dynamics of choice, change, and goals and the energy used to pursue each of them. In addition, Bolt suggested that human beings must seek to understand the impact of external factors to make wise choices and foster change in individual well-being. He added that through these wise choices, stronger bonds are built. As positive strategies are applied to a person's life, he fosters self-esteem and self-worth. Looking at positive psychology's history, one is more able to understand the roots and fruits of human strengths such as love, empathy, and self-control. As the contributions of positive psychology are measured, Bolt reminded readers to consider individual differences and recognize the virtues of civic responsibilities and openly review value judgments. Finally, Bolt urged researchers to recognize the significance of being one's own person while admitting the need to belong. He paired the need for relatedness and autonomy as a primary fulfillment of well-being. Hughes (2006) suggested that sociologists need to include dimensions that reflect the meanings of life that people use to define purpose and significance. He cautioned that in the past, research has not included affect, happiness, and satisfaction which are more likely to provide us with validity and coherence that help define social relationships. Layard (2006) noted that there are other truths regarding happiness. Happiness is an objective and can be measured. Humans are programmed to seek happiness, and when possible, they choose to live in the society which offers the most happiness. Social beings recognize the need for trust and are able to adapt. This ability to adapt is a major significance for persons with disabilities. Layard (2006) submitted that most of people have a deep positive force within, allowing us to overcome any negative thoughts, and our education goal should be

to use the range of spiritual practices available that help bring peace of mind. Part of improving one's inner life should be to accept and to feel more for others. Asch's (2005) research underscored the urgent need to reform how Americans deal with life-prolonging or life-ending decisions. She cited how the media and movie industry deal with the end of a person's life as callous and unfeeling, as those who hear the preferences to die rather than live with certain disabilities. This causes confusion for those who believe in the sanctity of life but may allow the quality of life to be more significant. She stated that a more sensitive decision-making process is necessary to reach sound conclusions with many factors considered. a) What gives life meaning? b) What value do we place on our lives? As caregivers, psychologists and researchers study the methods of positive psychological strategies, opportunities to provide that quality of life for persons with disabilities will become more familiar and accessible.

Summary of Types of Methods

Although quantitative studies have been used in the past regarding chronic illnesses, (Bogardus, Concato, & Feinstein, 1999; Creswell, 1994; Gilgan, Daly, & Handel, 1992; Lorig & Holman, 1993; Casebeer & Vernhoef, 1997; Kravitz et al. 1996) a growing amount of research currently being used to study MS and additional neurologically involved diseases is qualitative with an increasing emphasis on narrative studies (Bair et al., 2009; Blaney & Lowe-Strong, 2009; Borges & Waitzkin, 1995; Borreani et al., 2011; Corner, 1991; Motl et al., 2006; MS Society, 2012; Zalewski, 2007). Having accounts of a more personal nature enables the newly diagnosed MS patient to become more familiar with the parameters of the disease. More exposure is

being given to the disease, and education is more prevalent than in the past. As research

continues, perhaps an even greater shift to personal experiences will follow. This is

evidenced by the publication of MS material and the connections with public

communication such as Facebook, Twitter, and websites. The ability to share experiences

helps alleviate some of the fears of the unknown (MS Society, *Momentum,* 2012, 2017).

Therefore, the use of the narratives may present objective ideas and opportunities for MS

patients to consider issues which could lead to more satisfying lives and a deeper sense of

well-being.

Summary

Research and personal experience show that MS is a widespread, crippling,

frustrating disease that has gained global notoriety. Zagieboylo (2012), a writer for the

MS publication, *Momentum*, and caregiver for an MS relative, continually urges everyone

to make connections which will benefit not only the MS patients, but also the caregivers

and organizations that work tirelessly to aid, educate and financially undergird the

families who face the challenges of MS. She calls on others to makes these connections

because her primary goal is to help MS patients take charge of their own lives by

becoming knowledgeable of all facets of MS. In a recent article, she wrote howpeople

with MS are buoyed by the idea of finding each other, sharing their experiences and

problem-solving together. Empowering MS victims to feel great about themselves while

facing MS is a challenge that she and countless others are accepting. It is clear that MS is

one of the foremost research topics, not only in the medical field, but also in areas of

government regulations, and even the entertainment business. Recently, Mark Millar,

action figure comic hero writer, created a young hero whose alter ego has MS. Millar

shared that a superhero with a secret identity who has MS will raise awareness of the

disease and offer hope to children who have MS by providing a positive role model

(Budgar, 2012). The more knowledge available regarding MS, the more opportunities

researchers, physicians, and scientists will have to develop medications which address the

root causes, symptoms, and eventually, a cure.

In, Chapter 2, I gave a comprehensive insight of the literature review. I gave an

in-depth description of the definition, symptoms, and disease process of MS. I covered

the impact of MS on Quality of Life, and the possible lifestyle changes which occur as a

consequence of MS. I also included the major psychological effects of MS: depression,

anxiety, cognitive impairments, fatigue (physical, mental and emotional). I listed the role

of the support systems for the person who suffers from MS which includes personal

support, educational and professional support, and access to national non-profit

organizations and a multitude of programs available.

In Chapter Three, I introduce a description of the methods that were used in the

research, the study design and rationale, the role of the researcher, methodology

(including the participation selection, target population, and accessible population), the

criterion and sampling strategy, the interview guide, the procedures, data analysis plan,

issues of trustworthiness, IRB requirements, and ethical concerns. In Chapter Four, I

analyze the data and in Chapter Five, I explain the conclusions of the study and make

recommendations for further research.

Chapter 3: Research Method

The purpose of this study was to collect and examine the narratives of persons with MS in order to understand the meaning of resilience and coping with a disabling, chronic illness. Using the theoretical framework of Seligman's (2011) positive psychology, I explored the themes of positive emotion, engagement, meaning and purpose, and accomplishment. Positive psychology offers the persons diagnosed, as well as their caretakers, methods of tapping their own potential to achieve a more fulfilling life (Seligman, 2002).

I selected seven members of the Lone Star Chapter of the National MS Society to participate in this narrative study. I used a semi-structured interview guide to ask participants to reflect on their experiences of resilience and coping, beginning with what their life was like before they were diagnosed, and how these experiences have changed since they were diagnosed.

Descriptions of the study design, the study participants, instruments used in the study, research procedures, data analysis procedures, and ethical considerations for the participants follow.

Research Design and Rationale

I used narrative analysis to explore the following research questions:

1. What is the meaning of resilience to individuals living with MS?

2. What is the meaning of coping to individuals living with MS?

3. How do the themes of positive psychology illuminate the experience of a "meaningful life" in individuals living with MS?

Using the model of positive psychology as the theoretical framework (Emmons, 2007; Haidt, 2003; Pressman & Cohen, 2006; Seligman, 2011), I have described how individuals with MS are enabled or constrained by their disease, and what their stories have to say about resilience and coping.

Riessman described the key feature of narrative analysis as attention to sequences of action, focusing on the events and experiences of relevant people and places that shape a person's self-understanding. It is also grounded in how the speakers use language to communicate meaning. An individual's behavior is linked to the personal meaning he or she gives to the events and behaviors. By interrogating the intention and language, the *how* and *why* of the behaviors are given an integral part of the overall story. Riessman (1993) described narratives as representations where individuals construct past events and actions in personal narratives to claim identities and construct lives. Further, she defined it as talk organized around consequential events. Individuals tend to make sense of an experience by using the narrative form of communication (Bruner, 1990; Cronon, 1992; Gee, 1985; Mishler,1986a). Given that my intent was to understand how persons with MS make sense of their illness, narrative analysis was particularly appropriate.

Narrative analysis offers the opportunity for more attention to language form, social context, and audience than other approaches. It also treats extended accounts as units, rather than fragments (Riessman,2008). For example, phenomenological research focuses on the lived experience, but narrative studies focus on the details of how and why a certain event is part of the story that is being told. Many voices and subjectivities can be reached through the use of a narrative (Riessman, 2008).

Role of the Researcher

In narrative analysis, the role of the researcher is to use the stimulus/response model (Riessman, 2008) to seek a sustained account or story from the participant, allowing the interviewee an opportunity to relay a meaningful account of events and experiences (Mishler, 1991). The reader is prompted to think beyond the surface and offer a broader commentary (Riessman, 2008). Narrative investigators need to give up control of fixed formats and encourage greater equality for the interviewee (Riessman, 2008). Allowing impulse sharing provides deeper insight into the relationships (McQuillan, 2000.) As *observer*, the researcher records the key elements and important issues reported by the participant, much as a secretary takes notes, to yield the attitude of the person being interviewed. This is done not by pushing or cajoling, but by allowing him or her to openly give opinions and concerns. As *participant*, the researcher engages in active conversation, noting the opportunities to interject meaningful questions and comments which are relative to each person's situation. As *observer-participant*, the researcher's experience and first-hand knowledge of the day-to-day challenges of the participant are useful in creating a harmonious atmosphere in which she will feel at ease.

In 2003, my daughter, aged 21, was diagnosed with relapsing-remitting MS. Over the past 14 years, my family and I have seen the ravages of MS and how many areas of a person's life can be affected. We have also seen how tenacity of personal will, and education about the disease can contribute to managing the challenges. I have also witnessed how my daughter's positive attitude has affected how she deals with MS. As a result, I have considerable experience with how the condition affects daily living, and

how it affects family and friends' relationships. MS is not the result of something people

do or do not do in their lives. One cannot "catch" MS by exposure, nor can one receive a

vaccination to avoid it. Some parents blame themselves when their children are

diagnosed, believing there could have been some way to avoid it (MS Society, 2013). I

experienced this myself when my daughter was diagnosed. Learning that Vitamin D or

sunlight may have a relationship to MS, I chastised myself for not taking my daughter out

into the sunshine more often. A parent grasps at any explanation, but tends to feel

responsible for the diagnosis. Given this background, I was able to genuinely empathize

with all of the participants.

There were no anticipated personal or professional relationships between the

participants and me, save membership in The Lone Star Chapter of the MS Society. I

have been an active member of this organization for the past 14 years, but my contact

with the members is primarily once a year at the MS walks. I had no relationships with

the members who were part of the study. Specifically, I had no prior contact with any of

the participants, and had no supervisory or instructional relationships that involved power

over the participants. I have participated in about 15 MS Walks and bike rides, and have

advocated for people living with MS at the state capitol in Austin.

Researcher biases are understood to be present in all forms of qualitative research,

so I employed several strategies to minimize their influence. Prior to beginning data

collection, I recorded the detailed answers to all the questions, and transcribed them as a

way of bracketing my experience as separate from that of my participants. I used an

audit trail (see Shenton, 2004) to document my thoughts and feelings throughout the data

collection and analysis process. Both procedures allowed me to actively reflect on how my personal experiences intersected with those of the participants.

The plan for addressing other ethical issues such as conflict of interest, power differentials, work environment analysis, and justification followed the guidelines of the American Psychological Association. One issue that Devereaux (1967) noted as important for the interviewer is giving up the control of a fixed interview format. However, Riessman (2008) warned of the possibility of a power shift with more emphasis given to the participant in such instances, possibly bringing uncertainty in the conversation. This did not occur, but if it had, more emphasis would have been placed on how the questions were worded, and I would have been cautious in open-ended questions which provide more varied narrative opportunities.

Methodology

Participation Selection

The target population consisted of women with MS who have been diagnosed for at least 2 years. My rationale for using this time period was that the disease process tends to take up to 2 years to fully manifest into the regions of the body (MS Society, 2011). MS sometimes affects a person's speech and makes it difficult to understand. This was not an issue for my participants, but if it had been, I would have accommodated this limitation by allowing for extra time, breaking the interview into smaller segments, and allowing the person to read and review the entire transcript to confirm its accuracy. I took precautions to note any slurred speech or hesitancy in expression. Since my focus was on resilience and coping, this time frame was sufficient for the participants to have

accumulated sufficient experience to be able to narrate how things have changed. The accessible population consisted of women with MS who are part of the Lone Star Chapter of the National MS Society, are 18 years of age or older, and who have been formally diagnosed with any form of MS. The Lone Star Chapter of the MS Society supports programs and services for 20,000 persons living with MS in 174 Texas counties (MS Society-Become a Member, 2013).

Criteria and sampling strategy. I selected females who are 18 years and older who reported being diagnosed with any of type of MS prior to 2012 and are members of the Lone Star Chapter of the MS Society. A homogenous sampling strategy was used to reduce variation so as to describe a small type or sub-group in-depth (Patton, 2002). While often used for focus groups, homogenous sampling is also recommended for reaching saturation when the potential sample size is small (Guest et al., 2006). The Lone Star Chapter of the MS Society was the primary source for inviting participants, as it is an extremely active and publicly visible organization in Texas and the four other states which are included in the Lone Star Chapter. Founded in 1955, Lone Star is committed to providing quality programs and services to 20,000+ Texans living with the daily challenges of MS in 174 Texas counties. Through events such as the annual Bike MS rides, Walk MS and more, they also raise money to fund research into the cause and cure of MS.

Sample size. Seven participants were selected for the study. Qualitative research regards the saturation point is achieved when a marked consistency in the answers from the participants are similar (Guest et al., 2006). Guest and colleagues found that in

purposive samples with participants who have common criteria, and are homogeneous with regard to the phenomena of interest, saturation is reached at a lower number such as twelve. In this study, the nature of MS projects a common course of the illness, so that saturation was expected at less than 12 participants. Guest et al. (2006) added that if the goal of the research is to describe shared perceptions, beliefs, or behaviors, a smaller number of participants would serve the purpose.

Considerations for sample size also include the unique issues of individuals with MS; particularly the changeable nature of the condition (Rosenwald & Ochberg, 1992). Keeping the number of participants low allowed me to be flexible in scheduling and time frame.

Procedures for Identification, Contact and Recruitment

I posted an invitation to participate on the Chapter's Facebook page. The invitation to participate is provided in Appendix A. Interested individuals contacted the researcher by messaging from the Facebook page or contacting the researcher by email or phone text.

I sent interested participants an explanation of the study and Informed Consent by email, followed by a text, email, or phone call to review the study and set up a time for the interview. When the person agreed to participate, she signed or scanned the consent form and emailed the form to me.

Instrumentation

I used a semi-structured interview with open-ended questions to explore the narrative of individuals with MS and their experience with coping, resilience, and the

themes that are consistent with Seligman's five elements of well-being: positive emotion, engagement, relationships, meaning and purpose, and accomplishment (2011). Emmons (2007) stated that a positive attitude is not obtained through conscious striving, but a learned practice as the situations in his life warrant. Furthermore, changes occur in stages. Prochaska (2000) stated that people tend to progress in different stages on their way to successful change and they progress at their own rate, using different methods of coping. Emmons (2007) noted that taking steps to modify their behavior using a variety of techniques is often the critical factor in finding positive changes. This interview style allowed the participants to share their methods of coping with MS, including the different stages from the onset to the present. In an interview from a study which had two MS patients, Riessman (2003) stated that she resisted the constraints of the fixed interview format when the participant began to explore areas of his illness that allowed him the freedom to express his feelings. Riessman (2008) also suggested that it is preferable to employ questions that open topics to allow meaningful responses, and attempt to provide guidelines to elicit desired outcomes. This method did call for follow-up and probing questions in some areas which gave more information and description. Therefore, a semi-structured interview guide was used.

The first two questions ("How does the narrative begin?" and "What are the turning points?") are implicit, and helped to direct the participant about where to begin and how to think about the unfolding of the story. The other interview questions guided the participants to reflect on the central phenomena of the study.

Research Questions	Interview Guide Question
How does the narrative begin?	What was your life like before you were diagnosed? • What was the most significant life challenge at that time? • What brought you the most joy? • What was meaningful in your life?
What are the "turning points"?	Tell me about the circumstances surrounding your diagnosis. • What were you most concerned about changing? Losing? Gaining? What was the next big milestone after your diagnosis? • What were you most concerned about changing? Losing? Gaining? (this is repeated until the participant comes to the present) What is your life like now? • What is the most significant life challenge at this time? • What brings you the most joy? • What is meaningful in your life?
What is the meaning of resilience to individuals living with MS?	What does the word "resilience" mean to you? • Please describe a recent experience you had that epitomizes your experience of resilience? • Can you tell me about a time when your resilience waivered?
What is the meaning of coping to individuals living with MS?	What does the word "coping" mean to you? • Please describe a recent experience you had that epitomizes coping? • Can you tell me about a time when your ability to cope waivered?
How do the themes of positive psychology illuminate the experience of a "meaningful life" (Seligman's five elements of well-being) in individuals living with MS?	Note: Direct questions will not be asked; rather the narratives will be explored to see if any of the PERMA concepts emerge.

