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Transformative Learning in the Multiple Sclerosis (MS) Community An Ethnographic Study examining how and in what ways transformative learning is realized and lived out among members of an MS community.

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Transformative Learning in the Multiple Sclerosis (MS) Community  
*An Ethnographic Study examining how and in what ways transformative  
learning is realized and lived out among members of an MS community.*

National-Louis University  
Chicago, Illinois

A Critical Engagement Project  
Submitted in Partial Fulfillment  
of the Requirements for the Degree  
Doctor of Education

Mary N. Lewis

March 2009

Transformative Learning in the Multiple Sclerosis (MS) Community  
*An Ethnographic Study examining how and in what ways transformative  
learning is realized and lived out among members of an MS community.*

Mary N. Lewis

*Certification:*

In accordance with departmental and University policies, this Critical Engagement Project (CEP) is accepted on behalf of Mary N. Lewis, in partial fulfillment of requirements for the Doctor of Education (Ed.D) Degree from the College of Arts and Sciences, National-Louis University in Chicago.

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March 2009

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Date

## DEDICATIONS

May this work bring glory to my heavenly Father,  
the creator of my soul

To my wonderful husband, Buddy,  
encourager, strong supporter and heart throb,  
and

To our fantastic and amazing children,  
Jonathan and Mary Rebecca; blessings of our lifetime

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**Abstract**  
**Transformative Learning in the Multiple Sclerosis (MS) Community**

**By Mary N. Lewis**

The purpose of this study was to examine how transformative learning takes place in the lives of participants who are in the MS community with the hope of identifying coping strategies and motivational factors influencing transformative learning. This research also seeks to discover and examine the lived experiences, meaning and consequent changes made in the lives of the research participants. The focus of this research asks how and in what ways the learning process differs prior to and after a diagnosis of MS and how these individuals reconstruct their lives after experiencing the day-to-day challenges brought about by this disease.

It is the intention of this study to use Dr. J. Mezirow's 'transformative learning' theory and Dr. R. Boyd and Dr. Myers view of transformative learning which is incorporated in the concept of 'individuation'. The theoretical perspectives guiding this research which are: constructivism, critical reflection, the relationships between chronic illness, disability and MS and lastly the MSer and their relationships.

In an effort to collect and examine the daily experiences of a particular group of people or individuals this study is qualitative in nature. This research paradigm has been found to be a powerful instrument that aides in the understanding of individuals in the social and historical context in which they live, work and play (Merriam & Associates, 2002, p. xv). This research perspective will allow the researcher to focus on the "process, meaning and understanding" of the particular individuals and/or group under investigation (Merriam & Associates, 1998, p. 8) and will result in a large collection of descriptive material that will lead to a greater understanding of the participants' frames of

reference and uncover unique interpretations of the meaning-making process. Patton (1985, p. 1) states that qualitative research “is an effort to understand situations in their uniqueness as part of a particular context and the interactions there”. Denzin and Lincoln (1998) explain that qualitative research further by providing a flexible approach to investigation by allowing the researcher to:

stress the socially constructed nature of reality, the intimate relationships between the researcher and what is studied, and the situational constraints that shape inquiry. Such researchers emphasize the value-laden nature of inquiry. They seek answers to questions that stress how social experience is created and given meaning. (p. 8)

Hence I will use the lens of critical ethnography to investigate to workings within and without this community. “Critical” ethnography that investigates how the strictures caused by hegemonic powers with value-laden agendas” (Merriman & Associates, 2002, p. 236) effect and interplay with the “historical, social and economical situations” of a particular culture. Critical ethnography seeks to shed light on the “unfairness or injustice within a particular lived domain (Madison, 2005, p. 6) by examining the status quo and the taken-for-granted assumptions which entrench a particular group of individuals and bring to light the hidden operations of power and control that adversely affect or influence the group’s well-being physically, emotionally, socially and/or economically resulting in a diminished degree of personal and collective freedom and equality (Denzin, 2001; Thomas, 1993).

It is my intention in this study to use critical ethnographic principles to examine and explore the powerful underlying face by MSers in an effort to bring understanding, importance and validation to the views and experiences of those in the MS community who do not feel that their lived experience is of little worth to themselves and others. The

development of “how power operates, of how social, political, and economic life is structured” is vital to the development of workable strategies and procedures through which “existing discourses and institutional structures can be restructured, if not revolutionized” (Inglis, 1998, p, 2).

# CHAPTER ONE

## *Introduction*

When writing of your own misfortunes, it's difficult to avoid portraying yourself as filled with self-pity. At the same time, it's difficult to live with illness over a long period of time without becoming self-centered. In the past, I've attempted to understand what a future with multiple sclerosis (MS) holds for me from clinical books and conversations with physicians and specialists. Yet due to the nature of the disease, the physical and psychological experiences always remain a mystery. I am constantly having to wrestle with the ever-present, confusing neurological effects of MS, for which there is little or no relief, as well as the anxiety of not being able to determine the impact this disease will make on my present and future life. This process helps me to acknowledge that life is fragile and must be handled with great skill and care.

Describing how it feels to live with this disease is difficult, but I can say that every day brings about a new set of challenges; one day, you may begin to have difficulty with your sight, only to get up a day or two later with another symptom that could range from swallowing to speech difficulties. Every MS patient has a unique version of the disease, which contributes to feelings of helplessness and desperation. There are no certainties with MS other than you know that you will struggle with some issue each day; you just don't know what your next challenge will be until the day arrives. Life with MS becomes a series of lessons and opportunities to practice virtues that are needed and much coveted in our society such as patience, kindness and courage, though I believe no one would race to be first in line to participate in the circumstances that build these well-esteemed virtues in a person's life.

What does one do or say after being told that you have a disease such as MS? I received that proclamation almost 25 years ago, and I can still remember that day as if I had just heard the news today. At first I just sat in the doctor's office attempting to make sense out of the diagnosis while at the same time consoling my compassionate doctor who was crying while giving me this news. As I left the physician's office many things started spinning around in my mind. How was I going to take care of my two small children? Who was going to take care of me? How am I going to afford the visit to the neurologist? What will the future look like? So many questions! But as I soon realized, life goes on. Sooner rather than later, I was thrown back into life and left to confront this new reality for which I had no previous experience to make sense of my world. It was a bit like learning to swim by being thrown in the water. I felt as though I had been presented with a problem to solve for which I had no prior training to draw from. How could I know what to do or how to act, given this news that was sure to change my life?

One of the most difficult things about living with this disease has been the uncertainty of how MS is going to affect my life physically and emotionally. Little is known about the cause and course of the disease for any particular individual. What is "normal" in the world of MS for one person may not be "normal" for another fellow MSer. At the time of my diagnosis I was told that I should understand that my children would probably grow up without my ability to care for them because I would need someone to help me meet my everyday needs. Then and there I made the conscious decision to make it my first mission to focus on helping my kids become strong, self-reliant children and adults in society. I didn't want them to become too dependent upon me as they continued to grow and mature. Little did I realize that this major shift in my

view on childrearing would only be the beginning of many strategic changes necessary to adapt and function in my world. Over the past 25 years, I have had to examine and redefine my view of the world many times due largely to the physical, social, emotional and mental effects of MS.

### ***Statement of the Problem***

The uncertainty of MS presents constant struggles. One frequently ignored factor of MS is the mental and emotional toll of this uncertainty, which may take many forms. It may include changes in the dynamics of family relationships, a continuing sense of helplessness or possible frustration over the “cards that have been dealt” or the difficulty of dealing with societal perceptions of an individual who has a disease. Because most of the research today is focused upon finding a cure, all too often patients are left to their own devices to cope, or at least to find some way to relieve the pressures that result from trying to balance health and social commitments.

As a person who has had her own ups and downs over the last 25 years dealing with MS, I have found that my emotional and mental well being plays a vital role as I deal with the issues that this disease presents. In an ongoing attempt to explain and to help myself, loved ones, other MSers and individuals who express a desire to better understand this disease, I have chosen to conduct and participate in research with the hope that the information found here might bring a measure of assistance and relief

physically, emotionally and/or spirituality to all who are touched directly or indirectly by the presently incurable disease of MS.

### ***Purpose Statement and Research Questions***

The purpose of this study is to examine how transformative learning takes place in the lives of participants who are in the MS community, while identifying coping strategies and motivational factors that influence transformative learning. Although I found that I could agree with the overall transformative learning process expressed by Mezirow, there were some areas of my transformative journey as a MSer that were not addressed and answered by his theory. The area most glaringly missing was the part emotions played in process of dealing with my diagnosis of MS and it was this lack of discussion and inclusion of emotions into the transformational process that led me to explore other theories and individuals who had something to say about this incurable disease. Yet no discussion was forthcoming on the subject of how emotions enter into the learning process. In fact, while researching this matter of emotion it must be noted that a common critique of Mezirow's transformation theory relates to the lack of adequately addressing emotions (Wiessner & Smith 2000, 334).