Procedures

  Recruitment. I placed a notice for members on the MS Society Facebook page

of The Lone Star Chapter, explaining the project, inviting anyone who is 18+, has had

MS for at least two years, to participate in the study. The participants responded by

email, text, or message board. I contacted interested persons by phone, and provided a

thorough explanation of the project. I scheduled for an interview appointment and

emailed the Informed Consent letter. The Informed Consent Letter is included in

Appendix B. Participants returned the signed Consent form by email before the

interview.

  Data collection. After agreeing on a time to hold the interview through the initial

contact, the phone call was scheduled to last approximately one hour. If the participant

needed to stop the interview for any reason, I would have rescheduled. This did not occur

in any of the interviews. The participants could have withdrawn from the interview at

any time with no ill will and no reason for regret. Neither of these incidences occurred.

Both situations were stated before the interview. I recorded the conversations using an

audio recorder in the computer. The time period was scheduled for timing, but there was

flexibility to address any needs the participant may have had (restroom breaks, fatigue,

stress, personal needs). In one interview, the participant had to stop to let her dog out. In

another, the participant's daughter arrived at home, and needed attention.

  Lincoln and Guba (1985) described the ultimate purpose of peer debriefing is to

enhance the credibility, or truth value, or a qualitative study. For the debriefing, peers

both within this field of study and outside this field were asked to participate in the

debriefing. Spillett (2003) noted that in order to acquire feedback regarding the accuracy and completeness of data collection and analysis procedures, it is necessary to meet with one or more impartial colleagues to critically review research methods. Spall (1998) indicated the importance of trust when choosing debriefers and reminded the researcher that in order to have a high-quality product, a commitment from all parties must be present. I chose a professor in the field of ethics and a psychologist to debrief my research. These individuals agreed to the confidentiality requirements prior to reviewing the results.

Data Analysis Plan

I transcribed the interviews and transferred them to MSWord™ text files. No identifying information was included, and participants were referred to using pseudonyms.

According to Riessman (1993), there are no standard set of procedures for narrative analysis as there is in other forms of qualitative analysis. Riessman (2008) further described the "fully formed" narrative as one which includes six elements: an *abstract* or "point" of the story; *orientation*, including the time, place, characters, situation; *complicating action* or plot, a crisis or turning point; *evaluation*-where narrator comments on meaning and communicates emotion; (she refers to this action as the "soul" of the narrative); *resolution* or outcome of the plot; and a *coda*-the end of the story and coming back to the present time. Considering these elements allows the narrator to compare and contrast the accounts of each case. Riessman also noted that case

comparisons may show additional findings and reveal the points that each participant has to make.

The analysis process was guided by the positive psychology conceptual framework. I identified words, phrases, and examples that represent any of the five elements. I coded and examined them for consistency and discrepancy with the published meanings. The analysis process also took into consideration the nature of the "illness narrative." Chronic illnesses interrupt lives, and significance must be placed on the interruptions by allowing the participant to share their full stories (Charmaz, 1991). Frank (1995) indicated that some patients employ "restitution" narratives which have positive conclusions, while others indicate "chaos" narratives which suggest unclear continuity when addressing the past compared with the future.

Credibility

To establish credibility, my contact with each participant was prolonged, in this case for up to an hour, to establish familiarity and trust. To promote credibility, I focused on two primary levels: the story told by the research participant and the story I tell as a result of the interview. I already possess a "familiarity with the culture" (Lincoln & Guba, 1985) of the participants as my daughter was diagnosed with MS fourteen years ago, and I have been actively involved. I used this tool of familiarity to establish a relationship of trust with the participants. Erlandson, Harris, Skipper, and Allen, (1993) urged the interviewer to acquire a prolonged engagement with the culture involved in the interviews. I have been involved with the culture of MS for over thirteen years.

Many qualitative methodologists (i.e., Patton, 2002; Shenton, 2004) have recommended tactics to help ensure honesty in informants, and integrity of the data gathering and analysis process. I established a rapport with the participants, urging them to be frank and honest with their responses. I used iterative questioning methods such as rephrasing questions to clarify a possible discrepancy in the participants' answers. I used peer debriefing sessions to discuss alternative approaches, and utilized these debriefing partners as "sounding boards" to help recognize any biases I may have, scrutinize the interview process, and facilitate detachment from the material so that my closeness to the topic would not cloud my perspective. In coordination with peer scrutiny, I used member checking. I sent a summary of the interview to the participants, and they considered if my summary is consistent with the intent and descriptions from the interview. I recorded a detailed or "thick" description of the situations and the contexts that surround the interview and the interviewee's experiences so that I could better understand how the shared episodes are representative of the actual situations. I examined previous research findings and made an assessment of how my own findings compare and contrast to past findings. After the interviews, I shared with the participants that I have personal experience with MS.

Reflexivity -- the critical self-awareness about how the research was done and the impact of critical decisions made along the way was maintained; as well as the use of an audit trail - an account of all research decisions and activities throughout the study prior to and during the data collection process, and throughout the data analysis process (Carcary, 2009; Creswell, 2007; Koch, 2006; Riessman, 2008; Rosenwald & Ochberg,

1992a; Seale, 2002). I employed journaling to describe my own experiences and values that influenced my choices during the data gathering and analysis process (Harrison, MacGibbon, & Morton, 2001; Ortlipp, 2008). I transcribed each interview as soon after the session as possible. This helped eliminate any memory loss or confusion.

Transferability

Transferability refers to ability of the researcher to make the process and results of the research accessible to the readers so that they can find meaning relatable to their own experience (Constable et al., 2012). I was concerned with the extent to which the findings of this study may be applied to other studies with the same situation. Shenton (2004) stated that a primary concern of transferability is the ability to apply the current study findings to a wider population. Bassey (1981) added that researchers would be able to relate the findings to their own beliefs if we find similar conditions and situations. Shenton (2004) suggested including: (a) the number of organizations taking part in the study those and where they are based; (b) restrictions in the type of people who contributed; (c) the number of participants involved in the fieldwork; (d) the data collection methods that were employed; (e) the number and length of the data collection sessions; and (f) the time period over which the data was collected. I provided specific information and detailed description about the subjects, location, methods, and role in the study when writing the results. This allows readers to make an informed judgment about whether they can transfer the findings to their own situation.

Dependability

The dependability of the results balances on the dependability of the data

collection process. I did strive to implement the protocols developed to invite, select and

interview consistently. Shenton (2004) reminded researchers that dependability is

present if similar results would be obtained if the study were repeated using the same

methods and procedures. In striving for credibility, I was more assured of having

dependability (Lincoln & Guba, 1985). One of the primary goals in this research is for

the readers to have a thorough understanding of the procedures and the effectiveness of

the study. To reach this goal, Shenton (2004) advised the need to include the research

and its implementation, describing what is planned and executed on a strategic level. He

added that the operational details of data gathering should address exactly what will be

done in the field. He concluded with the need of a reflective appraisal of the project,

evaluating the process of inquiry.

Confirmability

According to Shenton (2004), confirmability is defined as the qualitative

investigator's comparable concern to objectivity. I took steps to ensure that the findings

of the study represent the experiences and ideas of the participants, and not my own

preferences. I followed the premise of Miles and Huberman (1994) who stressed that the

opinions of the researchers which drive the choice of particular methods need to be

explained, and if there are weaknesses in the process they must be admitted. Any

preliminary ideas which were not found in the study should also be made known,

according to Shenton (2004). In addition, an "audit trail" or method of tracing the course

of the research step-by-step was used (Shenton, 2004).

Ethical Procedures

The agreements to gain access to participants or data can be found in the Consent

Form seen on Appendix A.

Confidentiality of participant information was maintained throughout the research

effort. Participants were given pseudonyms, and actual identifying information was

stored in files separate from data. Audio tapes and print materials were kept in a locked

filing cabinet. Electronic files (transcripts, coding, and results) were password protected,

and only shared with the dissertation chair. Interview summaries were reviewed and

approved by participants, and presented without personal identifiers to minimize the risk

of unwanted public disclosure. All files (electronic and print) will be kept for five years

after the study is completed, and will then be destroyed.

Summary and Transition

In Chapter 3, I introduced a description of the methods that were used in the

research, the study design and rationale, the role of the researcher, methodology

(including the participation selection, target population and accessible population) the

criterion and sampling strategy, the Interview Guide, the procedures, data analysis plan,

issues of trustworthiness, IRB requirements, and ethical concerns.

The questionnaire was designed to focus on the current research, on the well-

being of MS patients, and the coping and resilience each one employs.

I performed data analysis using Riessman's (1993; 2009) thematic analysis approach to exploring the interview data, and recurring themes and to acknowledge the differences in their narratives. In addition, I used Seligman's (2011) framework of positive psychology to determine the presence of positive emotion, engagement, meaning and purpose, and accomplishment were explored.

In Chapter 4, I described the results of the data collection and the analysis of the themes recognized from transcribing the interviews. I noted the similarities and differences of the participants' life stories and the demographics of each participant.

Chapter 4: Results

Introduction

The purpose of this qualitative study was to explore the coping and resilience strategies used by women diagnosed with MS for at least two years. I conducted a narrative analysis to relay their "life stories" and categorize their similarities and differences. In addition, I explored positive psychology themes of positive emotion, engagement, meaning and purpose, and accomplishment. Seven themes emerged from the participants' descriptions of their lives.

The research questions were:

1. What is the meaning of resilience to individuals living with MS?

2. What is the meaning of coping to individuals living with MS?

3. How do the themes of positive psychology illuminate the experience of a "meaningful life" in individuals living with MS?

In Chapter 4, I present the data collection process, discuss the analysis and themes from the interview transcriptions, and highlight the different facets of MS. I also provide evidence of trustworthiness. It was my intention to explore how positive psychology strategies are used, and how quality of life is experienced by those who suffer with MS.

Setting

I conducted seven telephone interviews, and made an audio recording of each interview using the voice recorder on a laptop computer and cell phone. There were very few technical issues. On the call with the first participant, I learned that she must speak a little louder than normal voice so that the transmission would be more clearly received by

the recorder on the laptop. I advised the following participants to speak a little louder.

Reception was clear with all of the participants, as they were all in the same region. However, there were a couple of interruptions with the calls. The daughter of one of the participants came home in the middle of our conversation and she had to leave the phone for a few minutes to address her daughter's needs. All other participants completed the interviews with no interruptions.

There were no personal connections shared by participants and me with the exception of membership in the National MS Society. I also shared no family affiliations with any of the participants.

Demographics

There were seven female participants in the study, all over the age of 18. All women had been diagnosed with MS for over two years, and all of them had the relapsing/remitting type of the disease. Six participants were married, and one divorced. Six of the participants had children. All of the participants live in Texas, and all were college graduates. Two have Masters Degrees, and one has a Ph.D.

Data Collection

Six of the seven interviews lasted close to 45 minutes, and one lasted 70 minutes. I audio-recorded and transcribed all of them. My original plan was to use a device connected to the phone and computer, but it did not operate the way it was portrayed in the advertising, so I used a cell phone to transmit the information and the laptop computer's audio recording device to record it.

There were no technical difficulties in the audio recordings. With the exception of asking the participants to speak loudly and into their receivers, no other problems arose. All interviews were conducted at the original time of contact. Transcribing was time consuming, but became easier with each one. I used a second laptop to record input of the conversations as the interviews were being conducted. I typed the questions for each participant and the general format was in place before the call was made. I used short cuts and symbols during the interviews. For example, many participants used the phrase "you know" very often. The shortcut "YK" would be used for that phrase. These shortcuts were helpful in decreasing the time it took to transcribe each one.

Data Analysis

As described in Chapter 3, I used Riessman's (1993; 2009) thematic analysis approach to exploring the interview data. As I reviewed the transcripts, I expected to find statements relating to the main points of interest in regard to diagnosis, the role of family and caregivers, overall health situations, challenges, resilience strategies, and coping mechanisms. These were all identified when I reviewed the transcripts using the primary questions from the initial interviews. I then summarized each of the interviews, which are presented in the next section. Because of my close proximity and personal experience with this condition, I also summarized and have included my reflection after each summary.

For analyzing the data, I used Saldana's (2016) structural coding method. He stated that the original questions in a research interview can be used to structure the coding process, where each question's content helps in labeling codes and categories so that examination of similarities and differences across cases is possible. For each question, I selected words and phrases that seemed to represent the focus or intent of the statement, and then named a "code." Codes were combined into categories and themes.

Summary of Interview Narratives

Prior to examining the data across cases, I read, re-read, and summarized the interviews for each participant. The summaries were shared with the participants as part of the member-checking process. A summary of each participant's interview is presented to illustrate the narrative arc of the illness and post-diagnosis experience.

Participant 1 (PA1)

Before her diagnosis, PA1 indicated that her life was "very stable and fun with few concerns about problems of any kind." She was employed and living with her parents, receiving income plus her parents' help. She indicated that her biggest enjoyment was shopping and "having a good time," with no health problems.

The diagnosis process began with a collapse at her workplace, "probably due to the hot weather and fatigue." She was taken to a hospital, but the doctors were unable to find the reason for her illness. After 2 years and several doctors, she had an MRI and the doctor diagnosed her condition as MS.

After the diagnosis, she began taking medication that helped her overall. She stated that her memory suffered as a consequence of the onset of the disease, making it

very stressful to go out or travel. She indicated that she understood that too much heat affected her body and realized she had to stay out of the sunlight.

She became pregnant, and did well during her pregnancy. However, after her son was born, she had a "huge setback" and felt that she returned to the original diagnostic condition. She was weakened and her memory continued to decline to the point where she minimizes travel and has made provisions to get her to work safely. Her work is just a few minutes from her home.

Exercise did not seem to help, and she is concerned with her eating habits and intends to adjust her eating to have a healthier diet. Her support system includes her husband, her son, and her mother and her father—all of whom offer her daily encouragement.

Her milestones included graduating from college with a degree in accounting, and having a child. Her primary goal now is to create the most "normal" living conditions for her family and deal with MS in a proactive way. She works and meets challenges of MS with a "determination to cope the best way possible." She described several techniques for managing memory problems. To remember to take her medication, her husband bought her a keychain to remind her to take the pills inside. If she has her keychain, she can remember her pills, and noted that "it is a good tool to share with others." She put her work destination in her navigation system to cope with getting lost on the way to work. We discussed how she felt about how long it took for the diagnosis to be made. She shared that the injections she received at the beginning of the diagnosis were very

hard to endure, and has now switched to the pill form. However, it is difficult for her to remember to take the pills, hence the keychain.

Researcher reflection. PA1 was very forthcoming and exhibited a courageous attitude about MS. She is determined and uses any tools available. It was an honor to speak with her and I appreciated her participation and enlightenment in regard to her battle with MS. I was a little nervous before the interview began, since it was the first interview of the project; however, PA1 was very easy to talk to and very forthcoming, open, and honest in her answers. I was moved by her account of her feelings about wanting to become a mother, and her willingness to risk her health to make sure she had a child. I was impressed by the support of her parents and husband.

It was very touching to me that she admitted the problems that accompany MS and gave them matter-of-factly as she covered so much of how the disease affects her life. Her willingness to exercise and eat healthier was an indication of her commitment to doing her part in keeping her quality of life as high as possible.

Participant 2 (PA2)

Before her diagnosis, PA2 shared that her life was stable and enjoyable. She was in the Marines and married to a Marine, and felt this was her life's dream. Health problems became an issue in basic training. She sustained a stress fracture and it took longer than average to complete training. After training, she continued to have health issues (stomach problems, vision problems). After the birth of her children, she developed back problems. Her husband left the marriage without warning, and her health problems got worse.

Her mother, sister, and brother moved in with her and added to her stress, as they increased her financial demands and were unreliable in their support. She was in and out of the emergency room regularly. At what seemed to be her breaking point she saw a neurologist. He performed an MRI and explained the lesions on her brain and spine. He diagnosed MS. She shared that her life "spiraled downward from there." Although she was in line for a promotion, that prospect was taken away when her supervisors found out about her condition.

Before the diagnosis, her work and her children brought her the most joy, but afterwards, she could take care of neither. She shared how her faith in God "motivated her to keep striving," although the odds seemed stacked against her in all areas of her life.

She was most concerned about her employment after the diagnosis, as it related to caring for her children, and reaching her goals. Health issues interfered with her ability to work, and she experienced significant financial strain. After absences, due to fatigue, access to her VA benefits was bureaucratically delayed.

As a single parent her joy comes from being with her children, and being able to walk. She feels that others have so much more trouble with MS than she does. She expressed gratitude for her home which she was finally able to purchase on her own. She advised that people with disabilities need pets to add a dimension to their lives. She described the loneliness of disabilities and how pets take away some of that fear.

She defined *Resilience* as "relearning herself" and shared "that God provided a way to teach me about myself" and her capabilities and showed her how to discern who her real supporters are. She defines *Coping* as "enduring-when you don't have a choice

and God giving you the grace to do it." One of her main experiences in coping is masking the damage of MS. She enjoys dating, and it is difficult to date when her legs are not strong. At the onset of diagnosis, she urges "to work as long as possible and get all the information available to make sure you know how to take care of yourself and your family."

Researcher reflection. PA2 was possibly the most difficult for me to interview because it is the saddest and most heart wrenching interview. PA2's life seemed to be on the right track before she was diagnosed when her whole world came crashing in on her. She was left with two small children to rear by herself. Her goals of being a Marine were squashed because of MS, and the lack of support from her family caused many heartaches and hard times for her. I did not expect her family's reaction to her illness. They were not supportive, but added to her stress. Although it is not uncommon for MS patients to divorce, it is uncommon not to have the support of your closest family members.

I identified with her because my daughter is the wife of a Marine, and they have three young children. At times, tears were streaming down my face, and it was difficult to talk. At one point, I was afraid I would have to stop the interview and call her back later. She displayed courage, and an attitude of determination to learn to cope with MS and to take care of her children with or without support. She stressed that one must take care of her own business and not depend on others, but she expressed this in a matter-of-fact way without placing blame on her family members who were not there to support her. PA2 also expressed that her children appreciated the time they have together and she

is dependent upon God's direction. She mentioned that "God has shown her what is important" and she "thanks God for what He has allowed her to endure."

Participant 3 (PA3)

Before the diagnosis, P3 was employed full time and going to graduate school. Her first symptoms included mostly fatigue and lack of energy. Her children and family activities brought her the most joy in her life. She enjoyed travel and watching her children in sports activities.

In addition to fatigue, she experienced weakness in her feet and difficulty in movement, in general. Other issues followed, and while on a trip to New York City she fell and sprained her ankle. After that trip, more falls came. While participating in a ropes course, she became overheated and lost use of her grip. Finally, while on vacation with her family, she experienced numbness, indicating a problem more extensive than fatigue. At the initial visit, the doctor prescribed steroids, and she regained use of her hands. Shortly thereafter; upon a follow-up visit, the interim doctor mentioned he thought she had MS. At that point, she learned about MS and symptoms. The diagnosis was made within a few weeks.

The most significant change in her life was the fatigue, and she tried medication to alleviate fatigue and improve clarity. The issue that concerned her most after the diagnosis was being able to care for her family, but she realized that energy to do all the things she wanted to do was lapsing.

She gained a great deal of knowledge about how MS works in the body, and she became involved with the MS Bike program. She shared that she refused to feel sorry for

herself and explained she "did not want MS to rule my life." She rides 240 miles in two days on the MS Bike Rally held each year. She began to help others help themselves. She has become the "go to" friend to whom others reach out when they need someone to talk to with MS. A major challenge is keeping up with her kids who are older, and have daily activities: "their activities require more energy."

Researcher reflection. PA3 was perhaps the most difficult interview to conduct. She has a Ph.D. in human services field and was very familiar with interviewing. She was direct and to the point, and it was more difficult to feel a connection with her. Her interview was the shortest primarily due to her short answers and lack of desire to allow the conversations to reach a more personal level. It seemed to me that she wanted to give me "correct" answers, but they felt like surface answers and none really gave me much insight to who she really was. It seemed that she may have had a safeguard in place to give me the "head" answers and not so much the "heart" answers.

Participant 4 (PA4)

Before her diagnosis, her main concern was her work, as her job sometimes required 60-80 hours. When she began experiencing flu-like respiratory problems, she thought it was because of the heavy work schedule and lack of rest.

On a week-end hike with friends, she felt her gait was abnormal, and she felt her leg buckle as she attempted to climb a step and realized she'd lost control of movement. She thought she might be having a stroke, and needed assistance back to her vehicle. She attempted to give blood at a charity event, but was refused because her blood evidenced dangerously low iron levels. Walking was difficult but over a couple of weeks'

time, her leg improved. The fatigue worsened, and a doctor's visit revealed concerns for vitamin deficiency and thyroid dysfunction. An MRI displayed lesions on her spine. Numbness went from her legs to her chest, and after a lumbar puncture, she received the diagnosis of MS.

She wore a brace to aid in walking and for safety. Her neurologist designed treatments of medications and exercise. When discussing the *quality of life* at that time, she stated that she was determined to improve because of her new job prospect. She began taking a very popular MS treatment and adjusted her diet. She had digestive problems causing anxiety in addition to the other symptoms which are common in MS.

The most significant challenges she faces now are cognitive issues and problem-solving skills. She gains the most joy from just enjoying life. She rides a bike with an MS Bike group and is meeting with others to ride. Her family is her support system, especially her sister, with whom she shares many activities, like yoga. Resilience for her is testing herself physically with long bike rides, which present a challenge for healthy people, and more so for persons with MS.

Coping was difficult at the onset of her diagnosis. She experienced vision problems, pain in her head, and intestinal distress. She shared that she now is more concerned with her quality of life and monitors her diet and exercise. She was very forthcoming and encourages others to contact the National MS Society and research the disease and its medications. She especially noted the importance of "having others advocate for you to lift your spirits and walk with you."

Researcher reflection. PA4 seemed to be a very strong-willed person who understands the challenges of MS. She shared that even though she now understands the facets of MS, the actual bearing each has on her life must be met almost on a daily basis. She explained that her quality of life is relative to the issues she is dealing with at the moment. She encourages MS victims to accept help and not become so absorbed in the disease that they forget to live their lives to their fullest, whatever that may be after the diagnosis. She helped me realize how important the sense of belonging to the human race becomes to those who feel that they have lost connection with it somehow.

Participant 5 (PA5)

Before she was diagnosed, PA5 maintained a very busy schedule with a husband, large family and a busy life. The most significant challenge at that time was some health issues. Her family brought the most joy and they enjoyed a lot of activities together.

Bladder problems and a visit to her urologist resulted in a brain scan. Multiple lesions on her brain were identified, and it was recommended she see a neurologist. The urologist acknowledged a "bladder issue" and the neurologist diagnosed MS.

Before the diagnosis, her active life included being a runner and going to Yoga classes. She worked with many specialists to learn how to take care of her digestive problems and offered help with how to combat the balance issues, fatigue, and other MS issues.

Her biggest milestone after she was diagnosed was giving herself weekly injections. The most significant challenge in her life at the time of the interview was vision problems. She gets the most joy from her family "the most meaningful thing in

her life." Family activities are very important to her. Resilience means "picking yourself back up and keeping going." *Coping* to her is like resilience in that the "problem is there and you have to deal with it." She learned to cope with digestive problems. As a teacher, she has had to learn how to manage her challenges on a day-to-day basis.

Her advice to others facing MS is to find ways to cope, including adding activities to your daily routine and challenging yourself. She has been challenged by becoming a biker. Her biking group offers a strong support system.

Researcher reflection. It was easy for me to relate to PA5 because I was a 7th - 8th grade teacher for over 20 years, and understand the levels of stress she addresses every day in the classroom. Like the others, her main concern is the interaction with her family. I felt that she has grown stronger in her coping skills because of her support system, and that is an area which she shares with the majority of persons diagnosed with MS. Coping and resilience are two attributes she has maintained throughout her teaching career, and they help her deal with many of the uncertainties she faces on a daily basis since her diagnosis. It was interesting to hear that she did not want to rely on others as care-givers or helpers, and how fast and involved she became a part of the bike riders group. It is obvious that giving over some of the control in her life was difficult, but very rewarding when she allowed it.

Participant 6 (PA6). Before her diagnosis, PA6 worked long hours as an EMT, played softball, and enjoyed being a mother. During one of her softball games, she experienced the beginning of her symptoms with MS. She became paralyzed and in extreme pain with back spasms, and was unable to move. She couldn't stand and had to

be carried from the field by her husband and a doctor who was attending the game. That initial problem led to hospitalization for a month and a bout of pneumonia before leaving.

The biggest change in her life was inability to walk and inability to care for her child. She has regained her strength enough to participate in powerlifting and just began riding bikes again. She was scheduled to participate in the MS Bike Ride of 85 miles. She rides for herself and for those who cannot ride.

The most significant challenge for her involves her short-term memory. Warm weather inhibits brain function and causes memory problems. Her joy comes from her family activities and from working with her fitness group. She is working toward a trainer's license to help others. They volunteer for MS and other organizations.

Resilience means to "spring back into whatever you were doing before you had a problem." She used the term "*still do.*" Coping means acceptance and understanding of what's going to happen in your future. She shared that knowledge of the condition of MS is a useful tool.

Researcher reflection. PA6 was another brief, but very succinct interview. As I listened to her step-by-step explanation of the time surrounding her diagnosis, I felt that she was someone who had met MS head on, and was determined to deal with it in a manner which would be least upsetting to her family. I related to how she cared for her daughter's welfare, and it was clear that she would do whatever it takes to make sure she met her daughter's needs. That's how I feel about my daughter's MS needs now, and that has been my attitude from the beginning of her diagnosis. I felt compassion for PA6's fear of losing her memory and appreciated her "never give up attitude." She shared that

this part of her life was on the path she believed she should be on, so there was no room for pity in her attitude.

Participant 7 (PA7). Before diagnosis, PA7 was working her way through college, paying her own way. While in college, she had problems with her legs and was unable to walk. Initially, she was diagnosed with Transverse Myelitis, although her doctor said she "might" develop MS. A lumbar puncture revealed lesions on her brain, and she was diagnosed with MS.

After the diagnosis PA7 was afraid of losing her independence, and found that as the MS worsened, so did the stress. Financial freedom and the ability to pay her hospital and medical bills were foremost in her plans. In coping with MS, she originally declined the medication offered and tried to work through the health problems which came. Coping effectively now includes medication, a healthier lifestyle, exercise, and the help of others, including the MS Society.

She accepted the reality of not advancing in her career, and used her knowledge about MS to help others. Working with the National MS Society, helping others, coaching, and giving advice relieved stress and brought personal satisfaction.

Her milestones became her accomplishments and her ability to travel and enjoy her family activities. Her biggest challenge is the fatigue. Instead of running, she uses Yoga as her primary exercise activity. She stated that resilience and coping with MS is inspired by her Mother and the skills she learned from her. She urges others to take care of themselves on all levels "emotionally, spiritually, and physically." She is a motivational coach though her time is limited by fatigue.

Researcher reflection. PA7 was very direct and has had MS for the longest time-over 25 years. She was forthcoming with her answers to all questions, and was very direct with her answers. Her life, like the others, has been totally transformed since her diagnosis but her dedication to her family is very strong. I related to her admiration of her Mother, who also struggled with physical problems. I admired my own Mother so much and she was always supportive of everything I did, so this portion brought back some good memories for me. Her desire to make her Mother proud of her rang true in my own life. One thing I heard in her voice that I had not heard in the others was a desire to be "done" with MS. Where all the others seemed to be hopeful of where the medical discoveries might help them in the future, she stated there probably won't be any new discovery that will change her life. She shared that she is so tired and her body has seen so much stress in the past 25+ years that it has taken a toll on her psyche and she is ready to leave it all behind. It wasn't a defeated attitude that I heard. She said she had accomplished all she knew she could, and had lived a happy life and now, she was ready to move on. I felt a sadness for her, but also felt that she had reached a point in her life that is usually difficult for all of us. She easily admitted that she's reached that time in her life that she realizes there probably won't be much improvement in her condition. She seems to have made peace with where she is in her life and accepts that she's done all she can do. Her attitude was inspiring to me, and one that seems brave.

Narrative Themes

As described in Chapter 3, the first phase of the thematic analysis was driven by the narrative arc of the illness experience, which was consistent with the order and focus of the interview questions.

Before the diagnosis. The primary categories that emerged included: children, family, stability, employment/career, education, and enjoyment. All participants described, looking back, that life was stable with few problems. All were employed and PA3, PA5, PA6 had children. All participants had completed at least a Bachelors Degree before diagnosis. In describing their quality of life:

PA1: Oh, wow. I was uh, I guess, young, in college, I was a young college student, I worked at a car lot, and let's see, I spent nights partying, but still got up and went to work in the morning. I was young and just enjoying, young, you know...young college student having fun doing whatever I wanted to do-going out when I wanted. I didn't have many challenges.

PA2: I left a low-income family and I joined the Marine Corps; I planned on being a Marine my whole life. I did my four years and at the end of my enlistment, I married.

PA3: Uh, I was working full time. I was going to grad school while I was working full time, too. I was in school in Psychology. I had lots of energy. Everything was going great.

PA4: Work was my main concern. The project was going through audit. We were traveling…lots of travel…lots of work.

PA5: I don't think it was much different than it is now...four kids, a husband, busy life. Nothing was out of the ordinary. Family activities and work.

PA6: Before I was diagnosed, I was very active. I played sports, softball, worked at a hospital. Sometimes as an EMT and a tech there. Constantly back and forth and always on my feet. Had a one year-old.

PA7: I enjoyed helping my Mother and I enjoyed school. I wanted to better myself. I mean, having been raised by a single Mom and going from, you know, being living on an Air Force base in a two-parent home and to living in a single parent home where we were kinda latchkey kids. My Mom was working. I just wanted to contribute and get ahead and be independent, basically.

Diagnosis process. Common categories emerged from the description of the diagnosis process, and included: fatigue, weakness, immobile, stress, pain, numbness. Fatigue played a major role for all women as they began their search to manage their disease. PA1, PA2, PA3, PA4, PA5, PA6 and PA7 all experienced walking, weakness in legs and feet, and immobility problems. All experienced stress related issues and numbness in feet, hands, or legs. Some were more severe than others.

PA1: I was selling cars and we had to be outside all day. Memphis, Tennessee in the middle of summer-it's a good 125 degrees…it feels like 125 degrees. One day, I collapsed. (regarding medical infusions for energy) I go in there and I'm all sluggish and I say, "Oh, My, Gosh, my gosh, I'm tired."

PA2: To lose mobility. You're trying to rebuild, and losing your self-control. The normal things that a 30-year old female should be gaining control of her body, her

self-awareness, you know. Gone. So, the most single thing I can add would be losing physical mobility.

PA3: Just the fatigue. Yeah, and that continued to be my main issue. I'm just exhausted and I actually take Aderol to help. I also take it for clarity of mind. At first, I thought it was just the fatigue. The more tired you get, the harder it is to think clearly. I was presenting at a conference. I tripped and fell and that was the first time I'd noticed the weakness. I started falling and because I twisted it, it was more like a sprain. It was August and I was totally numb from my knees to my feet. It's like when you go to the dentist, and they deaden your mouth, but you still feel some sensation.

PA4: I didn't even understand fatigue. I remember thinking, I'm O blood type, a universal donor, (she was unable to give blood because they advised that her blood was too weak and iron deficient). I noticed a hitch in my step-not my normal gate, having to think of moving my left leg. I would have to make my leg move. It felt like I'd lost control of my leg. Even walking was difficult. Numbness spread up to my knees and went up to my hips and up to my mid chest. I was really concerned about walking. I had to wear a brace.

PA5: Little things that had been bothering me like balance issues, fatigue, it all kinda made sense after listening to the specialists. MS related-battling extreme fatigue-go to bed early, take your vitamins and supplements. Follow the rules they give you.

PA6: (at a softball game) I walked over to the bench. I felt my spine crumble and I could not move again. I had to hold myself up with my fingertips because I couldn't put pressure on sitting. The pain was excruciating. I couldn't stand. I had back spasms.

I kept trying to get up so I could at least walk to a base…but I could not move. For a month, I was unable to use my legs. I was learning to walk again. With a baby in a playpen, I was not able to crawl around—everything paused at that moment and I didn't know what the future would be.

PA7: I had my first experience when I was a junior in college, um, I was hospitalized because I could not feel my legs and [health] declined and couldn't walk for a short period of time. That was pretty traumatic—I was only 24 maybe, and I didn't have insurance. It was scary, too.

PA2 and PA5 experienced vision problems.

PA2: My vision started to go in and out. The Marines diagnosed it as optic neuritis.

PA5: When you deal with one thing and another different problems pop up. I'm still having a lot of eye issues and going to see doctors.

Diagnosis after. The common categories which appeared in the third theme included employment and financial issues, independence, the symptoms associated with MS (e.g., memory impairment, fatigue, stress, inability to walk, vision problems), and general anxiety and fear.

All participants were concerned with employment. PA2 and PA3, PA5, and PA6 were fearful of not being able to take care of their children. All participants began some type of medication program. All experienced a continuation of fatigue and stress. PA1, PA3, PA4, PA5, PA6, and PA7 experienced memory loss and cognitive confusion. PA5

continued to experience vision problems. All participants experienced mobility problems

with PA4, PA5, PA6 having extreme difficulty in walking.

PA2: Employment was the biggest issue because, like I said, I was Federal, so I

fell underneath the, what is it called-Lord Jesus, please help me think, not FAFSA, but

SMLA. I've been a Federal employee all my life…my Supervisor called me in the office

and she said, "Mam, you've exhausted your SMLA." I didn't know it could even be

exhausted. So, I went into work, and I told my supervisor the doctor recommended to

find a job where I can work less hours. How am I going to support 3 kids? ….to be able

to provide for your children was my # 1 goal.