It is my intention in this study to use critical ethnographic principles to examine and explore the powerful underlying forces faced by MSers in an effort to bring understanding, importance and validation to the views and experiences of those in the MS community who feel that their lived experience is of little worth to themselves and others.

This research also seeks to discover and to examine the lived experiences, meaning and consequent changes made in the lives of the research participants. The focus

of this research asks how and in what ways the learning process differs prior to and after a diagnosis of MS, and explores how these individuals reconstruct their lives after experiencing the day-to-day challenges brought about by this disease.

Interview questions cover the following topics: the meaning making process, the emotional aspect of meaning making, the relationships of MS participants and the power issues encountered while dealing with this disease. This study seeks to answer the following questions:

1. How do participants make meaning out of the diagnosis of MS?
2. What factors were influential in the participants' understanding and coping with this disease?
3. In what ways do subsequent life experiences alter the perspective transformation that resulted from the participants' diagnosis of MS?
4. What factors have hindered the participants' ability to deal effectively with MS?
5. What role did relationships play in their transformation?

### ***Importance and Relevance of the Study***

Interests and priorities change throughout our lives, and adulthood is considered to be the time when we strive to make sense of a situation or experience by finding explanations through traditions, individuals that we look up to for advice or using “mental pictures to explain or bring understanding to our lived experiences” (Mezirow 2000, p. 3). A theory referred to as “transformative learning” describes the process whereby educators, researchers and individuals understand, clarify and make sense of the

many facets that make up lived experiences. This theory results from the research conducted initially by Jack Mezirow, and this process of learning has been the topic of extensive studies by various researchers for a number of years (Taylor, 1998, p. vii). One researcher, O'Sullivan (2003) suggests that transformative learning includes not only one's intellect but includes "our body awareness and visions of alternative approaches to living" (327). This accurately describes the MSer's lived experiences of continually seeking for adaptive ways to successfully participate in one's community. In fact, transformative learning for some has been linked to survival on a personal, communal and planetary level (O'Sullivan, 2002, 8).

MS affects all areas of life, and it is my goal to examine a number of issues that are vital to the health and well-being of the MS community. One of the first and most difficult barriers for an individual with MS to face is the uncharted, unknown future that comes from being a member of this group. It is hard enough to come to terms with the idea that your life will be forever changed; it is quite another matter to envision your future with any degree of hope when the way that this disease will affect your body is anyone's guess. Even physicians are reluctant to make any projections for your future life experience. How do MSers successfully come to terms with their "disorienting dilemma," which in this research is the diagnosis of MS, accept their "lot-in-life" and move on to tackle future struggles brought about by this relentless disease (Mezirow 1995, 50)?

A earlier study by Pakenham (1999) explored the emotional coping skills of 98 MS patients over a 12-month period and concluded that not only was there an increase in physiological distress but also an increase in depression and poorer social adjustments. This led the researcher to suggest that MS patients needed assistance in acquiring the

necessary emotional coping skills to successfully navigate this ongoing disease process. Although Pakenham's research solidly helped to identify a need to create various coping mechanisms specific to the MS community, I know of no set course of action to include such help via the attending physician at the time of diagnosis. It is my opinion that we MSers can also learn from each other and bring a more meaningful level of help in the area of our coping strategies due to our position as individuals who know firsthand what it is to be a part of the MS community. This would make this research worthwhile in my community.

MS is highly unpredictable and at times relentless in its assault upon those who have this disease. It is a chronic, autoimmune disease that affects the central nervous system, manifesting itself in a wide range of symptoms. Symptoms may be categorized as mild, such as unusual fatigue, to severe and crippling, such as blindness and paralysis. Through the disease was first documented in the 1800s, little progress has been made in slowing the its progression or finding a cure, and the very nature of the disease makes it hard to find assistance of any kind that is effective in the ongoing struggle of disease management. Very little is known for sure: with MS, your own immune system attacks your nerve fibers, causing scarring on nerve cells that are found in the central nervous system (brain, spinal cord and optic nerves). The result is that the communication between nerve signals is disrupted. This interference of nerve signals leads to the symptoms of MS (Multiple Sclerosis Society 2005b, 1).

MS affects approximately 400,000 people in the United States alone and 2.5 million people worldwide, and the number of individuals with MS is increasing at an alarming rate (Multiple Sclerosis Society 2007, 2). The cause of MS is unknown, and

symptoms of MS vary from person to person and can be unpredictable. The more common symptoms are the following: fatigue, double vision, weakness of one or more limbs, numbness and tingling, stiffness, dizziness, slurred speech and loss of bladder control (Multiple Sclerosis Society 2005b, 1). Some people may experience a sudden worsening of an MS symptom (i.e., a greater degree of stiffness), or the appearance of new symptoms. These episodes can last from 24 hours, a number of weeks or continue to be a symptom for the rest of your life. For most, MS progresses over time, but early diagnosis and treatment may help slow disease progression and manage symptoms (Multiple Sclerosis Society 2005b, 1).

This study is not only for individuals who have been diagnosed with this disease but for all who desire to be informed, concerned and caring to those who are the real heroes, the elite members of the MS community. Indeed, the latest findings suggest that membership in the MS community is growing by leaps and bounds. The National Multiple Sclerosis Society (2006–2007) figures state that 200 cases of MS are diagnosed each week, and that MS attacks people in the prime of life, usually between the ages of 20 and 40 (2). It is the most common disease of the nervous system affecting people from all walks of life.

Many reasons, some not yet mentioned, make this study of value and interest not only to the MS community but also for the world at large. I envision the implications of this research to extend beyond the world of the MSer into the communities of other individuals affected by other neurological diseases like lupus. It may bring insight into how to help MSers in their personal relationships, for MS takes a large toll on family relationships. Families in which one partner has MS have a divorce rate of 75–80 percent,

one of the highest rates of divorce in marriages where a partner has a chronic illness (Hitch 2007, 1). Caregivers, physicians and other interested individuals may be better able to empathize and/or care for those with MS, helping to bring awareness of the many issues faced by the MSer. This in turn may result in acquiring more funding for the care and cure of MS.

For the educator, this study will bring greater insight into a more holistic approach to the learning process. This research may help to supplement the lineal approach to the learning process by demonstrating that the whole person—the complete self—steps up to the plate to face each day. This indicates a need for a more holistic approach to the learning process. This approach to learning is important in education because adults enter the learning process with multiple ways of constructing knowledge. It will expand the understanding of how adults with MS come to learn, feel and know about their experience, and may be an opportunity for others to learn how to use multiple modalities in the teaching and learning process. We may possibly as educators help students understand more about themselves (and ourselves) than could be learned by using a linear approach alone.

### ***Chronic Illness and MS***

MS is considered a chronic disease, defined by the U.S. National Center for Health Statistics as a disease that persists for a long time, lasting three months or more (MedicineNet.com 2004, 3). In a study that explored the lasting and long-term affects of the chronic illness rheumatoid arthritis, the researcher noted the toll upon the patient by stating that the phenomenon of chronic illness makes a “significant impact upon the physical, social, psychological and even the political events in a patient’s life” (Bury

1991, 452). Chronic diseases generally cannot be prevented by vaccines or cured by medication, nor do they just disappear. Bury argues that the meaning of an illness can be defined in terms of its “consequences which refers to the impact it has on practical aspects of the person’s roles and relationships in everyday life or in terms of its “significance” which relates to the cultural connotations, symbols, and significations surrounding different sorts of illness and disability” (453).

Attempting to adjust to living with a chronic illness introduces problems of gigantic inconsistency and irregularity, which is strongly linked to and influenced by the patient’s social and environmental settings (Bury 1982, 176). The initial impact of being diagnosed with an illness can include feelings of fear, shock and even relief, depending on whether or not the diagnosis was expected (Glacken, Kernohan and Coats 2001, 109). Following this initial period, there seems to be a movement toward acceptance and modification of one’s life in order to deal with illness (Sutton and Trelor 2007, 338). According to Pakenham’s (1999) study that examined stress and coping models relevant to MS patients, overall adjustment to life with a chronic disease improved over time (390). It has been suggested in the past that this adjustment period is seen as a opportunity by the individual to begin to rethink and rearrange their self-concept in the new situation and to reassess plans and expectation for the future (Bury 1982, 169).

The findings of Bury and others mentioned above seem to be consistent with the overarching theoretical frame of analysis used in Jack Mezirow’s transformative theory, which strives to explain how adults make sense and act on their own “purposes, values, feelings and meanings” rather than unconditionally accepting the views assimilated from

others which brings about personal control over their lives as socially responsible decision makers” (Mezirow 2000, 8).