PA3: Being able to take care of my family-being healthy enough to take care of

my family-not being able to have enough energy to do the things I needed to do.

PA5: My independence-my ability to go have fun with my family-to go do things.

PA6: At the time, the world stopped…I won't lie. I had my daughter...she was in

a playpen. The doctor would come in and I would shush him so he wouldn't wake her

up. I was not able to crawl around—everything paused at that moment and I didn't know

what the future would be.

Role of family and caregivers. There were several categories which emerged:

primary caregiver, members of family, support systems, extended family and friends.

PA1, PA3, and PA5 had husbands who were their primary caregivers. In addition to the

husband for PA1, her parents were also caregivers. PA3's extended family were also

caregivers. PA5's four children have also been her caregivers. PA7's life partner has

been her caregiver. Fitness groups and MS Bike groups have been caregivers and

supporters to PA3, PA4, PA5, and PA6. All participants had favorable situations with their caregivers except PA 2. In her case, her husband left her and three children shortly after she was diagnosed. Her family did help out, but only if they were paid to do so. This caused overwhelming stress and grief.

PA2: but then me and my husband separated and my mom moved in from [another state]. She moved down and my sister and brother, who were a junior and sophomore at the time…they were supposed to be with their dad, they ended up moving in as well. My stress level peaked out of control to the point where I couldn't breathe. [MS] was compounded with having your husband…your spouse walking...walk away while you're trying to rebuild, and losing your self-control. Gone. So, the most single thing I can add would be losing physical mobility and realizing that everybody in your inner circle is untrustworthy.

Health challenges. The categories which emerged in this section include continued short memory loss, loneliness, going back to work, fatigue, decreased problem solving skills, vision, and hot weather. Memory and cognitive issues continue for PA1, PA3, PA4, and PA6. PA3, PA5, PA6, and PA7 all battled fatigue. Loneliness is the major problem for PA 2, along with walking. PA5 is still coping with bladder problems. Hot weather is a problem for all participants, as it exacerbates fatigue and other symptoms.

PA1: Yeah, mainly memory cause I guess it all ties together. I try to do things; I don't remember them in the morning. I get caught up doing things. I get so busy I don't remember to take my pill.

PA3: The more tired you get, the harder it is to think clearly. We still travel but I have to pay more attention to what I do.

PA4: I started back to work and when I started back to work, I was very concerned about "was I going to be able to handle cognitive issues and different types of stuff like that? I would wonder, how do I deal with the overall anxiety?"

PA6: Memory. I have no short-term memory. When it gets hotter, Oh, my God. I can't remember to lock my car and I can't remember to lock doors. I argue with my poor husband.

Resilience. The categories which emerged in this section were: bouncing back, attitude, acceptance,

PA1: I guess it was a resilient moment for me to bounce back from having my son, and really, I was in denial.

PA2: Well my idea about resilience is bouncing back from something...an event…Relearning myself. After dealing with a spouse that all the income and all the benefits walk away…I had to relearn *me* and accept *me*, which, you know, I'm trying to summarize. When you're married, it's easy to become intertwined, co-dependent, right? And to deal with that…find a way to…God will give a way to deal with it and accept that. I am so grateful that God will give me a way. I am so grateful that...I'm really...He really taught me who my inner circle is…so many people...when you're well off and you're making it, when you have friends and family, everything is good.

PA3: I consider myself a resilient person in spite of having MS. I'm still trying to live my best life. Just because I have this *I can* attitude. I would never have thought I

could go through something like this. It's not giving up. When I was diagnosed, I knew nobody else who had it. I contacted the MS Society and got involved with Bike MS to try to do something. I didn't want to feel sorry for myself.

PA4: I think part of that means to accept whatever adversity comes and being able to adapt. It was a test…functioning.

PA5: Resilience means picking yourself back up and keeping going. Like MS related-battling extreme fatigue—go to bed early. Take your vitamins and supplements. Follow the rules they give you.

PA6: It's a recovery...able to spring back into whatever you're doing. I think that it's the ability to "still do." Trying to get your mind to wrap around how you will bounce back and not using your legs.

PA7: It means that you bounce back...it's not that you don't incur hardships or incur challenge, or you're gonna get knocked down….I always get back up and keep tryin' and um, you know, I just think I learned that again from my mother who was, you know, disabled with scoliosis as a kid, but never did I hear her say the word *disabled*. I had done Yoga before and started doing it again when I left the workplace. I do Yoga almost every day. I was doing Yoga to music. There was something about doing it to music that made it challenging for me and I later learned it helps develop neurons...you know, um, and so it's very meaningful to me.

Coping. The categories that emerged in this theme were relying on parents and husband for support, continuing work, prayer, music, maintaining independence,

spirituality, God, sources of strength, knowledge of MS, dropping "non-friends", and using life experiences.

PA1 continues to rely on her husband and parents for support. Prayer and spirituality are part of PA1 and PA2's strategies. All participants rely on knowledge of MS and effects on one's body as tools for coping. PA2 and PA3 have found that "dropping" some so-called friends/family has added to their peace of mind and advises it as a strategy.

All participants used some type of exercise to cope. PA-1 goes out with her husband and family; PA2 walks her dog; PA3 and PA5 -travel with their families; PA4 and PA6 participate in MS Bike rides; PA7 volunteers as a National MS Society coach and is the "go-to person for people with MS in her community.

PA5: Coping is kinda like resilience. I have to cope with knowing what foods I can and can't eat. I'm a "suck-it-up" type kinda person. I teach 7th graders. I have to deal with all kinds of situations on a day-to-day basis. I usually cope with whatever comes my way. You got be strong and find ways to deal with it. I'm part of a bike team.

PA4: Coping is just accepting. How you deal with it...if you choose to deal with it. How you adjust to a situation? I remember calling over there (to the doctor's office) and you don't know you can be so strong. I'm having to manage their process—I didn't feel like they were doing their part. You have to be very bold. I don't have the Quality of Life. I'm having vision issues, this head pain…intestinal distress…this isn't how I'm supposed to feel. I'm on this drug six weeks with these issues and the drug company

won't even call me back....*I'm going to reclaim myself!* I monitor my life from that point.

> PA6: Coping is acceptance, understanding. Coping for me...it's not just me coping, its family and friends...understanding of what's going and what's going to happen in the future. I have to write things. You've got to stop *and breathe.* Sit there and breathe for a second...realize its part of life. Knowledge about what the rest of my life would be like. You feel like you're growing. I have realized that I have to do things.

> PA7: Dealing with, um, whatever life throws your way with the skills that you've learned, you know. I think it probably has been to my benefit that I went into Psychology and the helping field because, you know, while I was once teaching coping skills to other people, now I use those coping skills for myself. The trick is—it's using everything I know every skill I have to just get through today when it happens.

Positive Psychology Themes

The second phase of data analysis turned to examination of the transcripts for concepts and stories that mirrored/represented any of the five elements (PERMA) of positive psychology (Seligman, 2011): Positive Emotion, Engagement, Positive Relationships, Meaning and Purpose, and Accomplishment. When analyzing how the themes of positive psychology illuminate the experience of a "meaningful life" in individuals living with MS, all of the participants expressed seeing their diagnosis as part of a bigger picture in their life's journey.

Positive emotion. PA1, PA2, PA3, PA4, PA5, PA6, and PA7 described the experience of positive emotion through motivation from family members and jobs (both employment and MS tasks).

PA1: I'm just taking it as it comes…I can't stress over stuff, you know, every little detail, every little thing right now—especially having a young child…we try to stay active...we walk to the park and go swinging. (She spoke of her Grandmother) You know, you cherish those moments.

PA2: I realize that the diagnosis was a blessing. God has shown me what is important and I get to be with my children, and the good days…the good days, they become more appreciative people, and don't take anything for granted. I try to mask the damage the disability has done, hopefully enough. In my mind, the Marine is telling me, "You can do it. You can do it. Go running, go walking, you can do it, you can do it." I'm gonna have everything mapped out.

PA3: I definitely feel better than after I got diagnosed. I feel like I've gained a lot of strength…things like I thought… I don't know how to put it. That which doesn't kill you makes you stronger. I've gotten involved with the bike rides. Being part of something positive has changed the health and mindset. People I've met have encouraged me and urged me to try whatever I'd like to try. We have become dependent on each other and you really find out who is there to tell you to put your big girl panties on. I would never have thought I could go through something like this. It's not giving up and having a positive attitude so I can still do things I love to do and enjoy.

PA4: I'm in a state where things change from day-to-day. You're waiting for the next level, if there's going to be a flare-up or exacerbation. If it happens, I do what I have to do. It's a matter of how hard or how severe it is. I don't sit there and dwell on it. My thoughts—they all very positive. Right now, I guess my demeanor hasn't changed. Just being able to deal being around people. Some people see it as a life-defining thing. I don't think it has defined me how I want to be. I don't see it as I'm going to play a victim. I've never had that, "Oh, why me?" Not saying there wasn't ever a time when I was angry about it. There may times in the future I will be angry, but its part of my life. We did the Bike MS in 2012. We're trying to start the MS 101 thing. I want people in there that are positive to offer that hope to other people. I'm in the group that is positive. I try to convey strength. We put a positive spin.

PA5: I'm a "suck-it-up" kinda person. I teach 7th graders. I will tell you that you got to be strong and find ways to deal with it. My friend and her charity gave me a bike and I am now part of their Bike Team. They are so helpful. There are 110 on the Team. I have just found them to be a strong support system and understands right where you're at and cheers you on. Anyone with a chronic disease needs to find the people that will be there for them. I never wanted to go to a support group, but they make you feel like you can ride that 10 miles…that is an important part of dealing with a diagnosis like MS.

PA6: I am going to tell them to breathe…You know. You've got to stop and *Breathe*. When I tried to run a half marathon…I've gone through everything...And just realize you're on this path for a reason. There's a reason, like where I am now. Helping

others understand, but it's gonna get frustrating…sit there and breathe for a second...realize it's part of life.

PA7: Put yourself first. If you don't take care of yourself from an emotional aspect/spiritual aspect/physical aspect, you can't help anybody else. I was coaching people with MS and teaching them all about it and helping them be resilient. I am very blessed, you know. I want for nothing…except a cure for MS.

Prayer, music, strong spiritual faith, and being helpers and advocates for others were motivators for PA1, PA2, PA3, PA4, PA5, PA6, and PA7. Putting others before themselves is a strong motivation for all of the participants. PA2 overcame family disappointment but remained positive. PA7's positive reinforcement came from her Mother. PA7 remarked that "realizing your blessings" is a key factor in coping with any life stress.

Engagement. Seligman (2011) taught that engagement allows us to "experience a state of flow" and "concentrate intensely on the present." Defining engagement as involvement in their day-to-day treatments, and the many facets of maintaining their lifestyle, all participants were involved before and following their diagnosis. PA1 was working and finishing college. She enjoyed shopping and was a car saleswoman. After the diagnosis, she explained:

PA1: I went to the hospital; they did several tests...I went through three different doctors before I finally got it….it took about two years before I was ever actually diagnosed with MS.

I haven't changed things, but I know my eating habits…I'm concerned about them because I don't really know how to eat right now. I know that's something I need to modify and work on, definitely.

I try to stay out of the sunlight because too much sunlight…I know that kinda just that gets to me. Exercising is not really working for me but I guess I'm just taking it as it comes. I can't get stressed out over, you know, every little detail, every little thing right now—especially having a young child. We try to stay active...we walk to the park and go swinging.

PA1's degree is in accounting and she is still works, although she has extreme memory problems. She programs the directions to her work into her maps system in her car. She also has a timer on her telephone that buzzes when it is time to take her meds.

PA2's engagement issues were stressful before her diagnosis, as she performed her duties as a Marine and as a Mother of two little children. She was forced to carry out her parental duties alone when her husband suddenly deserted her and the children. Her failing health brought in her parents and siblings, whose presence complicated her life. She was deeply engaged trying to "balance" her new diagnosis with her family problems.

PA2: When me and my husband separated, my stress level peaked out of control and I was working for the Federal Government, I was in and out of the emergency room all the time. I wasn't sittin' on my butt…I was working. PA2 applied for disability through the VA benefits and it took a year for her to be approved. (She also had to reapply for her benefits and wait almost two years to get Social Security assistance.) You don't want to be alone. You don't want to do anything because you scared it's gonna be

gone…counseling…thank God for counseling because I wouldn't know…I don't know what I would have done with myself if it hadn't been for counseling.

I'm walking. I grab my Nikes. I have a dog. His name is Duncan. I recommend pets for people who are alone. I try to mask the damage the disability has done, hopefully enough…hopefully, enough for me to attempt to date.

PA3's experience with engagement before her diagnosis included full time employment and attending graduate school. She has a big extended family and has always been very active with them. Caring for her family is still her major concern, and she engages learning opportunities to educate herself about MS and what to expect. She became involved in the MS Bike group and has ridden 240 miles in two days on the MS Bike Rally. She mentioned that she dropped some of her old acquaintances who were not really "friends after all."

PA3: I was working full time. I was going to grad school while I was working. Spending time with my family in activities -- going out and getting together -we have a pretty big extended family and we like to travel. Watching our kids play sports...new activities like that.

(After the diagnosis) I had to learn to say no because I couldn't do it all anymore. I had to learn to say, "I can send something but I can't help." I had to start conserving my energy. I contacted the MS Society and got involved with Bike MS to try to do something. I rode like 50 miles on the bike. I've created a post. A support group for myself. I've also had to cut people out of my life. Those are people who really weren't friends to begin with.

Being able to maintain keeping up with my kids now they're old (challenge in her life today)...taking them to activities they have day-to-day. I still like to travel with my kids. We plan things differently.

PA4's primary engagement before diagnosis was her work, working many hours. She was single and took care of her elderly Mother. She hiked and was in engaged with employees' outings. She engaged in therapy after her diagnosis. She diets and exercises. She meets every issue of MS with a determination to learn and conquer. She is active with the Bike MS and still enjoys her family. She participates in Yoga. She has a profound statement, "I'm going to *reclaim* Myself." She monitors her nutrition and refuses to let MS rule her life.

PA4: Work was my main concern. A light week was 60-80 hours. We were traveling...lots of travel...lots of work. We went out hiking.

As far as diet, exercise are concerned, I plan to do my part.

Where we had been actively engaged in things before, things had to change.

I'm in a state where things change day-to-day. I do what I have to do. It's a matter of how hard or how severe it is.

You have to be very bold.

I monitor my diet as far as nutrition, vitamins, better stuff. I want the MS 101 for Dummies.

Family is a big thing…my support system-my family. My sister has been amazing through all this. She understands. She has started teaching Yoga. I'm going to work with them. That gives me meaning.

I try to convey strength.

PA5 is married and has four children. Her engagement included a very busy schedule with her children and husband. She had to give herself an injection each day, which she mastered. As a 7th grade teacher, she shared that she must deal with all kinds of situations on a day-to-day basis and copes with whatever comes her way. She is also part of an MS Bike Team. Although she did not originally prefer to join a support group, the group to which she belongs makes her feel "like she could ride the 10 miles" and she has learned what to expect in the MS process.

PA5: Family activities and work. We were busy with activities and taking care of the family. I actually gained a lot of answers to, you know, the things that were bothering me like how to deal with bladder issues. Finding out that I had to inject myself weekly. Actually, I'd have a glass of wine before the injections.

Still my family. We like to do things together, as a family.

I will tell you that you got to be strong and find ways to deal with it.

PA6's engagement before her diagnosis included sports, especially softball. She worked as an EMT and was busy with a one year old. Her primary enjoyment in life was watching her daughter grow and learn. Following her diagnosis, she still enjoys being with her husband and daughter. She loves working with her fitness group and is working toward a license to help others in the fitness profession. She pledged to herself to find ways to cope with her memory issues as they increase.

PA6: Before I was diagnosed, I was very active. I played sports, softball, worked at a hospital—sometimes as an EMT and a tech there. Had a one yr. old. I was paralyzed from the waist down. I was in X Hospital for a month.

For a month, I was unable to use my legs. I was learning to walk again. I was transferred to a rehab unit. It took me two weeks to learn how to walk again. I have to say I gained a lot of strength in myself; strength in others.

Right now, the ability to do what I'm doing in a gym (brings her joy). I'm starting to get my group fitness license so I can show others.

PA7's engagement before her diagnosis included a busy schedule as a college student working, paying her own way. After college, she worked in the corporate world as a supervisor. She was a runner and took care of her body and monitored her weight.

She no longer works in the corporate world, but is still able to take care of herself. She exercises and participates in Yoga. She works with the MS Society on a national level and coaches others with MS and their caregivers.

PA7: I took a step back (after the diagnosis) and thought *I'm not going to be climbing the corporate ladder.* I learned all I could learn about job accommodations for people with MS and I started to ask for job accommodations at my job, and thankfully they gave them to me. I was able to work for 13 years. I had a really bad relapse and I was going to be leaving work for two weeks to recover and I never went back. What brings me the most joy is when I can get a call from somebody that Googles my name and finds an article that I wrote on Job Accommodations. I spend time on the phone sharing my experience.

I always get back up and keep trying and um, you know, I just think I learned that again from my mother who was, you know, disabled with scoliosis as a kid.

I liked to exercise a lot and my joy was running. I learned it wore me out when I ran and um, when I started doing yoga instead of running, I was surprised I could love it as much as I loved running.

The trick is—it's using everything I know…every skill I have to just get through today.

Positive relationships. As humans and "social beings," well-being includes positive relationships that are meaningful and positive. (Seligman, 2011). PA1 had good relationships with her co-workers and excellent relationships with her husband, son, mother and father, grandmother (who has passed away), and other family members. She developed a working relationship with her third doctor-the final one who examined her.

PA1: My Mom...she was there the whole time. My child's father was in the delivery room with me and my Dad—I could never forget my Daddy. The big milestone is moving from Memphis, Tennessee down to Ft. Worth, Texas. I've never left Tennessee...it's like a big move for me and I'm still letting it sink in...oh my gosh, my whole family is in Memphis, and well, it's just me, my son, and my man.

My son. He's two so he's a busybody, always happy…he puts the puppy dog eyes on, and he melts my little heart. He'll say, like "Mommy please," and Oh, God, I can't stay mad at him.

When I lost my Grandmother…me not being able to be there physically, that was kinda hard cause I couldn't give her, like, kiss her goodbye. You cherish those moments.

Yea. I have my Man, my Dad, my Mom, and Son. As long as I have them, I'll be all right. I'm Daddy's little girl.

PA2 was a Marine to begin her career, but that ended when she was diagnosed with MS. She did have a good relationship with her co-workers and her Supervisor advised her how to claim benefits after her husband left. Her relationship with her husband ended in divorce, and her parents and siblings were not supportive in a way which added to her well-being. She has a strong relationship with her two sons, and has made "new friends" to replace the family members who did not help. Despite the circumstances, she does not seem bitter. She shared that she has "learned" from these events and will be aware in the future.

PA2: But when you hit rock bottom, you really see-believe it or not…it was the strangers who helped me more than my family. Yea, they followed through (from a request when she was in the hospital) but it came at a price to me. Nothing is free...My Mom came and helped but I had to pay her. I had to pay her $100 a night (to watch her Grandsons). She moved down and my sister and brother, who were a junior and sophomore at the time…they were supposed to be with their dad, they ended up moving in as well. My stress level peaked out of control to the point where I couldn't breathe.

PA3 had strong relationships with her co-workers, her children and family members. She has maintained these relationships and developed new ones with members of the MS Society, especially the MS Bike group. She also "dropped" some of her old acquaintances who weren't friends at all.

PA3: Spending time with family-spending time in activities, going out and getting together...we have a pretty big extended family and we like to travel. Watching our kids play sports.

Being able to take care of my family.

I got involved with the Bike MS and that changed everything. I've created a Post. It's a support group for myself. I've also had to cut people out of life...those are people who really weren't friends to begin with. They were friends who took from me.

Traveling and time with family. Like my husband and I went in November to Hawaii. It was a trip of a lifetime.

PA4 had strong relationships with friends and co-workers. She often hiked and played sports with them. She had a strong relationship with her Mother who was a single Mom. She has a strong relationship with her Sister who is an advocate and caregiver to her. At the time of the interview, she also had a strong relationship with a Boyfriend. She has developed relationships with members of the MS Bike Ride. She has also developed a strong relationship with her MS doctor. She has a new MS friend diagnosed at the same time she was.

PA4: I was looking for a new job. My Mom was stabilized in a nursing home. I was so exhausted when I got home, just making dinner with my Boyfriend was a job. Where we had been actively engaged in things before, things had to change. It's not that I'm tired all the time. He got to where he could identify it and my needs.

You know, family is a big thing…my support system-my family. My sister has been amazing through all this. She understands. She works to help me.

Then the doc said, "Let's go back and compare it to the MRI." (The lesions were downgraded from the previous check-up.) We both sat there and hugged each other.

The following year, I had a friend who was also in the MS Society. Her and I both got diagnosed in 5-2011 together. We did the Bike MS in 2012. We're trying to start the MS 101 thing.

PA5 had strong relationships with her family of four children and her husband. She maintained good relationships with her co-workers. She is a 7th grade teacher. She has also developed a strong relationship with her Bike Team of 110.

PA5: We were busy with activities and taking care of the family. I like to run and take Yoga classes. Having four kids keeps me very active.

Regarding current relationships…Still my family. We like to do things together, as a family.

I have just found them (MS bike team) to be a strong support system and understands right where you're at...and cheers you on.

PA6 had a strong relationship with her co-workers and played sports with some of them. She has a strong relationship with her husband and daughter, who is eight yrs. old. After her diagnosis, she developed a good relationship with her MS Bike Team. She also "loves" working with her fitness group and is working on a license to help others.

PA6: My family...my family is so meaningful to me. My husband…my husband is doing water rescues right now….my family brings me such happiness.

It's not just coping…it's not just ME coping, it's family and friends, understanding what's going on and what's going to happen in the future. My family had

to start coping with...you may have to tell me something 50 times. (regarding her memory loss).

PA7 had a good relationship with her co-workers. She had an excellent relationship with her Mother to whom she calls her inspiration and her brothers and sisters. She has a strong relationship with her Life Partner. She has developed good relationships with her MS Society members, helping others, coaching, and giving advice.

PA7: Five brothers and sisters. I'm the middle child and um, and always been, you know, the communicator and problem solver.

You know, I had a very inspirational Mother…my Mother had scoliosis when she was 13 back in the 1950s. She was always exercising.. I had her as my role model, so I um, just wanted to be healthy—like my Mother, I wanted to handle things as well as my Mother did.

I have a large family. I love seeing all my nieces and nephews getting together with them and encouraging them in whatever they're doing and so it's when I can make a difference.

I have a wonderful family. I have a beautiful wife. Um, she works very hard and um, I just…I'm very lucky I get to spend my day seeing what I can do to help somebody else.

Meaning and Purpose. Seligman's (2011) definition of meaning and purpose is that it is acquired by serving a cause that is larger than we are. It may be a religious cause or some other reason that betters humanity in some way. To have a sense of well-being, we need meaning in our lives.

PA1 shared that she gets meaning in her life from her husband and her son in creating a new life for them in a new town.

PA1: Cause I do want to see my son, my Man, my family. It's like Me, My Son, and his Father...we're in a new city together. It's a new start.

PA2 shared that the most meaningful things in her life are her children and her job. She has overcome some family problems which were not common to the other participants, but her sense of purpose in her life has never wavered.

PA2: Working toward something...putting in those hours, and the time and my children, coming home every day, to be able to provide for your children was my # 1 goal. Those two were my happiest things. I've got to support 3 babies.

I realize that the diagnosis was a blessing. God has shown me what is important, and I get to be with my children, and the good days…the good days, they become more appreciative people, and don't take anything for granted.

PA3 shared that her children and family remain her highest concern. She is educated and had a successful career before her diagnosis.

PA3: Being able to take care of my family…being healthy enough to take care of my family. I had to start conserving my energy. Things I used to do weren't as important any more.

I've gotten involved with the Bike MS rides. Being part of something positive has changed the health and mindset. People I've met have encouraged me and urged me to do whatever I'd like to try. We have become dependent on each other and you really find out "Who" is there to tell you to put your big girl panties on.

I consider myself a resilient person…in spite of having MS, I'm still trying to live my best life.

PA4 found meaning in her employment before her diagnosis. She was always ready for a new project and often worked 60 hours per week. She has a strong relationship with her Boyfriend and family relationships are important.

PA4: I'm in a state where things change from day-to-day. You're waiting for the next level, if there's going to be a flare up or exacerbation. If it happens, I do what I have to do. It's a matter of how hard or how severe it is. I don't sit there and dwell on it. My thoughts…they're all very positive. Right now, I guess my demeanor hasn't changed...just being able to deal being around people. I don't think it has defined me yet. I don't see it as I'm going to play a victim.

Um, right now, it's just life. We all get a bike and ride-.never do or seek miracles.

You did this - you owned it – we'll do it again.

This happened to me; I'm just rolling over it.

Here's my thought…I don't have the quality of life. I don't know what's going to happen next…I'm going to reclaim myself!

I try to convey strength.

PA5 shared that her main fear was "losing her quality of life," but she has resolved to "pick herself up and keep going." She still teaches 7th grade and finds meaning and purpose in her career, but her primary concern is for her husband and four children. She has a busy life and continues to travel and participant in activities on a smaller scale.

PA5: My independence...my ability to go have fun with my family- to go and do things. Quality of life. So that's probably my biggest challenge...feeling like you're doing really well.

I'm a "suck it up" kinda person. I teach 7ᵗʰ graders...I have to deal with all kinds of situations on a day-to-day basis.

I will tell you that you got to be strong and find ways to deal with it

PA6 previously worked as an EMT in a hospital and was very involved in her service to others. Her primary concern has always been for her husband and daughter. She still loves working with her fitness group and helps others. Her daughter works with Special Olympics and this brings joy to all of them. She shared that she realized she was on this "Path" for a reason. She is helping others understand about MS.

PA6: My daughter...definitely it's a life-changing event…always busy.

I gained a lot of strength...by that I mean strength in myself...strength in others. A new light to see what was going to happen. In other words, you feel like you're growing.

My family...my family is so meaningful to me. My husband…my family brings me happiness.

And just realize you're on this Path for a reason. There's a reason, like where I am now…helping others understand. There's gonna be times when you are sad or anxious about something.

Sit there and breathe for a second…realize it's part of life.

PA7 gained meaning and purpose from her employment before her diagnosis. She described a very busy schedule which required a lot of her time. Now, she finds

meaning in her family relationships and activities with them, traveling, helping others understand how to cope with MS.

PA7: Being a supervisor took its toll on me and I ultimately, um, resigned. I would say (it was) a turning point because up to that point in my life …up to that point, I was driving to climb the corporate ladder…go to the top…be successful, that's how it works, but when my health was compromised, I took a step back and ..and thought, *I'm not going to climb the corporate ladder.* That decision – learning about the accommodations—led me down um, a totally different career path-one that I found much more, I would say intrinsically rewarding that the clinical work I was in.

I eventually left the work force completely in 2012, um, I did spend at least-I don't know-maybe five years coaching people with MS, which I really like and loved to do. I continued to work part time for the managed care company, but I really saw myself as going to specialize in helping people with MS.

Accomplishment/achievement. Seligman (2011) teaches that we try to better ourselves and achieve a higher goal. We *flourish* when we accomplish.

PA1's primary accomplishment in her life is her son. Her biggest fear was not being able to have children, and when she had her son (against doctor's advisement) it brought her so much happiness. Among her other accomplishments are graduating from college with a degree in accounting and working in an accounting department. Although she stays at home now, she enjoys taking care of her husband and son and delights in visits from her Mother and Daddy.

PA1: Usually my son can make me just like happy when I'm feeling down. It's so cute. My son knows. I have my Man, my Dad, my Mom and my Son. As long as I have them, I'll be alright.

PA2 was a Marine and was "living the dream of her life" when she was diagnosed with MS. She had planned to be a lifetime Marine. She was in line for a promotion when she was diagnosed, and that did not occur when her supervisors found out about her MS. In addition to her health problems, she had family issues which brought her great distress. Her husband deserted her and their two children. Her Mother and siblings moved into her life, demanding payment for all support they gave. Despite all these burdens, she managed to work through all the problems and maintain a positive attitude to find a good job and take care of her children. She was also able to purchase a home, her first, and is now able to live a full life with her children.

PA2: Working toward something…putting in those hours, and the time and my children, coming home every day...to provide for your children was my number one goal.

I realized that the diagnosis was a blessing. God has shown me what is important, and I get to be with my children.

Other than my children, I'm just blessed that I have my own home. This is the first home I bought without him (husband)…myself.

God has allowed me to endure...coping is enduring…when you don't have a choice and God giving you the grace to do it.

PA3 has maintained a full-time job after graduating from college. Her children and her family have brought her the most satisfaction. She became active in the MS Bike

group and has ridden 240 miles in two days on the MS Bike Rally, an accomplishment

for which she is very proud. She has become the "go to" friend to whom others reach out

when the need someone to talk to their own friends, newly diagnosed with MS.

PA3: I was working full time. I was going to grad school while I was working

fulltime, too. Spending time with my family-spending time in activities…going out and

getting together.

Being able to take care of my family...being healthy enough…to take care of my

family.

I have a very positive attitude. I would have never ridden 240 miles in two days

without the diagnosis. I know it was because I wanted to help others. I have become the

go-to person, so friends of mine who know someone who has MS will call and say, "Hey,

would you talk to my friend?" I've gotten involved with the Bike Rides. Being part of

something positive has changed the health and mindset.

I'm still trying to live my best life.

PA4 developed a tremendous work ethic, sometimes working 60-80 hours per

week. She was educated and enjoyed working and helping her Mother. She enjoys being

involved and considers being able to take part in sports a reward for taking care of her

body.

PA4: A minimum of 60 hours per week. I was just looking for the next job I was

going to get involved with.

Disability -That's not an option. Therapy...going forward. We've talked about

the therapy. Get the job, stay employed, stay physically active.

I don't think it has defined me yet. I don't see it as I'm going to play a victim. We're all here together (her Bike friends). Right now, it's just life. I was out riding yesterday and I'm riding with my friend. That's the kind of positive things that other people with MS do.

I'm going to go to work for them. That gives me meaning. And now I see her and it's fun getting to work together.

If I hadn't gotten laid off, and had the time to check with some people, I wouldn't be given this opportunity to get the bike. It's a 150-mile bike ride. Combine the distance, and temperature, and physical difficulty...It's a lot. Maybe it's because I'm turning 50 that it means even more.

We did the Bike MS in 2012. We're trying to start the MS101 thing. I want people in there that are positive to offer that Hope to other people. I'm in the group that is positive.

I try to convey strength…we put a positive spin.

PA5 has accomplished many milestones. She is educated and has been a teacher for many years. She maintains a very busy schedule with a husband and four children. She continues to teach and enjoys activities and travels with her family. She also participates on an MS Bike Team.

PA5: I like to run and do things, like I would run and take Yoga classes. Having four kids keeps me very active. Anyone with a chronic disease needs to find the people that will be there for them.

My friend and her charity have given me a bike and I am now part of their Bike Team. They are so helpful.

I never wanted to go to a support group, but they make you feel like you can ride that 10 miles…that is an important part of dealing with a diagnosis like MS.

PA6's accomplishments include attaining a degree and becoming an EMT and working full time. She also participated in sports. She has a husband and young daughter and admits they are her biggest enjoyment in life. She participates in the MS Bike Team. Service to others is very important to her.

PA6: Before I was diagnosed, I was very active. I played sports, softball, worked at a hospital, as an EMT and a tech there, constantly back and forth and always on my feet.

Most joy? Um, my daughter…definitely…it's a life-changing event…always busy.

After the diagnosis, I have to say I gained a lot of strength. By that I mean strength in myself and strength in others. A new light to see what was going to happen. In other words, you feel like you're growing.

What was challenging? To be able to give others hope and go forward.

My family …my family is so meaningful to me. Even with everything we're struggling with, we try to help others.

PA7 has many accomplishments. She was the middle child of five and was the communicator and problem solver, even as a child. She graduated from college while working and paying her own way. She was also responsible for her medical bills at a

young age of 24 since her family did not have insurance. She has worked with the National office of MS Society, helping others, coaching, and giving advice, especially about working accommodations for persons with MS. She claims to be an "overachiever," and she is proud of her accomplishments. She was a distance runner and mastered Yoga. Her primary concerns now are for her family.

PA7: I enjoyed school and taking care of children. I wanted to better myself, I mean having been raised by a single Mom and going from, you know, living on an Air Force base in a two-parent home to living in a single parent home where we were kinda latchkey kids. My Mom was working. I just wanted to contribute and get ahead and be independent, basically.

I was afraid of incurring debt and that would harm my independence because I was very self-motivated and driven.

Being a supervisor took its toll on me, and I ultimately resigned. I learned all I could about job accommodations for people with MS.

I've always been a doer. I think what's most meaningful is my relationships with my family and friends. Because I still… I get a lot of joy helping people. So, um, when I can do things for friends or family, um, then I still feel like I have a sense of purpose.

I have a large family. I love seeing all my nieces and nephews getting together with them and encouraging them in whatever they're doing and so it's when I can make a difference.

Researcher reflection. It was very interesting to note that all of the participants seem to have what we Southern Baptists call "A Servant's Heart" and all of them

expressed a desire to learn more so they could share more and help more. It is inspiring that the MS Society has so much participation in their bike program and gives the MS patients encouragement.