Chronic illness can come to call at any age, and the likelihood of entering into this population of the chronically ill increases as people age. According to the U.S. Department of Commerce statistical abstract, approximately 25 percent of persons age 45–64 and more than half of persons age 65 or older are limited in their activities by at least one chronic condition (1980). MS is a chronic disease that affects the central nervous system; it usually lasts over several decades with little or no reprieve. This study is an effort to become better acquainted with the lived experiences of individuals with the chronic disease of MS in the hope that such an honest and open dialogue may inspire and help all who are affected by this dreadful disease. Greater understanding and information can be used to make the MSer’s day a little less hectic and a great deal more enjoyable.

### ***Disability***

At this point we should discuss another aspect that presents itself in the MS community, the concept of disability. While I am the researcher, as I previously stated I am strongly entrenched in the MS community by the shared experience of having the disease for a great number of years. I am aware that many individuals who claim to be a part of the MS community are not disabled, and some MSer’s who do fit the definition of being disabled choose not to use such a misunderstood marker to describe their lived experience. The term *disabled* has numerous definitions and presents many unfavorable mental pictures. This study explores what it means to be disabled, and explores what my fate will be if I choose to make the word “mine.” To what extent does this label help or

hinder the MSer's lived experience? Are there societal forces or structures in place that make living with this disease and this label a challenge?

The Americans with Disabilities Act (ADA) defines *disability* as a physical or mental impairment that substantially limits a person's life in one or more major life activities. The law further designates a disability as having an impairment that will have a lifelong impact in a disabled person's life (Clark 2006, 312). For the "able-bodied" individual, the idea of disability is quickly and easily defined as a person with a visible defect or physical impairment (meaning a person with a body or body part that does not match up with the common societal norm) or a person having a sensory or mental impairment (trouble hearing, seeing or processing deficit) (Davis 1995, 1).

What doesn't occur to many people is that disability is not a minor issue affecting a relatively small number of unfortunate people; it is a common occurrence. Disability affects 15–20 percent of every country's population. An analysis of disability statistics shows that: A) 51.2 million people in the United States have some level of disability. This represents 18 percent of the population; B) 32.5 million people live with a severe disability. This represents 12 percent of the population; and C) Worldwide at least 650 million people live with disabilities (United Nations Convention on Rights of Persons with Disabilities 2007, 1). Given the fact that over the years these numbers only increase and never decrease, it is only sensible that "abled" individuals stop and consider their possible future plight.

Disability is both a private and public experience, and various groups have spoken out about the need to address disability in the light of discrimination (Davis 1995, 161; Despouy 1993, 1). A number of researchers suggest that the disability experience is a

“socially constructed category” (Clark 2006, 307; Davis 1995, 7; Kelly 2001, 396).

Philosophers and scholars have argued that the idea of discrimination involves the “contempt or devaluation of individuals based on their membership in a social group” (Wasserman 2001, 240). Feminists have argued that the design of physical structures and social practices for one group—able-bodied males—constitutes a significant form of discrimination against the rest of society.

For some disability is a personal catastrophe; for others, disability is a matter of empowerment which subjects the impaired individuals to the same measure of oppression and segregation experienced by other populations on the “basis of the characteristics of race or ethnicity, gender and aging” (Hahn 1997, 174). Over forty years ago, tenBroek (1966) recognized what he believed to be the marginalization of the disabled and stated that in order for the disabled individual to participate freely in society he or she has the right to:

free and safe physical access to it through the use of streets and sidewalks, roads and highways, and the common modes of transportation, communication, and interchange. It includes as well full and equal access to places of public accommodation, places designed to accommodate men in the course of gaining access to the world. The right to live in the world consists in part of the right to live out of it (917).

Wasserman (2001) likens the refusal to make changes in the “physical and social order” of society to accommodate the needs of individuals with impairments to the exclusion of blacks and women from public facilities (240).

Disability can place people at the margin of society, and permanent disability may lead to a lifelong “feeling of otherness” (Viitanen, E. and Piirainen 2001, 132). The term

*other* or *otherness* has been used by Africanist, Latino, gay/lesbian, and feminist scholars to indicate their marginalized status within society (Sheared and Sissel 2001, 13). The term is most often used to emphasize and draw attention to society's silencing of a particular group of people. Even though the term *other* is not readily associated with the disabled individual, many disabled people can describe their lived experience among various groups and institutions as limiting because they are given the impression through comments, actions and reactions that they are not worthy enough to participate in the decisions and intricacies of society forcing these individuals to use creative means in order to just exist in our society.

It is my intention to help to identify and encourage discussion on how MSers could work individually and collectively to change the mindset of those who, in an effort to assist the MS patient, really place him/her in physical and emotional harm. The disabled MSer should always seek not only to be heard but also to be recognized for the wealth of knowledge and ability he/she brings to our society. Freire suggests that to be human is to "name the world, to change it . . . [We] are not built in silence, but in word, in work, in action-reflection" (1973, 43). What I suggest and long for is a holistic change in attitudes and behaviors—a new vision for we are responsible for the society in which we live.

To many living outside the MS community, MSers are perceived as individuals with impairments who lack wholeness and are therefore pushed to the margins of society. In our society, bodies are categorized as good and bad, which usually describes people with perceived disabilities as creatures of disorder (Davis 1995, 143). This perception leads to the disruption in the power and status of the disabled, including the MSer (151).

## ***Relationships and MSers***

MS is a medical condition that brings you face to face with an endless stream of health care professionals with varying areas of expertise. It also places the MS patient into social settings that take on new meanings and challenges that result from entering a world that places conformity to the perceived norm as the gauge that determines one's status and degree of participation in that society. In spite of our orientation towards an individualistic mindset and practice, our awareness of who we are and our place in the world is continually being defined for us by the quality of participation and acceptance we experience in our community, the number and level of our friendships, whether we are respected and loved and to what extent we sense that people seem glad to see us, to want us around and to miss us. We probably look for social cues to judge our value far more than is personally healthy, but that's human nature.

Our need for membership in a group becomes very strong when we are faced with health problems and possible disability because these experiences tend to threaten our personal identity and performance; even the most individualistic of us needs others and looks externally to others for support and validation. Since a chronic illness and/or disability are seen as countering current values such as "prosperity, speed, independence, self-reliance, and productivity" (Lyons 1999, 1), it is hardly astonishing that individuals and their relationships struggle to adapt to this new, unknown strange environment.

Social networks influence everyone's sense of self-identity in many ways, some positively and some negatively. Goffman (1971) states that a physical deficit with visible symptoms may be "a minor thing according to a medical or biological frame of reference, but is likely to be of tremendous significance socially" for the MS patient (473). Grytten

and Per Maseide (2006) conducted research that investigated the significance of stigma in social relationships and how people manage this experience within social settings. The researchers found that the impact upon social relationships tended to produce a need to overemphasize or exaggerate the perceived differences between the “abled” and perceived “disabled” MSer or alternatively to ignore the disease or visible “disability” entirely. Both responses result in the inability of the MSer to deal seriously with the disease when communicating with others, which often leads to isolation due to lack of understanding on the part of all parties in the social relationship and the MSer’s perceived degradation of status within the social community (199–200).

The amount or lack of support an individual receives from family members, friends and their medical provider directly affects the perceived degree of wellness and general overall outlook on life (Boise, Heagerty and Eskenazi, 1996, 75). Grytten and Maseide (2006) concluded that emotional support from family members enhanced the MSer’s sense of well-being and attributed to greater social adjustment (202).

It is also common to discover those individuals with MS and the professionals to whom they turn to for help and guidance have differing perspectives on the issues and challenges the MS patient faces. One such study was conducted by Rothwell, McDowell, Wong and Dorman (1997) who explored the interactive role between the physician and the MSer. The study consisted of 47 patients between 28 and 68 years of age; it concluded that while the physician was more concerned with physical manifestations of the neurological disease, the MS patient was more concerned with “less tangible qualities [of life] such as mental health and vitality.” The researchers suggest that doctors should

at least bear in mind that their concerns may not agree with those of their patients when considering whether to prescribe treatment, (1580).

After dialoging with many MSers over the years I have found that it is typical for the patient to go through various tests in order to confirm or eliminate the possibility of having MS and upon completion of those tests to discuss the results with the doctor. If the test results are negative the patient may leave and go on to other things. But if the diagnosis is positive for having MS, research suggests that many of the newly diagnosed patients feel that after the initial patient-physician consultation to determine if they have MS, they were then expected “go away and live with it” (Robinson 1991, 20; see also study participant Danny). This feeling was due mainly to the lack of information offered by the physician on how to proceed after their initial diagnosis, leaving the MSer alone to try to answer a myriad of questions like why, how or what now?

The impact of a chronic illness such as MS brings about a number of changes in many relationships, including family, friendships, coworkers and community members. Illness and disability can change relationships substantively, and the impacts on network structure, function and quality are surprisingly similar across a broad range of disabling health problems (e.g., cancer, multiple sclerosis, spinal injury) (Lyons 1999, 2). The changes in one’s societal network include the diminished size of one’s social group, decreased frequency of interaction and the loss of friendships (1991, 245). It has been suggested that illness not only affects the amount of time one may devote to participation in a social group but also brings about discomfort in communication and support processes (253). Inevitably, relationship *quality* is affected as a result of the lack of

valued relationship opportunities and the complexity of working through relational limits formed by illness and disability (Lyons 1999, 6).

Other research that primarily focuses on the MS population suggests that contact with nondisabled individuals and support from family and friends have been shown to also enhance psychosocial well being (Cohen and Wills 1985, 332). Wineman (1990) studied the role of social support among MS patients and found that a lack of supportive relationships brought about an increase in depression and a lower sense of purpose in life (298).

Being diagnosed with MS certainly does change every aspect of your life. Some things that change you just finally resolve to accept and to manage the best way you can without trying to look too long at the past. Looking backward places you in danger of viewing your history as a place of very green pastures and no earth-shaking surprises. Yet managing relationships can be a struggle that never seems to abate. After hearing the news about my MS it took all my courage to tell my family and friends about my situation. Emotions were so tricky; I wanted to tell my friends and loved ones in an effort to be understood and to feel their acceptance no matter my condition; yet I was afraid that they would see me as a helpless, pitiful creature that needed insincere affirmation. Maybe they would think I just wanted attention because I looked so “normal.”

Through the years all of the above statements have played out in my lived experience. My social circle has changed a number of times throughout this ordeal; I believe it has been a result of not only the awkwardness and demands of this disease, but also people move on, myself included. Needs change, goals change, life is not static.

Some of my friends just could not or were not ready to become so familiar with disease, and some found the experience too much to handle.

The realization that you have a disease makes you stop and consider things that are usually not in the forefront of your mind, things our American culture avoids at all costs. Illness also changes the way you see yourself in relationship to others. It is paradoxical that the loss of relationships due to having MS occurs at just the time when you really need major support from your friends. To a person with MS, relationships are not taken lightly because they can mean the difference between social isolation and social integration. The type of support at the MSer's disposal could possibly influence whether the individual with MS will be able to live at home as the disease progresses or will live in an institution of some sort.

Many MSers quickly realize that most people have a low tolerance for anyone with an illness. Many express verbally or through their actions their propensity for wanting to "fix things," and their lack of ability to "fix" this situation only makes them feel helpless when confronted with another person's health problem. Individuals with chronic conditions are frequently urged to "get on with it" or "snap out of it," anything except talk about it. To examine the role that relationships play in the lived experience of the MSer, we must identify the qualities necessary to create and maintain a supportive relationship. What dynamics within an MS relationship bring victory or struggle? By questioning the role of relationships in the life of an individual with MS, I seek to extract suggestions that will serve to strengthen MSer's relationships on a daily basis. This task is best done by going to the very knowledgeable and helpful MS community.

## ***Summary***

This paper is written with the intent of being the catalyst to open the door to a better understanding of the MS community and its members for people and institutions outside of the world of the MSer. May it open the eyes of all who dare to take part in the MSer's journey. It is the intention of the researcher that the information found within these pages may prompt all interested individuals and the society at large to dialogue about the effects of this disease in an effort to bring a commitment and urgency to finding at least relief to the sufferer of MS and at best a cure.

The next section of this study addresses the transformative process that takes place in the life of the individual who receives the diagnosis of MS. This study will use Dr. J. Mezirow's "transformative learning" theory along with Dr. R. Boyd and Dr. Myers's view of transformative learning incorporated in the concept of "individuation." Also covered in detail within this paper is the review of the theoretical perspectives guiding this research: constructivism, critical reflection, the relationships between chronic illness, disability and MS and finally the MSer and relationships.

## CHAPTER TWO

### *Literature Review*

#### **MS and Transformative Learning—Mezirow**

The way that individuals view the world is the result of our knowledge and interaction with the world, our tradition and our inner self. MS patients have been given the opportunity to develop a number of virtues that are highly regarded in our society, for example, patience and courage, from which MSers may draw strength to inform and lead our society to a greater awareness and understanding of this terrible disease. Since this disease is dealt with on a daily basis, I find that I must continually search for ways to balance the demands brought on by this disease and the need to be an active participant in the community and world in which I live, work and play. A successful redefining of priorities and self-identity will help me to be better equipped to avoid the risk of confusion and uncertainty in today's society.

This redefining of self is a process that closely resembles the theory of “transformative learning” first introduced by Mezirow in 1978. This theory has stimulated much discussion in the field of adult education (Taylor 1997b, 1). A large part of the literature base for this study incorporates a theoretical framework introduced and developed by Jack Mezirow over a period of years that has become known as Transformative Learning Theory (1978, 1981, 1990a, 1991, 2000). It is considered the “most researched and discussed theory in the field of adult education” (Taylor 2007, 173). According to Cranton, Mezirow's theory has become a “comprehensive and complex description of how learners construe, validate and reformulate the meaning of their experience” (1994, 22).

His theory addresses the issue of how and why personal experiences, especially crises, change the way people view, understand and participate in their world. Analyzing perspectives is one way that adults transform their foundational beliefs and practices (Henderson & Hawthorne 2000, 15; Murphy 1999, 66). Mezirow (1981) states that transformation is:

The emancipatory process of becoming critically aware of how and why the structure of psycho-cultural assumptions has come to constrain the way we see ourselves and our relationships, reconstituting this structure to permit a more inclusive and discriminating integration (6).

Transformative learning is a process that “purposively question[s] one’s own assumptions, beliefs, feelings and perspectives in order to grow or mature personally and intellectually” (Herod 2002, 1). It attempts to understand both the process and outcomes of important, meaningful learning in adulthood (Dirkx 2000a, 80; Daloz 1986). Adults have acquired a way of seeing the world that is interpreted through their experiences and set of values. As new information and experiences meet up with prior learning, this old and new experience and knowledge integrate to create better understandings and actions for the adult. Difficulty arises in our understanding of our lived experiences when the ideas and experiences do not integrate, and in some instances this contradiction or dilemma forces the adult to examine and adjust prior learning in order to make sense of his/her lived experiences. Mezirow places this shift in worldviews at the core of “educational practice or technique” (Taylor 1998, 12).

This endeavor to understand how adults make sense out of their lived experiences was a result of a research study conducted by Mezirow exploring the learning process of 83 women returning to college, and it led to his eventual “outline of a theory of adult

development and derivative concept of adult education” (Mezirow 1978, 153) that was later identified as Transformative Learning. According to Mezirow’s theory, one’s journey toward learning transformation is brought about initially through as a result of an adult experiencing what would be defined as a “traumatic event” (possibly a death in the family, loss of job, etc.) in life that challenges the worldview (1991). This leads to the critical examination and reflection upon one’s belief systems, and then a shift in how one interacts with one’s society and the world.

Kolb (1984) recognized that experience is key to the learning process when he defined learning as “a process whereby knowledge is created through the transformation of experience” (38). Adult learners, in order to make sense of their world and experiences, must continually transform ways of thinking, deconstruct “assimilated half-truths of conventional wisdom and power relationships . . . [and] come to recognize being caught in his/her own history and reliving it” (Mezirow 1981, 11). This enables the adult to identify and defend what they “know, feel, believe and act upon” in order to successfully interact in their ever-changing world (Mezirow 1995, 46). This learning theory has helped to define the field of adult education.

The transformative learning process also relies upon the use of critical reflection, engaged when the individual’s traumatic life experience fails to fit one’s expectations and creates a “disorienting dilemma” (Mezirow 1991, 1995; Taylor 1998, 8) or crisis that leads to “an awareness that something does not fit, or . . . does not sit right within them” and then leads the adult learner to become a critical thinker (Boyd & Fales 1983, 106). It is when the individual “realizes something is not consistent with what [they] hold to be true” (Taylor 1998, 9). According to Mezirow, making sense of a situation is a process

that involves the making of “meaning schemes” (2000, 293), which are habitual rules for interpreting, and “meaning perspectives”(16), which include one’s beliefs and theories that are founded upon one’s experiences. These can then be deconstructed and acted upon in a rational way (Taylor 1998, 8).

Changes in these meaning schemes are deemed necessary when an individual is presented with a situation where one’s new knowledge does not match up with one’s previously established knowledge base. This disconnect is the catalyst that compels an individual to reconfigure or even change their meaning schemes and meaning perspectives in order to make sense of their world. Meaning schemes and meaning perspectives both act as grids through which personal experience is understood and solutions are derived.