      Structure. Structure was identified in all of the themes. Each participant realized the importance and necessity of managing their diagnosis of MS. Similar strategies were used by all of the participants, though several different aspects were emphasized. For example, PA1, PA3, PA4, PA5, and PA6 allowed their families to be part of their treatment for MS, allowing them to become primary caregivers. PA2 and PA7 preferred to depend more on themselves and had limited help from family. All participants chose to gain more knowledge about MS, and used that knowledge to acquaint themselves with what was happening to their bodies at the time, and what possibly will happen in the future. All participants, except PA2, continued to work for an extended period after the diagnosis. All chose to cut back their hours to lessen the stress of a full workload. PA2 was forced to leave her position because of government regulations regarding insurance benefits. PA4, PA6, and PA7 have become a part of the MS Biking Program, and use this program as their primary exercise. PA1, PA2, PA3, and PA5 exercise with their families in activities. All participants are on some type of medication regimen. PA5 chooses to supplement her medication with vitamins and supplements. All had to deal with the facets of MS in their own ways. PA1, PA3, PA5 all had stronger family support systems, while PA 2, PA4, PA6, and PA7 relied more on friends or themselves for their motivation.

Discrepancies within Themes

   Aspects of identity. There were very few discrepancies within the themes. One

discrepancy was with PA2. While the remaining six participants maintained their support

from their families, PA2 did not. Her husband left her at the onset of her MS diagnosis.

She was denied insurance and living benefits because they were both in the Marines and

when they divorced, she was unable to get benefits for her two children or herself for

over a year. During this time, several of her family members came to "help out" but this

presented more stress than it did help, as they charged her for their assistance. All six

remaining participants had strong support from their families, especially their spouses.

Some, like PA1 and PA7 were inspired by their own parents' strong resolve to be

independent and help them remain independent. None of the participants were willing to

be labeled or pitied. They all chose to overcome the stigma of being disabled. All of the

participants exhibited elements of hope in their battle against MS except one. Whereas

PA1-PA6 clearly followed doctor directions and suggestions of others who have MS in

the plan to improve physically, mentally, and/or spiritually, PA7 displayed a more

resigned attitude of *que sera*. She even voiced an opinion of being "done" with MS with

a welcoming of the end of her trials with MS, even if it meant her demise.

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Evidence of Trustworthiness

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   As I mentioned in Chapter 3, I used guidelines for managing trustworthiness as

stated by Guba and Lincoln (1989) and Shenton (2004) to establish transferability and

credibility. Open-ended questions were used which allowed the participants to share their

thoughts, feelings, and experiences, and the interviews were conducted with the intent to

provide rich descriptions. Further trustworthiness was enhanced by giving the

participants ample time to answer the questions, and giving opportunity for them to ask

any questions they might have. The interviews ranged from 30 to 70 minutes. All

participants reviewed a summary of their interview. One participant (PA 2) contacted me

via telephone to tell me how much she appreciated being selected for the interview and

hoped it would add to the information available to help others. One other participant

(PA5) contacted me via telephone to clarify a question about the timeline in the

summary. There were no changes needed. She was just making sure I understood, and I

did.

I attempted to (a) offer detailed descriptions of the coping and resilience

mechanisms used by women diagnosed with MS and (b) convey examples of the themes

by offering experiences and incidents directly from the participants. For each topic of the

themes, I analyzed each participant's responses and included them in the proper category.

I reported how each participant responded to each theme and shared how they were

similar and how they were different. The data cover the lives of the participants, before,

during, and after the diagnosis process. I reported the role of the caregivers and family

members, showing how they were similar and how they differed. I compared and

contrasted the health challenges of each participant. I reported the resilience and coping

strategies of each participant and noted how they all included gaining knowledge on MS.

I also noted the presence and effect of positive emotions in the resolve and continuing

treatment success of each participant. All the participants mentioned a positive force of

some type in their ability to cope with MS and as PA7 explains, maintain a "peace" about

it.

Verification of the data analysis process through thematic identification included assistance from audio recordings, personal interviews, word-by-word transcriptions, and data analysis of each interview, review by colleagues for clarity of purpose, and evaluation to identify any bias.

Results

The purpose of this study was to explore the following research questions:

1.   What is the meaning of resilience to individuals living with MS?

2.   What is the meaning of coping to individuals living with MS?

3.   How do the themes of positive psychology illuminate the experience of a "meaningful life" in individuals living with MS?

The Meaning of Resilience

The meaning of resilience varied somewhat, but were also similar. PA1 described resilience as to bounce back from having my son. PA2- my idea about resilience is bouncing back from something…an event. PA3- the other part of this coin…it's not giving up and having a positive attitude so I can still do things I love to do and enjoy. PA4-I think it means to accept whatever adversity comes and being able to adapt. PA5-Resilience means picking yourself back up and keeping going. PA6-It's a recovery—able to spring back into whatever you're doing…I think that's it's the ability to 'still do.' PA7-It means that you bounce back…it's not that you don't incur hardships or incur challenges, or you're gonna' get knocked down.

The analysis of the narratives revealed how each participant reached her own set of resilience and coping mechanisms to "live" with the diagnosis of MS. Looking across the narratives, some common elements were found:

Managing symptoms of the disease. Each woman has arrived at a place in her life where she feels she is managing the physical symptoms. These include: relying on spouses and other family members for reminders of daily needs, writing down reminders, programming dates, directions, etc. into calendar and guidance systems to enable ease of travel, use of pets to relieve stress, depending on God, spirituality, Holy scriptures, and Faith to help them, accepting challenges that accompany MS in order to verify their own strengths, continuing to gain knowledge about MS to bolster confidence and prepare themselves for what may come in the future, interaction with others who have MS to share each other's wisdom on how to cope with MS, exercising in different ways (powerlifting, yoga, bike riding, hiking, etc.) to keep their bodies in the best condition possible, and working with organizations who give aid to MS victims and their families. This includes getting and giving aid.

Managing the emotional consequences of the disease: These include daily challenges with fatigue, stress, anxiety, loneliness, fear, immobility, dependence on others, depression, loss of appetite, weight loss, to name a few.

The Meaning of Coping

The meaning of coping was similar in all participants. These are excerpts.

PA1 described coping as dealing with. I deal with it in my own way**.**

PA2: Enduring…when you don't have a choice and God giving you the grace to do it.

PA3: Learning to say no, learning to ask for help. Learning to live with what has been dealt…like the disease learning different ways of handling things. Like stress.

PA4: Coping is just accepting. How you deal with it…if you choose to deal with it. How you adjust to a situation? I didn't see it coming, but might as well make myself face it.

PA5: Coping-um…ok…coping maybe is... I told you I had all these bladder problems and I have to cope with knowing what foods I can and can't eat…I have to cope with that.

PA6: Um…to me coping is acceptance. Understanding, for me…wow…the words that you use, you just don't think of...Coping for me...it's not just me coping, it's family and friends…understanding of what's going on and what's going to happen in the future.

PA7: Dealing with um whatever life throws your way with the skills that you've learned you know.

As in their definitions of resilience, each woman has arrived at a place in her life where she feels she is coping with her the physical and emotional symptoms. They rely on spouses and other family members for reminders of daily needs, writing down reminders, programming dates, directions, etcetera calendar and guidance systems to enable ease of travel, use of pets to relieve stress, depending on God, spirituality, Holy

scriptures, and faith to help them, accepting challenges that accompany MS in order to verify their own strengths, continuing to gain knowledge about MS to bolster confidence and prepare themselves for what may come in the future, interaction with others who have MS to share each other's wisdom on how to cope with MS, exercising in difference ways (powerlifting, yoga, bike riding, hiking, etc.) to keep their bodies in the best condition possible, and working with organizations who give aid to MS victims and their families. This includes getting and giving aid.

How does the Narrative Start?

Before the diagnosis: All participants began by answering a series of questions which began with life before their diagnosis. Establishing a picture of their lives before their diagnosis allowed a comparison to current life. Each shared the people and events of their lives before the diagnosis. They described relationships with family, friends, and colleagues, and what gave meaning to their lives. They also described their workplace conditions and activities in which they were involved.

Diagnosis process. Each participant described her life and how it was impacted with the diagnosis of MS. Details of each diagnosis included health problems in one or more of the areas of vision, fatigue, stress, lack of mobility, weakness, bladder infections, being paralyzed, pain, spasms, and migraines, but not limited to these. The effect of the MS diagnosis was severe on all employment situations. The result eventually led to loss of employment in six participants. Five of the participants chose to leave their jobs when their health declined to an intolerable point; one participant is still working, and one participant did lose her government job due to her illness. At some point during the

diagnosis process, all of the participants were hospitalized and began a treatment or were advised to begin a treatment for MS.

After the diagnosis: All of the participants experienced more intense symptoms of MS. Most had problems with memory and cognitive issues. Many had additional stress and fatigue. Anxiety, fear, and lack of energy increased in all of the participants. Heat and humidity presented problems for all, as did digestive problems. Fear of losing their independence was of paramount concern, as well as caring for family and children. Lack of mobility in six of the participants was present. Personal injecting of meds and adjusting to medications were two additional problems. Another major concern for some of the participants was mounting medical bills.

Role of family and caregivers: For six of the participants, the primary caregiver is the spouse. For one participant, her expectations for help from her family were not met. Her relationship with her family members was severely damaged. All of the participants have found additional help from friends and MS Society organizations. The MS Bike Organization has been extremely meaningful to several of the participants. Each noted the importance of reaching out to others for help, although they were independent before the diagnosis, and did not routinely seek out others for help. This acknowledgment has prompted most of them to offer their own time and skills to help others who are in the same or similar life conditions. They also include their family members in the process of helping others. PA 4's sister participates with her in activities. The parents of PA 1 join with her in activities which bolster her confidence. The husband/partner and children of the other members participate in activities which

encourage and aid in the process of events. The participants have also joined exercise groups, Yoga groups, MS Bike organizations, and other types of activities which assure regular opportunities to be active. All of the participants noted that the inclusion of the activities and the assistance from their friends and family "lifts their spirits" and offers them a reprieve from many of the sufferings which accompany MS.

Health challenges: The ravages of MS are evident in all of the participants. Each suffers from a varied group of health issues. The most prevalent is fatigue and decreasing or challenging motor skills. Memory problems and other cognitive issues, along with problem solving skills are primary causes for concern. Vision problems, bladder issues, and soreness in muscles also plague many of the participants. These are some of the issues, but MS causes more varied health concerns than almost any other disease, so the problems are not limited to the ones the participants felt most commonly occurred in their lives. Their bodies are very sensitive to sunlight and heat, so constant monitoring of their body temperatures is necessary to stave off exacerbations which threaten to leave them unable to see or walk or sometimes speak. One participant mentioned *loneliness* and this was not common among the others. However, one participant mentioned that she was ready to die and was "done" with MS and had cautioned her partner NOT to seek life-saving efforts in case of imminent death. In both cases, there were extenuating circumstances which pointed to reasons of non-support from family for the first and extended time suffering from MS for the second. The other five participants had strong support systems in place and have not suffered from MS for as many years.

Resilience and coping strategies: All of the participants described their

resilience to the diagnosis of MS and recognized times during they had resilience and

times they did not. Most of the times they did not have resilience had to do with periods

following the diagnosis. Some occurred when they left their jobs, and some included

physical and emotional setbacks. They have all found strategies to cope with their

current situations. They rely on parents, spouses, and children to perform duties they can

no longer perform or have substantial difficulty. A difficult reality for all of them is

asking for help, and allowing others who seek to help them do so. Maintaining

independence is a constant struggle for MS victims. One participant (PA2) relies on her

pet to help her with mood swings. Most have spiritual convictions and shared how prayer

and music help them cope. Gaining knowledge is high on the list of "helps" and all have

sought answers through research with the National MS Society and testing ways to deal

with MS which may seem unconventional. Most are open to the experiences of other MS

victims, but most will also say if their counterparts offer negative attitudes, they are side-

stepped. None of the participants in this study were negative or allowed others around

them to be negative. Their own remarks indicate that they are determined to be positive

and look on the "bright" side of their circumstances. Instead of allowing self-pity,

sadness, depressing thoughts, or other negative emotions to overtake them, they employ a

positive mindset. Depression is a very real part of MS, and each participant understands

the burden it places on their mental health, so each has expressed a determination not to

become mired in a depressive state of mind. This task is not as easy as making the

statement, however, and they shared that they depend on others to steer them out of

depression's path. Sometimes, this means getting involved in organizations which may include more work than they would desire, but they understand they cannot give in to the pressures of fatigue or new experiences. Several of the women participate in bike rides sponsored by the MS Society, and join hundreds of others, many of whom are also MS victims. This seems to offer encouragement and exercise and a comradery that are valuable tools in fighting MS. They choose to go the extra mile in taking care of themselves such as extra vitamins and supplements; close attention to the effects of hot weather; more rest and sleep; more attention to exercise; more attention to diet; and sometimes, dropping people in their inner circle who are not uplifting or encouraging.

  Presence and effect of positive emotions. Each participant understood the value of keeping a positive attitude and not allowing negative expressions to overtake them. A fascinating aspect of their relationships made after being diagnosed with MS was what their psychologist Fredrickson (Cohn et al., 2009) labeled as "social connectedness." When participating with others in productive, thoughtful activities, the participant learns skills to "self-generate positive emotions which can help us become healthier, more social, more resilient versions of ourselves." The participants all experience negative emotions when they are physically ill or sad, etcetera especially in times of exacerbations (setbacks in MS which cause pain, loss of abilities and skills) but their abilities to "bounce back" from these occasions gives them power to move on and not dwell on the negative aspects. Another important note in regard to positive emotional stability is how the participants are developing a sense of meaning and purpose in their lives. Each participant shared the value of focusing on the good times and beloved people in their

lives and appreciating the times when they do feel healthy and have energy to participate in activities with family and friends. Assessing feelings of "well-being," the participants readily shared that they "count their blessings" on a regular basis. Instead of focusing on the past, they make efforts to take one day at-a-time and appreciate the moment. They are motivated by friends and family and accomplishments they attain through the help of others. They also relish helping others and motivating other MS victims. They use physical activities to gain and maintain not only healthy bodies, but also healthy minds, with the premise that the two are tied together, especially since the lack of a healthy body may lead them into depression on some level. Being able to participate in physical activities proves to the MS victims that they are not overtaken by the condition which robs so many of their ability to be mobile. Maintaining a positive state of mind helps them, as PA3 phrased it "refuse to let MS rule her life."

Summary

In Chapter 4, I described the results of the data collection, analysis and interpretation of the seven themes found in the participants' transcripts. I included the similarities of the transcripts, as well as the differences in their stories. Trustworthiness was explained. Through the themes, I revealed the participants' life struggles and resilience and coping strategies they use daily to manage their MS. These strategies may provide insight for others who suffer from MS and offer help to caregivers and medical professionals and may increase the quality of life for anyone battling an incurable, life-threatening disease.

I identified themes as: Before Diagnosis, Process of Diagnosis, After Diagnosis, Role of Family and Caregivers, Health Challenges, Resilience and Coping Strategies, and Presence and Effect of Positive Emotions.

In Chapter 5, I will take a closer look at the effects of positive emotions and will discuss how they relate to current literature regarding well-being with persons who suffer from incurable diseases. Alignment with the theoretical framework, along with any limitations and recommendations will also be discussed in Chapter 5. I will also reveal the potential for positive social change based on this study.

Chapter 5: Summary, Conclusion, and Recommendations

The purpose of this qualitative study was to explore the coping and resilience strategies used by women diagnosed with MS for at least two years. I conducted a narrative analysis to relate their "life stories" and identify themes that represent the narrative arc from before diagnosis through the present experience.

Telephone interviews were conducted with seven women who had MS for at least two years. Before each interview, I provided an explanation of the research, including how the interview would be conducted and how the answers would be used. All participants were asked a pre-designated set of questions about their experiences with MS. Their answers were recorded and each interview was transcribed. I emailed a summary of the transcribed interview to each participant, and all were given an opportunity to make changes or ask questions. I analyzed the answers using Riessman's (2009) thematic analysis guidelines, and seven common themes emerged, along with a few discrepancies across participants. I identified these themes as follows: (a) diagnosis before, (b) diagnosis process, (c) diagnosis after, (e) role of family and caregivers, (f) health challenges, (g) resilience and coping strategies, and (h) presence and effect of positive emotions.

Interpretation of Findings

Thematic Results

Life before diagnosis. Participants shared common experiences of the condition of their bodies prior to the time of diagnosis: immobility, weakness of limbs, and extreme fatigue. These symptoms are common among most of people living with MS, according

to the medical literature (Edmons et al., 2007; Fredrickson, 2000; Hind et al., 2014; Kirchner & Lara, 2011; Moskowitz et al., 1966; Pakenham, 2006). For example, Shapiro (2014) identified fatigue, spasticity, tremors as common symptom.