While these schemes and perspectives help to make sense of our experiences, they are not without some degree of what Mezirow calls “habits of expectation,” which often limits one’s ability to be unbiased (1990b, 4). We all bring social or cultural perspectives to our experiences, so Mezirow suggests that all new or reinvented interpretations must be validated through “rational discourse” in an effort to arrive at the best possible understanding of an action plan for our experiences. This discourse must include (as much as is possible) the participant’s disclosure of complete information, the ability to impartially assess ideas and the absence of duress (Mezirow 1990a; Daloz 1986; Freire 1973).

Daloz (2000) refers to this process as a journey into the unfamiliar, helpfully coached by a caring adviser or mentor (116). These mentors or advisers are external observers who help the individual learner to examine assumptions, attitudes and beliefs,

while at the same time increasing their self-awareness and confidence in themselves. In some cases a good mentor may even have to add a measure of conflict in order to help the learner to identify and question accepted and previously acted upon beliefs (Daloz 1986, 126). This may include “toss[ing] little bits of dither in the students’ path, little facts and observations, theories and interpretations . . . that raise questions about their worldviews and invite them to . . . think fresh” (223). In an effort to examine and redefine one’s assumptions, attitudes and beliefs, educational pioneer Paulo Freire—who was known for his work on the personal development and change agency of the individual—states that through the use of problem-posing, individuals overcome their false perception of reality (1970, 67).

For Mezirow, the “safety net” for an individual’s newfound or revised assumptions is the use of dialogue with others, which brings about the “greatest assurance of objectivity” (Mezirow 1990b, 10). It is through the use of “rational discourse” one becomes aware of how and why previously held assumptions have come to define understanding and perception of the world which lead to making and implementing plans that brings about new ways of knowing that make sense when dealing with the situations faced in the day-to-day rigors of life (Mezirow, 2000, 306).

Transformation is a process whereby meaning making becomes repetitively clarified. The transformed learner develops the ability to be more receptive to other points of view and more aware of their own “expanding frame of reference” (McGregor, 2004, 8). This shift in perspective, according to Mezirow, will lead the adult to take steps to engage in “emancipatory action,” taking deliberate action based upon and guided by

one's new perspective, that will in turn "liberate [the adults] from reliving [their] own history" (1990b, 18).

While identifying with the overall theory of transformative learning propounded by Mezirow, I noticed that some aspects of my transformative learning process did not match up with Mezirow's theory. Even though I found a great deal of camaraderie and validation in Mezirow's theory of transformation, my experience has also included an emotional component to the process of dealing with my diagnosis of MS that was not given voice in Mezirow's theory of how one makes meaning out of the traumatic experiences of life. This lack of discussion of the part that emotions play in the learning process led me to long for further discussion and investigation into what seemed to me to be a vital part of my transformation process. Given the fact that MS is a highly unpredictable disease, I find the results unsurprising from Pakenham's research that found that individuals with MS have a higher rate of emotional disturbance when compared with other patient groups having a similar level of physical disability (1999, 384).

While Mezirow's theory is directed toward personal development, his transformation is based on the "rational, autonomous, responsible adult" (1985, 27) an adult who controls experiences rather than being controlled by an experience (1990a, 375). It is the individual's capacity for rationality that determines what is to be trusted and incorporated into meaning-making process (Clark 1993, 51). For Mezirow, transformation is validated through a balanced discourse that will bring about one's "greatest assurance of objectivity" (1990b, 10), even though he states in his later writings that the restructuring of what an individual knows can be an "intensely threatening

emotional experience” (2000, 6) and that adults must learn to “cope with anxiety over the consequences of taking action” over a newfound belief system (6). Yet no discussion was forthcoming on the subject of how emotions enter into the learning process. In fact, while researching this matter of emotion it must be noted that a common critique of Mezirow’s transformation theory relates to the lack of adequately addressing emotions (Wiessner & Smith 2000, 334). As I continued to seek out other voices in an effort to validate and further explain what I considered to be one of my deepest turning points in my life, I found a number of scholars who defined transformative learning in such a way as to acknowledge and include the emotions of the learner in the transformative process (Boyd 1991; Boyd & Myers 1988; Taylor 1997a; Dirkx, 1997, 1998, 2000, 2001; O’Sullivan 2003).

### **Feelings/Emotions in the TL Process—Boyd and Myers**

According to Boyd and his colleagues, forceful and demanding feelings and strong emotions arise during transformative learning experiences that lead the adult’s attention and efforts to seek to resolve hidden issues or concerns that play a vital role in the formation of an individual’s personality (Boyd, 1989, 459; Washburn 1988, 55). Boyd’s work is based on the belief that the unconscious plays a strong and influential role in the formation of one’s thoughts, feelings and actions throughout one’s adult life. His view of transformative learning “seems to be grounded in Jung’s concept of ‘individuation’ that leads to the further development of the individual’s personality” (Dirkx 2000b, 1). This view of individuation supports the idea that emotions play a large role in the transformative learning process, using what is defined as “discernment”: extra-rational sources such as symbols, images and archetypes to assist in creating a personal

vision through the transformation of the individual's personality through the resolution of the personal dilemma. This brings about the expansion of consciousness, which results in greater "personality integration" (Boyd 1989, 459). For Boyd, transformation speaks to the core of the learner's being and plays a part in the determining of thoughts, feelings and actions on a day-to-day basis, often focusing on the "emotional and spiritual perspectives of learning" (Dirkx, 2000, 82). What matters most in learning is what matters to the deep ground of our being—the psyche or soul—that is primary, original, basic and necessary (Sells 2000, 3).

The use of discernment is critical to the transformative process (Boyd and Myers, 1988, 280). Discernment is comprised of three actions: receptivity (willingness to explore "alternative expressions of meaning"); recognition (acknowledgement that other ways of meaning may be valid to use for oneself); and grieving (realization that old patterns of perceiving are no longer relevant). When applied to the adult's dilemma, discernment results in both fundamental change in the adult's personality through the resolution of a personal dilemma and also new growth and understanding of "self" in relationship to the learner's world. This process of discernment allows for movement between the rational and the extra-rational, and this movement is one of the most vital components of the learning process in the life of an individual with MS. It allows the learner to recognize and develop an awareness of who they are and how they relate to others, which brings a greater appreciation for who they are apart from the social and cultural situations in which they are participating member (Dirkx 2006, 18).

## ***Theoretical Perspectives Guiding This Study***

### **Constructivism**

Not only is it important to know that this study will use Mezirow's transformative theory and Boyd's view on the important part that emotions play in the transformative process, but I must make my reader aware of two paradigms that will be the lenses or filters through which this research is viewed and disseminated. According to Denzin and Lincoln (1998), a paradigm is "a set of beliefs that guide action" (185). These beliefs form a worldview that impacts all relationships and actions. The first paradigm I will use in this research is a constructivist framework. It maintains that individual learning is affected by the surroundings, values and attitudes of the learner (Cannella and Reiff 1994, 32) and that learners are encouraged to formulate their own solutions and to try out these newly made ideas and hypotheses. Constructivism derives from the idea that each learner actively develops his/her own plan and course of action based on his/her existing knowledge (Kearsley 2007, 1). It seeks to explain how individuals adjust and refine knowledge, and in this paradigm meaningful learning is grounded in and determined by personal experience (Brown, Collins and Duguid 1989, 5).

The epistemological assumptions supporting constructivism suggest that the world does not support unambiguous "truths" independent of human perception, given to us through instruction; rather that the world is knowable only through the interaction of the knower and the experienced phenomena (von Glasersfeld 1996, 1). One of the assumptions of constructivism is that learning is the integration of individual understanding and negotiation with other individuals. Knowledge in the different disciplines is subject to change as different kinds of evidence are discovered and

members of the various communities debate about new ideas becoming part of the standard of truth.

All knowledge and actions are a result of the lived experience and existing internal knowledge of the individual, and it is the MSer's sudden realization that there is little or no previous lived experiences and existing knowledge from which to draw that forces the MSer to seek out information, knowledge and experience from individuals who belong to this community. This explains why this research is grounded in constructivism, because the newly diagnosed MSer's world will now embark on a journey that must include new experiences and knowledge produced by the influences of the culture. It will be developed, tested and redefined through growing participation within different communities of practice (Cole 1990, 106). It is vital that MSers eventually enter these communities in order to acquire the resources needed to successfully weave their way through the day-to-day struggles associated with MS through collaboration and problem solving, activities associated with this theory of constructivism.

Using a constructivist lens, the individual with MS would be an active participant in the creation and integration of new information. To not allow the MS patient to incorporate his/her thoughts and ideas into the learning process would be a great mistake. Learning activities in constructivist settings are characterized by active engagement, examination, problem solving and group effort with others (Educational Development Association 2001, 1). Given the fact that the effects of MS are never the same for any two people, the patient has no choice but to design activities that would fit and meet his/her particular needs.

This research study also acknowledges and brings to the table the demand for the respect for individuality. People are social beings who learn well through interaction with others, and learning increases when activities have meaning (Sadker and Sadker 1994, 372). It has been my observation and experience through the years that dealing with MS forces its host to seek relief from a multitude of symptoms in a number of ways that lead to the development of social virtues such as cooperation and tolerance. These help the MSer to become a more flexible and creative problem solver. By recognizing and seeking ways to accommodate the various aspects of the participant's own "individuality," this research will lead to what Boyd refers to as the expansion of consciousness that results in a greater awareness of "self" that is so vital to the well-being of the MSer and others who explore this research (Boyd 1989, 459).

### **Critical Reflection—Identification of Power**

Being a part of the MS community for a number of years has helped to make me aware of the fact that the exploration into just the physical and emotional needs of the MS participant would greatly limit the effectiveness of this research. In an effort to better their physical and emotional lives, the MS participant must navigate and function in a world where many individuals with whom they must go to receive help hold many assumptions and biases, which when demonstrated cause hindrances in the level of care received by the MSer.

A vital part of Mezirow's transformative learning theory is the use of critical reflection to identify and hopefully minimize the control other individuals and institutions have over the MSer's lived experiences, control that can bring direct positive and negative influence upon the goals, aspirations and livelihood of the MSer. According to

Mezirow, critical reflection refers to “challenging the validity of presuppositions in prior learning” and the “challenging the established definition of a problem being addressed” (1990b, 12). Other scholars offer more insight into the meaning of what it means to engage in critical reflection. Stein states:

Critical reflection is the process by which adults identify the assumptions governing their actions, locate the historical and cultural origins of the assumptions, question the meaning of the assumptions, and develop alternative ways of acting (Cranton 1996). . . . Through the process of critical reflection, adults come to interpret and create new knowledge and actins from their ordinary and sometimes extraordinary experiences. Critical reflection blends learning through experience with theoretical and technical learning to form new knowledge construction and new behaviors or insights (2000, 1).

Both Brookfield and O’Sullivan take this process further, stating that critical reflection should focus on “power dynamics and relationships” and seek to uncover “hegemonic assumptions” and “imperialism” (Brookfield 1987, 136–137; O’Sullivan 2002, 6). This research will incorporate critical reflection in my investigation into the lived experiences of the MS participants.

An individual with MS is reluctant to tell others of their condition for fear of the loss of acquaintances, friendships, misunderstandings, livelihood and labeling that results from making an announcement that you have a chronic and possibly disabling disease. It is quite common for the MSer to be thought of as an individual with an “undesired differentness” (Goffman 1963, 5), which moves the MSer from the position as a fully participating member of a community with all its entitlement into the lesser position that views the MSer as one who has “no abilities or social functions.” This makes it impossible for the MSer to continue as fully participating member of the community (Fine & Asch 1988, 12). This demotion in status in many cases then becomes a platform

for dominance over the MS patient. Dominance of one person over another turns impairment into disability (Kelly 2001, 396), which is why this study should explore the power dynamics and relationships brought about by this chronic disease.

### **Summary**

The purpose of this research is to examine how transformative learning takes place in the lives of participants who are members of the MS community and how these individuals reconstruct their lives after experiencing the day-to-day challenges brought about by this chronic disease. The goal of this chapter was to direct the reader toward an understanding of transformative learning as well as my need to demonstrate and include the importance of emotions in the ultimate outcome of this learning practice. Transformative learning theory explores how the adult acquires knowledge, grows and makes meaning through personal experiences, especially those infrequent experiences that create such personal turmoil that existing worldviews are shattered.

All research is based upon a variety of assumptions, which good researchers make known in their work. In this chapter I have also taken the time to briefly discuss my theoretical perspectives and the worldview that has influenced the creation and investigation of this study. This research is based on the underlying assumption that meaning exists within each person rather than in external forms such as the Internet, and that individual meanings attributed to experience are acquired and legitimized through human interaction and communication.

Not only have I presented the theoretical perspective but I have chosen to include my personal assumptions that helped to guide and direct this research. Realizing that the world of an individual changes dramatically after the diagnosis of one's having MS, I

have sought to understand not only the physical and emotional aspects of the living with this disease but also the vital importance to discover the changing power dynamics encountered by the MS patient. Some of the areas that are explored are the day-to-day interactions between employer-employee, the physician-patient and the family-friend.

The personal cost of living with a chronic and sometimes disabling disease is discussed within this chapter. Having a chronic disease not only incites havoc upon your physical body, it also creates at times the illusion to many outside the MS community that the MSer is no longer capable of being a fully functioning participant in their homes, communities and in the wider national and global world. In this section of the research I began to paint a picture that will bring resonance with individuals who find themselves in the clutches of MS and help to enlighten the non-MSer to the work that needs to be done to bring to light the socially accepted injustices and misunderstandings faced on a daily basis by those who are marginalized solely due to having this deplorable disease.

## **CHAPTER THREE**

### ***Methodology***

#### **Qualitative Method**

The overarching goal of qualitative research is to offer a perspective on a situation and provide well-written research that reflects the researcher's ability to describe the corresponding event. Researchers who use this method look for a deeper truth. They aim to "study things in their natural setting, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them" (Marshall & Rossman 2006, 3). This research should also take on "a holistic perspective which preserves the complexities of human behavior" (Black 1994, 425-6) leading to a richness and depth of explorations and descriptions characteristically found in qualitative research (Myers 2000, 1).

In an effort to find hidden truths, this study steps into the MSer's world and examines how transformative learning takes place in the lives of participants in the MS community. The goal and desire of this endeavor is to identify coping strategies and motivational factors influencing their transformative learning by examining the lived experiences, meanings and consequent changes this disease has made in the lives of the research participants. Answering these questions requires a research approach that not only allows me opportunities to examine in rich and open-ended ways the individual experiences of a group of people but also allows for the examination of their experiences within the contexts of their culture and communities.

In an effort to collect and examine the daily experiences of a particular group of people or individuals, many researchers use qualitative research, which includes

naturalistic inquiry, interpretive research, hermeneutical research, post-positivism and constructivism (Guba & Lincoln 1985, 7; Lincoln & Guba, 2005 1994, 191; Wolcott 2001, 5). Even though this research is given many names, the objective of this paradigm is to understand and describe the lived experience of individuals within a particular culture. This research paradigm has been found to be a powerful instrument that aides in the understanding of individuals in the social and historical context in which they live, work and play (Merriam & Associates 2002, xv). This research perspective will allow the researcher to focus on the “process, meaning and understanding” of the particular individuals and/or group under investigation (Merriam & Associates 1998, 8) and will result in a large collection of descriptive material that will lead to a greater understanding of the participants’ frames of reference and uncover unique interpretations of the meaning-making process. Patton states that qualitative research “is an effort to understand situations in their uniqueness as part of a particular context and the interactions there” (1985, 1).

This method helps the researcher to participate, to become more knowledgeable and to be better able to identify with the MSer’s experiences from the emic or subjective perspective (Patton 2002, 267). Denzin and Lincoln (1998) explain that qualitative research further by providing a flexible approach to investigation by allowing the researcher to:

stress the socially constructed nature of reality, the intimate relationships between the researcher and what is studied, and the situational constraints that shape inquiry. Such researchers emphasize the value-laden nature of inquiry. They seek answers to questions that stress how social experience is created and given meaning (8).

Because qualitative research is conducted in a many-faceted manner that incorporates an “interpretive, naturalistic approach to its subject matter,” the researcher may use various “interconnected methods” (for example, surveys and interviews) to obtain a better understanding and perspective on the subject matter at hand (Denzin & Lincoln 1994, 2).

## **Ethnography**

One of the methodologies that I will use in my study is ethnography. Ethnography is a form of qualitative research used by anthropologists to study society and culture (Merriam 1998, 13). Van Maanen defines culture as the knowledge held by participants of a particular group that is thought to enlighten, influence and account for their social actions (1988, 3). Ethnographers strive to show how some aspect of one culture makes sense from the perspective of another culture. According to Merriam (Merriam & Associates, 2002), “ethnography is not defined by how data are collected but by the lens through which the data are interpreted” (8). Because cultures cannot be understood by simply being “seen” through the eyes of the researcher, the researcher must interact with those being researched and “move from the role of inquirer to that of participant” (Stocking 1983, 93).

All ethnography begins with the same general query: “What are the cultural meanings people are using to organize their behavior and interpret their experience?” (Spradley 1979, 93). Cultural knowledge is more than a collection of objects or events that refer to something; it is a system of knowing and attaching meaning to objects or events in a way that interrelates to other meanings within the culture. Ethnographers do not simply interpret one culture’s meanings; they also redefine and rename them for another culture through written representations taking extreme care to see that these

representations are the views and ideas of the group being examined (Bishop 2000, 124). The mere manipulation of data associated with ethnography (for example, field notes and interviews) does not result in an ethnographic study unless there is a cultural interpretation of that data (Merriam and Associates 2002, 236).