Process of diagnosis. All of the participants described the physical and mental challenges brought about by the diagnosis of MS. While there was some variance in how many or how frequently symptoms occurred, all participants reported one or more mobility, vision, intestinal, muscle pain, and/or activity-related problem. All experienced cognitive and memory deficits along with depression and lack of mental clarity at one time or another during the process. These findings are consistent with other quantitative and qualitative studies describing the limitations of physical abilities, indicating that physical activity is indirectly associated with quality of life in persons managing MS, especially when considering symptoms of depression, fatigue, pain, social support, and self-efficacy (Ascherio & Munger, 2007; Christenbery, 2011; Compston & Coles, 2002; Fredrickson & Joiner, 2002; Gravetter, 2007; Motl et al.; Seligman, 2011).

Additionally, all participants reported attempting to learn as much as possible about MS, and all have sought ways to maintain their way of life while dealing with the consequential and sometimes unpredictable symptoms. All of the participants belong to the MS Society, and some have joined other organizations that help them to learn more about the disease and about their own bodies. My search of the literature revealed relatively few studies of how individuals diagnosed with a chronic or terminal condition see "knowledge as power"—that is, how they gain control over the situation by acquiring knowledge about their illness (Asbring & Narvanen, 2004). In fact, Joseph -Williams,

Elwyn, and Edwards's (2014) thematic synthesis of 45 articles showed that while knowledge about illness was critical, individuals identified the power to participate in shared decision-making about care as more important.

After diagnosis. The results of this study showed that all of the participants found activities and organizations to help them deal with their diagnosis. The most well-known organization is The National Multiple Sclerosis Society (MS Society, 2016). It is a "United States-based, non-profit organization and its network of chapters nationwide help people affected by multiple sclerosis by funding research, driving change through advocacy, facilitating professional education, and providing programs and services that help people with multiple sclerosis and their families. It is headquartered in New York City." It is mission-driven and provides patients with information regarding every aspect of MS. It has connections through social media, and has chapters in every state and many countries throughout the world. The MS Society offer opportunities to participate in activities such as MS Walks, MS Bike rides, information classes, and support for every stage and every type of MS.

In addition, there are companies such as MyWalkGear that offer "awareness products" such as t-shirts, jewelry, and an array of items which highlight support for people with MS. Individual MS people and their families also provide their own t-shirt designs when participating in MS Walks and activities. These shirts are designed to represent the families and friends, and usually have a theme, such as "XX's Crew," my family's annual t-shirt design. The design focuses on different crews and offers graphics that display some type of crew working together. For example, our last t-shirt had a

"Clean-Up Crew" sign with a maintenance man with mop and broom. The slogan was "Cleaning up MS." Bright colors and designs are used to draw attention to the cause of fighting MS.

There is a mobile app that can be downloaded to keep track of MS health issues (Biogen, 2016). The app offers diagnostic resources to help individuals learn about the different steps in the diagnosis of MS. These resources include: Join the Program, which offers tips, tools, and updates about MS; MS101, where users can learn all about MS ranging from the types of MS to the diagnosis and symptoms; and Stress Relief Techniques, where users can learn about ways to stay positive and reduce stress when living with MS. The popularity and use of these applications is consistent with other individual studies and literature reviews that have examined how to promote physical activity and empower patients with chronic conditions such as MS, cardiovascular diseases, and cancer (Kuijpers, Groen, Aaronson, & van Harten, 2013; Stephens & Allen, 2013).

In addition to learning all they could for themselves, most of the participants were also called to help others, particularly as previously work and social engagements became less accessible. Many of them joined MS biking groups. All of the participants chose to engage in activities where others benefitted. For example, several participants joined MS bike teams and help provide bicycles for others who could not afford them. One participant takes meals to shut-ins on a regular basis. Participant PA7 lectures and is available to share her journey with newly-diagnosed patients. Most participants use social media to keep in touch with other MS patients, and to celebrate milestones of the

club or organization to which they belong. Many who are still mobile offer transportation services to others who are no longer able to drive. They shared that although it is tiring, they feel compelled to give as much of themselves as they are able.

The comradery is amazing and admirable. Most participants are able to attend meetings and information seminars, and many advocate on political issues such as insurance benefits and access to public transportation. I advocated at the Texas State Capitol in Austin a few years ago. It is a deeply moving experience to hear the life-stories of these brave people, and realize what challenges they have, not only with their bodies, but also in everyday life, such as lack of ramps to access public buildings, loss of employment, loss of benefits, and an overall struggle to maintain their lifestyles. Each person was there not only for himself or herself, but also to support and advocate for everyone else who has MS. This is consistent with the concept of engagement, which refers to participation in activities and interests that create the experience of flow—the absorption in activities and events that are useful, fulfilling, and challenging (Maddux & Gosselin, 2003). The construct of engagement has been examined in great detail as a factor in work satisfaction, academic success, and therapeutic outcomes (Maddux & Gosselin, 2003; Tetley, Jinks, Huband, & Howells, 2011; Wimpenny & Savin-Baden, 2013).

In the illness literature, relationships include being connected to persons in meaningful ways for mutual support, friendship, and cooperation. Considerable research has suggested that relationships are a key factor in health, well-being and longevity (Holt-Lunstad, Smith, & Layton, 2010).

Another relevant post-diagnosis dimension of this theme is the concept of hope. All participants expressed the element of hope in their battle against MS, except the one who had been ill for more than 25 years. Hope is a crucial element in chronic illness. Madan and Pakenhan (2014) identified hope as "a resource that can assist in coping with the challenges and thwarted life goals imposed by illness." In their study of 296 people with MS, Madan and Pakenhan used focal predictors of stress, hope, agency, and pathways to assess questionnaires participants completed covering a 12-month period. The adjustment outcomes were anxiety, depression, positive affect, positive states of mind, and life satisfaction. The results of regression analyses showed that greater hope was associated with better adjustment after controlling for the effects of time adjustment and relevant demographics and illness variables (Madan & Pakenhan, 2014). Horton and Wallander (2001) defined hope as "an enduring disposition that is subjectively defined as people assess their agency (goal-directed determination) and pathways (planning of ways to meet goals) related to goals." In regard to practice implications, Snyder, Irving, and Anderson (2006) reported findings regarding the benefits of promoting hope in people with MS. They further explained that "hope may be fostered through identifying valued and personally meaningful goals, defining them in clear measurable terms, and identifying multiple potential avenues through which goals can be attained."

Role of family and caregivers. Friend and family support is common among MS patients, according to the published accounts of MS patients (MS, 2011). For all participants except one, family and friend support was an essential part of their post diagnosis support system. Curtrona and Russell (1990) reported that "people who

perceive themselves to be supported by others exhibit more positive physical health, mental health, and longevity than those who do not perceive themselves as not having support from others." In addition, Hanson (2016) described her personal experience with support as, "In searching for the life changes that would make me feel better, I chose a mentor who taught me that my life didn't have to be any different than it already was in order to change how I felt about it." Horton and Wallander (2001) reported that social support is a very important factor in predicting physical health and well-being in all stages of a person's life, including the ability to predict the deterioration of physical and mental health. Initially, it can determine success in overcoming stress, and is a factor in helping the victims of illness forget the negative aspects of their disease or physical condition. According to Stice, Ragan, and Randall (2004), family support is the most important element in a person's life. As children mature, they usually expect more support from their parents, and the parents usually provide more, especially psychological support such as encouragement and approval.

One interview participant did not have the support she needed. The stress on her life at that time was very harsh, and added to her financial and emotional problems. The absence of social support has also been discussed in the literature (Stice, Ragan & Randall, 2004; Horton & Wallander, 2001; Stephensen, 2012). Stephenson (2012) pointed out that "…if you belong to a dysfunctional family, it is doubtful that your diagnosis will change those long-forged dynamics…your diagnosis is unlikely to repair the torn threads of a frayed family, and may add additional strain." She also added that the lack of a support network often makes the situation even worse. Stice, Ragan, and

Randall (2004) reported that inadequate support from the parents is likely to result in depression among adolescents due to confusion resulting from the lack of help and positive reinforcement. Likewise, the importance of social support continues well into adulthood for everyone. It would benefit a person's general health and immune systems, with or without elevated stress. For example, the cardiovascular system functions much better in adults who have better social support (Uchino, Cacioppo, & Kiecolt-Glaser, 1996).

Health Challenges. All of the participants shared similar health challenges such as headaches, fatigue, stress, mobility problems, balance problems, stomach and bladder issues, cognitive and memory issues, mood swings, pain, tingling in feet and hands, and visual concerns. Shapiro (2014) and Johnson (2012) stated that fatigue is the most common symptom of MS, and occurs in 70-90% of patients. The MS Society (2016) reports that physical problems are often the symptoms which cause patients to seek help. Lack of normal mobility (Kirchner & Lara, 2011; Leavitt, 2013; Paturel, 2011) and the inability to move freely is common (Kirchner & Lara, 2011; Leavitt, 2013; Paturel, 2011).

Fatigue strikes about four out of five MS patients and has a biological basis (Kravitz et al., 1996). Personal freedom is lessened and sometimes destroyed (Layard, 2006). Loss of balance and coordination, cognitive ability, as well as in other functions, and in time, may become permanent (Abumaree, Aljumah, Pace, & Kalionis, 2012). Motor, cognitive, and neuropsychiatric symptoms can occur independently or

simultaneously, as a result of lesions in the brain and spinal cord (Chiaravalloti & DeLuca, 2008).

In addition to the physical deficiencies, the participants reported other mental and emotional issues, the participants reported issues such as fatigue, cognitive imbalances, forgetfulness, headaches, depression, anxiety, guilt, loneliness, fear, and sadness. According to the literature, depression, anxiety and other affective symptoms often accompany the physical challenges for persons with MS (von Steinbüchel, 2010; Wynia et al., 2008). Chiaravalloti & DeLuca (2008) reported that cognitive and mental issues occur in the majority of MS patients. Similarly, Sanford and Petajan (2003) stated that MS is a chronic illness that includes fear and apprehension, denial, grieving, depression, guilt, in addition to physical limitations and other emotional upheavals.

Resilience and coping strategies. All of the participants described the concept of resilience and observed that it fluctuated on a daily basis. Prior research has suggested that these skills may be the key to resilience which may guide people to experience fewer setbacks and a more meaningful and fulfilling life (Masten, 2001; Seligman, 2002).These skills are also called positive psychology strategies and include self-designed interventions that build the emotional strengths of persons who suffer either emotionally, physically, or spiritually. The participants used social media to connect to others with MS where they discuss their symptoms and issues, but also encourage one another by posting successes in daily struggles and involvement in events such as MS Walks and MS Bike Rides. These include the use of Facebook, Twitter, and Instagram. They participate in

these activities and donate their time and talents to activities such as Yoga, Special

Olympics, and community sponsored activities.

All participants developed coping strategies to aid in how to manage daily life.

Their stories were consistent with literature on actives of daily living for people with

chronic disease (Chen et al., 2010). An MS study showed that after the initial adjustment

phase, most persons with MS are able to regain and maintain a positive sense of self-

worth (Sanford & Petajan, 2003). McLeod (2014) reported that attitudes are part of

identity. They help individuals become aware of feelings, beliefs, and values. McCabe,

McKern, & McDonald (2004) examined the coping and psychological adjustment of

people with MS and determined how they were different in from the general population.

They also evaluated the levels of social support on coping style and adjustment and the

role of severity and duration of illness. The findings highlighted the importance of

developing educational programs that include strategies to adopt more problem-focused

coping strategies, so that people with MS can more readily adjust to their illness.

Through educational programs, people with MS are given methods of coping, the value

of the methods, and application of the methods. Hanson (2016) wrote that the person

diagnosed with MS must recognize what MS means to them, and not miss the

opportunity to find out what their "gut" tells them, and it will lead them to a "greater

awareness." This awareness, she stated, is "your power to choose different thoughts as

needed, to make your life even better."

Coping strategies vary in patients. Holland and Legg (2016) recommend "talk

therapy" with a licensed professional, or personal doctor, group therapy sessions with

other people who also have MS. In addition, strategies for stress relief include relaxation

management in breathing and muscle relaxation techniques, regular exercise, and

moderate activity. Dennison, Moss-Morris and Chalder (2009) researched 72 studies in a

systematic review to identify factors that are related to adjustment in people with MS and

may be modifiable through psychological intervention. The strongest and most consistent

strategies were those who were applied to relieve stress and downgrade emotion-focused

issues such as those mentioned above: talking, breathing exercises, and physical

exercises. Fredrickson and Joiner (2002) reported that persons with serious and

debilitating conditions can be a source for understanding the meaning of emotional well-

being which contributes to one's coping ability and may be joined with self-esteem,

performance and productivity at work, and even longevity.

Presence and effect of positive emotions. Each participant expressed the need

for a positive attitude. One participant expressed how important she felt it was to

maintain a positive outlook when dealing with her young son to prevent him from

becoming afraid. Another participant felt that it was imperative for her to remain positive

to fulfill her job as a teacher. All with children had the determination not to allow

negativism to rule over their time with their children. It was important to all participants

to share their stories with others and to be positive and encouraging when they do. Frank

(1995) indicated that some patients employ "restitution" narratives which have positive

conclusions, while others indicate "chaos" narratives which suggest unclear continuity

when addressing the past compared with the future. More recently Fredrickson's (2009)

studies on positive emotions recommend we attempt to maintain balance of negative

feelings, which are inevitable in life, with positive ones. She noted that there are many

health-related benefits. These include faster recovery from cardiovascular stress, lower

blood pressure and risk of cardiovascular disease, better sleep, fewer colds, headaches,

aches and pain, and a greater sense of overall happiness.

Her most recent study (2017) created *The Emotional Guidance Scale* which

includes the Upward Spiral and the Downward Spiral. The Upward Spiral, representing

the positive emotions in a person's life include: joy/knowledge; passion; enthusiasm;

positive expectation; optimism; hopefulness; and contentment. Frederickson stated that

these emotions 'broaden-and-build' experiences and positive emotions lead to novel,

expansive behavior. These actions lead to lasting emotional resilience, flourishing and

meaningful personal and social relationships. Positive emotions or behavior – like

playfulness, gratitude, love, interest, serenity, and feeling of interconnectedness to others

lead to lasting emotional resilience (Fredrickson, 2017). Each one of the participants

stated that negativity is damaging to their well-being, and made conscious efforts to be

more positive. Pakenham and Cox (2009) also produced a longitudinal study regarding

the benefits and positive adjustments with MS and the findings supported the theory of

positive emotions being beneficial.

Relevance to the Theoretical Framework

Seligman's (2011) PERMA model was used to guide the analysis and explore the

presence of the five elements necessary for well-being (positive emotion, engagement,

relationships, meaning and purpose, and accomplishment). When analyzing how the

themes of positive psychology illuminate the experience of a "meaningful life" in

individuals living with MS, all of the participants expressed seeing their diagnosis as part of a bigger picture in their life's journey. All five elements were found in the narratives of each participant, resulting in considerable alignment of the narratives to the model. For example, all of the participants expressed seeing their diagnosis as part of a bigger picture in their life's journey. Each described how their choices of treatments included positive elements. A treatment or intervention which serves to build the strengths of persons who suffer either emotionally, physically, or spiritually that acts as a buffer against adversity and against psychological disorders may be the key to resilience which may guide people to a more meaningful and fulfilling life (Masten, 2001; Seligman, 2002).

In addition, Bolt (2004) suggested that human beings must seek to understand the impact of external factors to make wise choices and foster change in individual well-being. He added that through these wise choices, stronger bonds are built. As positive strategies are applied to a person's life, he fosters self-esteem and self-worth.

Using a semi-structured interview with open-ended questions allowed the experiences with coping, resilience, and the themes that are consistent with Seligman's (2011) five elements of well-being. Emmons (2007) stated that a positive attitude is not obtained through conscious striving, but a learned practice as the situations in his life warrant. Furthermore, changes occur in stages. Prochaska (2000) stated that people tend to progress in different stages on their way to successful change and they progress at their own rate, using different methods of coping. Emmons (2007) noted that taking steps to

modify their behavior using a variety of techniques is often the critical factor in finding positive changes.

The Emotional Cost of MS

All participants mentioned at least one episode of depression and/or anxiety as a result of the symptoms, the diagnosis, and the challenges of living with a complex and unpredictable condition. For most of these individuals, normal activities (e.g., walking, folding clothes, driving) are a struggle or unattainable, and created significant frustration. As described in Chapter 2, coming to terms with chronic illness requires time and strength of mind, will, and emotions (Radford, 2005). Likewise, depression is a major concern for the majority of persons diagnosed with MS (MS Society, 2017). Depression, anxiety and other affective symptoms often accompany the physical challenges for persons with MS (Wynia et al., 2008). von Steinbüchel (2010) conducted a study of almost 800 participants from the ages of 13 to 65 who were assessed using the Glasgow Outcome Scale to measure quality of life. The study revealed that patients with disabilities reported anxiety and depression at a rate of two to three times higher than those who did not have a disability.