### **Critical Ethnography**

“Good ethnographies show the hand of the ethnographer” (Altheide & Johnson 1994, 493). Ethnographies emerge out of a relationship involving the ethnographer, the individuals within the cultural group being studied and the intended audience. As the ethnographer, I bring to the research my experience of living with MS for more than 25 years as well as my values and beliefs. Also incorporated in the study are the experiences and beliefs of a group of men and women who all share the experience of living with this neurological disease, and much thought and consideration was given to the audience for whom the research was written. Ultimately my responsibility is to present this material in such a way as to create a clear, precise description of this experience that will lead to an accurate and meaningful interpretation of the journey for all who take the opportunity to read and muse over this research.

Ethnographic research is a many layered process of “mediating frames of meaning” (Giddens 1976, 10). The investigation of a culture is the cornerstone of this type of research, but a more recent approach to this ethnography is called “critical ethnography, which investigates how the strictures caused by hegemonic powers with value-laden agendas” (Merriman & Associates 2002, 236) effect and interplay with the “historical, social and economical situations” of a particular culture. Critical ethnography seeks to shed light on the “unfairness or injustice within a particular lived domain”

(Madison 2005, 6) by examining the status quo and the taken-for-granted assumptions which entrench a particular group of individuals. It brings to light the hidden operations of power and control that adversely affect or influence the group's well-being physically, emotionally, socially and/or economically, resulting in a diminished degree of personal and collective freedom and equality (Denzin 2001, 155; Thomas 1993, 47).

It is my intention in this study to use critical ethnographic principles to examine and explore the powerful underlying forces faced by MSers in an effort to bring understanding, importance and validation to the views and experiences of those in the MS community who feel that their lived experience is of little worth to themselves and others. The development of "how power operates, of how social, political, and economic life is structured" is vital to the development of workable strategies and procedures through which "existing discourses and institutional structures can be restructured, if not revolutionized" (Inglis 1998, 2).

Being a part of the MS community for a number of years has helped to make me aware of the fact that the exploration into just the physical and emotional needs of the MS participants would greatly limit the effectiveness of this research. It is my desire to understand and describe a social and cultural scene from the insider's perspective of the daily lives and experiences of the MS community.

The MS participant must navigate and function physically and emotionally in a world where many individuals to whom they must go to receive help hold assumptions and biases that, when demonstrated, cause hindrances rather than help in the level of care received by the MSer. For example, most MSers want to continue to live life to the fullest, which usually includes some type of employment; yet some individuals with MS

find it necessary due to the effects of this disease to apply for disability status in order to better cope with the ongoing MS issues. Although other well meaning individuals in society feel that disability income is a help and charitable act, those who do receive this income soon come to realize that due to limitations placed upon the MSer, the acquisition of more income becomes an impossibility and the MSer finds him or herself at a standard of income near or below the poverty level with no recourse. So the very laws and institutions that purport to help the citizen in need actually cause a great deal of confusion, disillusionment and difficulties for the MSer.

It is very important for individuals with MS to realize that their feelings and experiences are valid even though those without the MS community do not give credence to their plight. Critical ethnography seeks to shed light on the “unfairness, or injustice within a particular lived domain” (Madison 2005, 6) by focusing on power dynamics and relationships of a particular community in an effort to uncover hegemonic assumptions affecting the MS community. The possibility of losing the ability to participate fully within one’s established community is very disturbing but it is more troubling to find that one’s participation in society is entirely predicated upon the possible misconceptions of individuals and organizations often not familiar in any way with your personal or professional situation. In a world that often expects individuals to live and function within very well defined parameters of expectations of what is normal, the MSer is often viewed as an object to be examined and studied rather than an individual who is fully capable to participate in their community and world turning their possible impairment into a disability. In many cases the MSer’s perceived disability leads to the intrusion and dominance of outside forces upon every aspect of their lives. Every individual in the

study has his or her own social history and an individual perspective on the world. Thus, I cannot take my task for granted. Humans are complex, and their lives are ever changing. Understanding how they construct their lives and stories is priceless.

### ***Participant Profiles***

A nonrandom, purposeful sample of 10 adults with MS were selected from among 25 prospective survey recipients who responded to an announcement placed in the Multiple Sclerosis Newsletter, *MS Connections: All American Chapter—West Virginia Division*. The newsletter was published and sent out in Fall 2006, and requested participation in an upcoming research project conducted by myself. It would explore the transformative learning process of individuals living with MS, address issues faced by the acquisition of this disease and discuss the ensuing challenges that have and continue to be a part of the MSer's lived experience (see Appendix B, Invitation to Participate).

The participants in this study range in age from 40 to 74, and all were diagnosed by their family doctor or neurologist to have MS. The length of time they have had the disease in this study correlates with the pronouncement by their doctor. This is important because many MSers usually can trace having the disease to times that are quite a bit earlier than their official diagnosis, which at times leads to a distortion in the actual recollection of an exact date due to the “coming and going” nature of this disease.

The mean number of years of living with this disease by this group of participants is 17 years. This allowed enough time for the MS patient to come to the realization that they were dealing with an ongoing and at present incurable disease. It was my intention not to interview members of this community who were newly diagnosed, given the fact

that one of the goals of my research was to determine how well the MSer has accepted and adjusted to a life with MS.

The 10 participants in this study were all unknown to me before becoming part of this research, and I will introduce each of them here. I used pseudonyms in order to protect their confidentiality. Cathy, a Caucasian woman, is 53 years old, married and at present has been living with the effects of MS for 18 years. Presently, one of her most difficult challenges is getting around due to her difficulty to control her right leg and balance issues that require assistance. She holds a bachelor's degree and teaches various courses at a local technical school.

Donna, a Caucasian woman, is 41 years of age, married and at present has been living with the effects of MS for 15 years. Presently, one of her urgent challenges is her need to acquire and install handbrakes in her car so that she can get around more freely in the community and lessen the fatigue she quickly experiences while driving. She holds a bachelor's degree and is the director of a local religious charitable organization that assists families in need.

Brenda, a Caucasian woman, is 59 years of age, married and at present has been living with the effects of MS for 25 years. Presently, one of her urgent challenges is her inability to get around due to weakness in both her legs for which she tries to compensate by having numerous chairs in strategic locations. She holds a bachelor's degree and is the owner and manager of a retail business.

Dick, a Caucasian man, is 55 years of age, divorced and at present has been living with the effects of MS for 11 years. Presently, his biggest challenges are fatigue and not

succumbing to the effects of the heat brought about by the season's higher temperatures. He holds a bachelor's degree in science and is on disability due to MS issues.

Danny, a Caucasian man, is 54 years of age, married and at present has been living with the effects of MS for 30 years. Presently, his biggest challenge is dealing with upper body weakness that is further hindering his mobility. Danny is wheelchair bound. He holds a bachelor's degree and a CPA Certificate, but because of this disease is disabled.

Connie, a Caucasian woman, is 74 years of age, married and at present has been living with the effects of MS for 44 years. Presently, one of her biggest challenges is mobility because of muscle weakness in her legs. She uses a walker to get around at home and in the community. She has a master's degree in library science and is presently retired.

Kate, a Caucasian woman, is 51 years of age, married and at present has been living with the effects of MS for 6 years. Presently, her biggest challenge is her eyesight, which could be an issue in successfully continuing her career. She has a 2-year Associate Paralegal Degree and is an elected official who works in a courtroom setting in a country in the state of West Virginia.

Doris, a Caucasian woman, is 68 years of age, divorced and at present has been living with the effects of MS for 8 years. Presently, much of her distress arises from vision difficulties brought about by the disease. These difficulties are magnified by the fact that where she lives there is no public transportation and her home is located in a small mining town. She has a bachelor's degree in science and headed up construction

sites until her forced retirement at the age of 59 because of MS issues. Doris is now disabled.

Jane, an American Indian, is 50 years of age, married and at present has been living with the effects of MS for 10 years. Presently, Jane feels that her disease is stable and giving her little, if any, difficulties in her daily life provided that she plan for extra rest when busy days are on the horizon. She has a high school degree and is working as a secretary in a legal office in a small community in West Virginia.

Nancy, a Caucasian woman, is 52 years of age, married and at present has been living with the effects of MS for 3 years. Presently she is battling depression and extreme fatigue, which she believes may affect her ability to continue to perform as she deems necessary in her demanding biology classroom. She has a doctoral degree in biology and carries a full teaching schedule at a local university.

### ***Ethnicity***

All participants in this study were initially were located by their responding to an advertisement put in an MS magazine that went out through the entire state of West Virginia. All the individuals that responded to my survey identified themselves ethnically as Caucasian or American Indian/Alaskan Native. These study participants are consistent with the demographics found in the state of West Virginia.