<p style="text-align:center;">Limitations</p>

As I mentioned in Chapter 3, guidelines for managing trustworthiness as stated by Guba and Lincoln (1989) and Shenton (2004) were used to establish transferability and credibility. Open-ended questions were used which allowed the participants to share their thoughts, feelings, and experiences, and interviews were conducted with the intent to provide rich descriptions. Further trustworthiness was enhanced by giving the

participants ample time to answer the questions, and giving opportunity for them to ask

any questions they might have. The interviews ranged from 30 to 70 minutes. All

participants reviewed a summary of their interview. One participant (PA 2) contacted me

via telephone to tell me how much she appreciated being selected for the interview and

hoped it would add to the information available to help others. One other participant

(PA5) contacted me via telephone to clarify a question about the timeline in the

summary. Otherwise, no changes were requested.

Dependability of the data collected was insured through use of audio recordings

of in-person interviews, word-by-word transcriptions, repeated reading and listening to

transcripts while analyzing each interview, review by colleagues for clarity of purpose,

including professors from Walden University, and Charles Christian, Ph.D., a professor

of Ethics, and evaluation to identify any bias. In addition, I attempted to pose the same

questions to all participants for the results to be consistent, although these may not have

been in the same order. This did not limit new discovery of data, an occurrence that

happens in many interview studies (Fisk, nd). To address this limitation, at the end of the

interview, a direct question to the participant was made, such as, "Do you have anything

you'd like to add to your comments?" This allowed the participant to include issues

which may not have been covered in the interview.

Madill and Gough cautioned (2008) about the risks of small sample sizes. I

provided sufficient details about the selection of cases and the data collection procedures

and analysis plan so that others may attempt to replicate the methodology, and share

similar and disparate findings. Further, I attempted to achieve saturation with a small

sample size by purposefully sampling for homogeneity of the phenomena of interest (Guest, Bunce, & Johnson, 2006).

Researcher bias can present problems, especially if the researcher is personally involved in the issue being studied. Riessman (2008) warned about emotions in interviews, from both the participants and the researchers. This could have presented a problem with authenticity of the participants' comments, and created exaggeration or embellishment of the actual experiences. Preventative measures were taken to assure that researcher bias did not occur, i.e. open-ended questions, and opportunities to explain in detail their ideas and opinions. Likewise, any comments I made from a personal experience could have encouraged the participant to add or subtract from her answer, so careful wording and clarification was used to prevent this from happening.

Mattingly (1998) reminded interviewers that narratives do not merely refer to past experience but create experiences for their audiences. The narratives may offer the audience an opportunity to associate the details of their hardships with the listener or reader's own life experiences. To address these limitations and enhancements, I redirected questions, and clarified answers to avoid misunderstanding by either the researcher or the participant. More time was given, when needed, on emotionally charged questions and comments. Clarifications were made on issues when needed.

Personal Reflection

This experience has broadened my knowledge base of the extent of the every-day life of a person who has MS. It has given me greater understanding of how others cope with MS, and it has given me a determination to do all I can do to create a more informed

and practical atmosphere for everyone I meet who has the disease or shares the life of

someone who has it. Balancing careers, family life, travel, and day-to-day activities,

while trying to maintain some semblance of order in the chaotic atmosphere that MS

imposes is a gigantic task. The medical issues, insurance problems and prescription

problems all seem insurmountable for those who do not have advocates or support

systems. As I listened to the comments and answers of those gracious women, my

thoughts included my own beautiful 34 year-old daughter whose body has been ravished

by MS. When the participants told me about their weight loss, I naturally compared it to

my daughter's loss of over 50 pounds during the past few years. She has lost almost eight

dress sizes and it is difficult to find pants to fit her tiny frame. When they shared the

issues of immobility and digestive problems, I thought about how my daughter went from

being an accomplished dancer to someone who uses a walker and motorized scooter to

get anywhere she needs to go. The effort it takes just to rise from a sitting position and

advance across the room is unbelievable for a person with MS disabilities. I think of the

times when we are out to eat at a restaurant, or just relaxing at our own homes, trying to

enjoy a nice meal, and the fact that she seldom sits through an entire meal without having

to excuse herself and know that it mirrors the experiences given by all of the woman who

participated in this study. I also understand the need to "help" others which all of these

women share. Each one of the participants have found a way to keep giving of

themselves, even though they must wrestle with pain, depression, immobility, lack of

energy, and a myriad of other burdens. All have a determined spirit of resilience and

have developed ways to cope with MS so they are not defeated. It reminds me of my

own daughter who has met the challenges of MS "head on" and refuses to let this horrible disease define who she is. After she was diagnosed, we were determined not to let MS control our lives. She returned to college, graduated Magna Cum Laude, earned her Masters Degree in Speech Pathology, got married and had three beautiful children. She's married to a Marine whom she supports with all her heart. She is active in her community, in her church, and is a Girl Scout Leader. She supports her daughter as a dancer and cheerleader, Girl Scout, participant in UIL competition in school, and her son who plays football, basketball, and is a Boy Scout, and her little son who is in gymnastics and T-Ball. She works with persons with disabilities at her church and at her work as a speech pathologist. She embodies the "hope" that I heard from the women in the interviews. She is a role model and her cousin who was in pre-med and "shadowed" her at the hospital where she worked, has now decided that a career in Speech Pathology is what she wants to pursue. I am confident it is partially because our daughter gave her encouragement and shared her love and expertise of her profession.

I am so proud of her and her determination, and as I interviewed these women, I could easily relate to each statement they offered about how hard it was to deal with MS, but how determined they were to give 100% to make their lives as full and meaningful as they could. I've been a part of a life which shares those ambitions and determinations and I understand. What a privilege it has been to learn from her and be encouraged by her dedication to have the very best life possible. She is strong and full of faith. She has been supported by family and friends and to think that others may not have enough support in their lives is very sad and disturbing. These are only eight accounts that I have

examined. I shudder when I realize there are over 400,000 women and men here in the United States who battle the same demons every day, and millions throughout the world. Providing more information about what they experience will create opportunities to learn how to better serve these brave women and men.

Recommendations

Narrative research starts from the premise that there are two stories being told—the story of the participant and the story as told by the researcher (Riessman, 2008). Neill (2007) stated that "the personality or thinking style of the researcher and/or the culture of the organization is under-recognized as a key factor in preferred choice of methods." My choice of this method emerged from an interest in the phenomena from both professional and deeply personal motivations. Therefore, it is recommended that future qualitative studies consider an alternative approach, e.g., case study or ethnography of an MS group, with an observer less intimate with the phenomenon. Perhaps the etic viewpoint would allow identification of concepts that would be missed by persons who are immersed in the experience as a part of daily life (Patton, 2010).

A common misunderstanding is that small, purposeful samples do not produce definitive conclusions, or that results of small samples of persons with illness are also difficult to replicate, since the experience of participants may change over time in relation to the illness. I suggested that future qualitative studies include a longitudinal component, such that time is spent at intervals over a year or more to understand how coping and resilience emerge and change over time.

A quantitative study with a large sample of MS participants would be of interest, particularly if one could examine regional differences in access to care and support. A quantitative study comparative study of cultures and countries might also be helpful to ascertain differences in treatment, social support and cultural differences.

Implications

Making the stories of persons with MS available to the MS Community and medical profession could increase awareness and inspire others to investigate ways to improve and preserve their quality of life. This would aid in the development of programs and the publishing of literature to be used by MS patients. A common format for adding to the existing information would be helpful. Every person with MS would benefit from having a central information source where he or she could access and read the "stories" of others who have already experienced MS exacerbations and could offer advice on how to "cope" with the changes MS will ultimately bring. In addition to offering encouragement to all who suffer from MS, sharing personal experiences would also offer suggestions on resilience methods and aid for those who find it difficult to deal with the issues which arise with MS.

The potential impact for positive social change for the individual who suffers from MS includes information from original diagnosis to the latter stages of the disease. Such information gives insight into what the person can reasonably expect to happen in their battle with MS. More methods of sharing the information are needed. I plan to share my findings with others through MS publications and presentations at MS functions. It recognizes the facets of the disease, as well as the phases which range from

mild relapsing-remitting MS to the final stages which are incapacitating and crippling. The potential for gaining knowledge from the experiences of others who suffer from MS and the methods others use to combat their daily living challenges offer the individual direction and assurance that others do cope and use their resilience strategies to assure a fuller and more fulfilling lifestyle, and help to provide each person with confidence to tackle the challenges that are faced with the progress of MS.

The potential impact for positive social change in regard to families is great. It includes a better understanding of the plight of the MS victim by the families. It offers methods of adjustment on the part of the family members, caregivers, and ways to help facilitate the needs of those who suffer from MS. It highlights the positive ways to identify the stages of MS and how the effects of MS determine the actions and responses of those for whom they care. I plan to share my findings with families of those who suffer with MS through the annual events which I attend. I will be available to share the results of the study, along with ideas on enhancing the well-being of the entire family.

The implications for positive social change for organizations include personal anecdotal information shared by those who suffer from MS, which gives insight and knowledge into the actual daily experiences and how treatment and methods of care might be improved to better serve the person with MS and their family members who provide care. I plan to share my findings with the National MS Society, of which I am a member, along with the state and local organizations. I will offer to speak on behalf of the MS organizations to add to the knowledge base which is currently in place.

The implications for positive social change for society, as a whole, include an increase in the knowledge base about the disease of MS and the effects it has on the physical, mental, spiritual, and financial well-being of those who are diagnosed with MS and those who care for them. By gaining more knowledge about the disease itself, the policies may be monitored, and reformed, as needed. For example, the Americans with Disabilities Act was created to assure equal opportunities in areas such as access to buildings, transportation, legal needs, job assistance, voting opportunity, financial needs, and others. The ADA is revised, as needed, as the parent agency becomes aware of the needs of those who are affected by disabilities. Through progressive policies and advocating for those who suffer with disabilities such as MS, the quest for a greater sense of well-being, and equal opportunities will be attainable. I plan to share my findings with organizations which lend themselves to the education of all in relation to the disease itself, the treatments, family roles, expectations for the persons and their families, and the impact that MS has on society in relation to physical, mental, emotional, financial, and spiritual concern. I will advocate for MS victims, as well as other Americans with disabilities and relate the circumstances of others.

The boundaries of this study were confined to the personal experiences of seven participants who were advised of the focus of the study. They were all asked the same questions, and were informed of the results of the interviews. They were each advised of the ability to stop at any point during the interview, and were given an opportunity to expound on any of the topics covered. The literature review covered issues which dealt with the commonalities of the participants' lives and related to their experiences.

Theoretically, the application of positive psychological strategies was evaluated with each participant, and the skills of the participants were highlighted. The acknowledgement of the importance of the involvement of family members and caregivers, along with the relationship with the physicians and medical personnel was noted. Also, the value their achievements and accomplishments provided a vital link to the participants' own sense of well-being. The empirical implications were upheld regarding positive strategies and coping mechanisms as they were identified in each woman's personal account of her journey with MS.

Conclusion

This study was a lesson in the unbridled spirit and the determination of *mankind*. In researching the lives of these seven women with Multiple Sclerosis, their acceptance of responsibility for their own well-being shone through like a beacon. From my personal experience as a parent of a young woman diagnosed with MS at the age of 21, and my involvement with her for the past 14 years as she battles this disease, my predetermined theory that positive strategies and coping mechanisms play a major role in achieving well-being in one's life was upheld and strengthened. The literature I reviewed added credence to my own thoughts, and responses from the interviews of the participants substantiated the previous studies and vice versa. I believe the questions posed in the interviews gave the women an outlet for expression, and allowed their voices to be heard on many levels--personal, emotional, spiritual, financial, and physical. They were allowed to air their grievances and extol their successes with candor and no fear of judgment. This opportunity for them is one of my proudest accomplishments. For me, it

added depth to the study and a sense of advocacy for all who suffer with MS. It exceeded

the annual MS Walks and activities to help in its pertinence, and is as important as the

scientific data which has been published. Sometimes, people just need someone to listen

to them. There is no cure for MS. They all know that. They shared their deepest

feelings and allowed me to uncover some of their hidden fears. For this, I am extremely

grateful, because I understand where they are in their battle against MS. At large, society

is encouraged to engage in the quest to understand and acknowledge the plight of those

who fight horrific diseases such as MS and have disabilities; recognize their rights;

encourage their actions to be treated equally under moral and civil laws, and hold

lawmakers accountable for the progress of attaining these rights or the lack thereof.

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Appendix A: Consent Letter

CONSENT FORM

You are invited to take part in a research study of   A Narrative Analysis of Resilience and Coping in Persons Diagnosed with Multiple Sclerosis.

The researcher is inviting Women, ages 18+ who have been diagnosed with Multiple Sclerosis and belong to the Lone Star Chapter of the National Association of Multiple Sclerosis. This form is part of a process called "informed consent" to allow you to understand this study before deciding whether to take part.

This study is being conducted by a researcher named   Mildred C. Alford who is a doctoral student at Walden University.

Background Information:

The purpose of this study is to explore the quality of life and determine the coping strategies of those who suffer with MS.

Procedures:

If you agree to be in this study, you will be asked to participate in a conversational type survey by phone with the researcher. It will take from 45 to 60 minutes. The data will be recorded and transcribed. Here are some sample questions:

- Tell me about yourself (age, current family, work), and when you were diagnosed.

- What was your life like before you were diagnosed? What event or example comes to mind?

Voluntary Nature of the Study:

This study is voluntary. Everyone will respect your decision of whether or not you choose to be in the study. If you decide to join the study now, you can still change your mind later. You may stop at any time.

Risks and Benefits of Being in the Study: There are no expected risks of being in this study. The benefits will produce information about the living conditions, personal and financial struggles of persons with MS and will be available to anyone who inquires. It will address satisfaction with lifestyles and efforts to maintain or increase satisfaction in areas of health care, mobility, financial issues, legal issues, and other areas of interest to those who have MS.

Being in this type of study involves some risk of the minor discomforts that can be encountered in daily life, such as being on the telephone for an extended time (30-45 minutes). If fatigue, stress, or discomfort arises, the conversation may be postponed for a more convenient time. Being in this study would not pose risk to your safety or wellbeing.

The study's potential benefits will highlight issues such as depression, anxiety, and lack of mobility, and provide "tools" in many problematic areas for all who suffer from MS.

Payment: There will be no monetary payment for participation.

Privacy:

All information you provide will be kept confidential. The researcher will not use your personal information for any purposes outside of this research project. Also, the researcher will not include your name or anything else that could identify you in the study reports. Data will be kept secure by Mildred C. Alford in a locked file in her home. Data will be kept for a period of at least 5 years, as required by the university.

Contacts and Questions:

You may ask any questions you have now. Or if you have questions later, you may contact the researcher via 713-466-0731 or mcaphd@yahoo.com. If you want to talk privately about your rights as a participant, you can call Dr. Leilani Endicott. She is the Walden University representative who can discuss this with you. Her phone number is Insert ONE number depending on location of participant 612-312-1210 (for US based participants) OR 001-612-312-1210 (for participants outside the US). Walden University's approval number for this study is IRB will enter approval number here and it expires on IRB will enter expiration date.

Please print or save this consent form for your records. (for online research)

Statement of Consent:

I have read the above information and I feel I understand the study well enough to make a decision about my involvement. By signing below, I understand that I am agreeing to the terms described above.

Printed Name of Participant

Date of consent

Participant's Signature

Researcher's Signature

APPENDIX B: CONFIDENTIALITY AGREEMENT

Name of Signer:

During the course of my activity in collecting data for this research: "Exploring the

Dimensions of Well Being and Life Satisfaction for Persons

 Diagnosed with Multiple Sclerosis," I will have access to information which is

confidential and should not be disclosed. I acknowledge that the information must remain

confidential, and that improper disclosure of confidential information can be damaging to

the participant.

By signing this Confidentiality Agreement I acknowledge and agree that:

1. I will not disclose or discuss any confidential information with others, including

    friends or family.

2. I will not in any way divulge, copy, release, sell, loan, alter or destroy any

    confidential information except as properly authorized.

3. I will not discuss confidential information where others can overhear the

    conversation. I understand that it is not acceptable to discuss confidential information

    even if the participant's name is not used.

4. I will not make any unauthorized transmissions, inquiries, modification or purging of

    confidential information.

5. I agree that my obligations under this agreement will continue after termination of

    the job that I will perform.

6. I understand that violation of this agreement will have legal implications.

7. I will only access or use systems or devices I'm officially authorized to access and I will not demonstrate the operation or function of systems or devices to unauthorized individuals.

Signing this document, I acknowledge that I have read the agreement and I agree to comply with all the terms and conditions stated above.

Signature: **Date:**

_____