### ***Data Collection***

All participants in this ethnography study were initially part of a larger investigation created by me for use by the local and regional MS Society that explored the availability and lack of necessary resources needed by the MS patient throughout the state of West

Virginia. Included on the last two pages of the survey (see Appendix C, Participant Survey/Personal Reflection) were four questions regarding the changes the MS patient made to cope with the daily lived experience of MS. These questions were an effort to identify individuals that seemed to have had demonstrated some degree of acceptance and change in their outlook on life from the daily experience of living with MS. These individuals were contacted by email, snail mail or telephone and asked to participate in the next phase of the study, making it clear to them that this study was in no way associated with the Multiple Sclerosis Society.

Out of the 25 who answered the original surveys, 20 were asked to continue in the next phase of the study, which consisted of a personal interview in their home, with the exception of one interview that took place in a secluded location at a local restaurant in order to get insight and understanding into the physical and cultural surroundings experienced daily by the MS patient. From this group of 20, two did not wish to participate due to pressing health issues, one participant moved to another state without supplying forwarding information and seven other invitees chose not to respond to my invitation to participate.

### **The Survey**

The survey used to identify individuals to participate in my transformative research was used originally as a survey that I created in an effort to help the local and divisional chapters of the MS society identify the availability of community resources and the present and future needs of MS patients. For the purpose of my research I incorporated a total of two sections of this survey: the socio-demographic characteristics

and the personal reflection sections, both of which account for 13 questions from the entire survey (see Appendix C).

## **The Interview Questions**

The main data collection method I used in this study was interviewing. Arkinson and Silverman (1997) believe that “the open-ended interview” offers the prospect for a genuine look into the “soul of another” (305). In-depth interviews should closely resemble conversations and are a useful way to get large amounts of data quickly (Wolcott 2008, 55). I found that individual interviews allowed me to get immediate clarification and follow-up that helped to enrich my study. An interview is a relationship where two share “reciprocity” of perspective where the interviewer and interviewee create a “we” relationship (Seidman 1991, 7). Warren (2002) notes that during an interview, the “interviewer and the respondent dance together for the moment in social space, backward and forward in time” (98).

Interviews were conducted with 10 persons with MS who had previously participated in a survey created myself to assist the local and divisional chapters of the MS society. The semi-structured interview questions examined the transformative learning process of the individual with MS. I tape-recorded all interviews, explaining to the participants in advance that the interviews would be taped. The interviews lasted an average of 2 hours in length. I usually began by asking how long the participant had been diagnosed with MS and then proceeded to discuss in-depth the following overarching topics:

1. How do you make meaning out of the diagnosis of MS?
2. What factors were influential in your understanding and coping with this disease?

3. In what ways do subsequent life experiences alter the perspective transformation that resulted from the your diagnosis of MS?
4. What factors have hindered your ability to deal effectively with MS?
5. What role did relationships play in your transformation?

To generate dialogue, open-ended questions were created and asked in various order depending upon the direction of the conversation. Under my overarching themes listed above I created anywhere from two to six open-ended questions that sought to draw out rich understanding and the topic of discussion (see Appendix D). Additional questions that were not previously created before the interview were asked when it helped to explain or bring about richer meaning to the interviewer and interviewee. At times, I asked questions that sought to explain a participant's facial or nonverbal gestures in an effort to get clarification or further insight into the depth and amount of discomfort or struggle associated with a particular line of conversation.

### **Transcription**

All interviews were audio-taped with the participant's consent. Transcription of interviews has become the norm in qualitative research (Sandelowski 1994, 704). The audio-taped interview was transcribed into written form. MacLean, Meyer and Estable (2004, 113) believe that how content is heard and perceived by the transcriptionist and the accuracy of the transcription play a vital role in determining what data is analyzed and the degree of dependability. As the researcher I must make a thorough and systematic review of the transcribed material to ensure quality analysis of my research. Johnson (2002) stated that the best ethical advice when interviewing is the "imperative to tell the truth" (116).

## ***My Role as the Researcher***

My role as the researcher is multidimensional. How one copes and overcomes the everyday stress and strain of living with the incurable disease of MS is a very dear topic of investigation for me. As an MS patient myself, I know first hand the many times I have had to push, pull or tug, reaching the point of exasperation, just to do things and complete tasks that the “abled” individual does with little effort. Lived experience within the MS community makes this research a very personal endeavor. Researchers Denzin and Lincoln seem to agree with me by suggesting that “all research is interpretative and is guided by the researchers feelings and notions about the world and how it should be understood and studied” (2000, 22). This being said, I believe it is impossible to fully remove my influence from the research study because as the creator of this material, my own beliefs and values are reflected not only in the choice of methodology and interpretation of findings, but also in the selection of a research topic. In other words, what I believe to be relevant, important, informative and needed will influence, if not, determine what is to be studied.

Traditionally we as researchers have been persuaded to entertain the notion that what we are studying has no personal significance, or that the only reason motivating our research is intellectual curiosity (which is a valid reason on its own). But when we critically reflect upon our motives, more often than not, we have our personal beliefs and views about a topic—either in support of one side of the argument, or on the social, cultural, political subtexts that seem to direct the development of the argument which ultimately will find its way into that research.

To be critically reflective in my opinion is more than just me casually looking over the material in this study. This type of reflection views thoughts and actions with the express purpose of changing society. This research is an endeavor to bring understanding, reflection and most definitely positive change to all who participate in any way in the lived experience of the MSer.

Brookfield (2007, unpublished class lecture) stated that the primary goal of critical reflection is the “transformation of society, not just the transformation of ideas, [we] must strive to bring about social transformation and the reduction and elimination of human misery”. Critical reflection is more fully explained as “the ability to recognize and then confront and change the process by which society uses prevailing ideology to convince people” that something should be accepted and not questioned because it is a “part of the normal state of affairs” (Merriam & Caffarella 1999, 282). By my becoming more aware of these ideologies, I desire to help not only my learning community but also others to see how they too are so strongly influenced and manipulated by power, hegemony, language and the status quo of our society.

Making marginalized persons aware of these strong influences must now take on a greater role in my sphere of influence. Transformative learning has both “individual and social dimensions and implications . . . demands that we be aware of how we come to our knowledge . . . [what forces] support [and] often conspire to foster conformity” (Mezirow 2000, 8). Applying the principles of critical reflection to my lived experiences has helped me to realize that many of the ways that I perceive reality has been greatly influenced and unconsciously shaped by dominant forces in the society in which I live, and it is that very

culture that seeks to label and at times hinder the MS patient from becoming an accepted and successful member of their community and society at large.

Scheurich (1994) remarks that historical position, economic status (which may or may not include changes over the course of a lifetime), race, gender, religion, and so on act together to sway, limit and constrain construction of knowledge (19). In other words, who I am determines, for the most part, what I want to study. To take this thought a little further, my changing self in relation to my career choices will continue to influence me in the selection of research topics (Mehra 2001, 73). I believe that researchers choose to study a topic because they see a “personal connection” to it at some level, either as a practitioner in the field or as an individual. Research should resonate with who you were, who you are, who you want to become, what you did in the past, what you do now and what you want to do in future. We only change what we are passionate about and we become true researchers when we begin to question what we know and what we believe.

### ***Managing and Analyzing the Data***

As the researcher I strove to incorporate a number of methods in order to obtain the true feelings and views put forth by my participants. First, I listened numerous times to the taped recordings of each interview, making sure that there were no differences between the recording and the transcribed copy. Next, as the researcher I followed up with the participants of this study in order to confirm or clarify the statements made by the participants of this study. Then I uploaded the recordings into the files of the software entitled *NVivo* in order to locate themes within my collected data. I continually examined, reexamined and compared the data from a number of different sources (interviews and

earlier surveys) in an effort to get a clear, unmistakable picture and understanding as to the meanings and implied meaning of the data.

Themes were identified by my personal readings of the interviews and with the help of the software program, *NVivo*. By taking the time to reflect upon my impressions and recollections of the interaction between me and the interviewee, the result was a greater identification and understanding as to the strongest themes that existed throughout the interviews. This gave me a level of identification that I felt was not entirely possible with a software program. As a longstanding member of the MS community, I felt that it was necessary and possible to identify with and place myself alongside my participants in order to get a more enriching view of the MSer's emotional aspects of their lived experiences, which led to a better identification of themes associated with this research. The recognized themes and responses were examined in light of the research questions identified at the beginning of this research study.

### ***Summary***

In this chapter I have identified the design and presented the foundation of how this research study was conducted. I have discussed the rationale for the qualitative direction of this research and have laid the foundation of how this research study was conducted. This chapter further explained the ethnographic lens used throughout this work, introduced and discussed the criteria for the selection of the participants in this study, laid out the data collection methods and clarified my role as researcher. I have also explained the management and analysis of the data. In the next chapter I discuss the findings of this research study.

## **CHAPTER 4**

### ***Findings: Meaning-making, Coping Strategies and Relationships***

#### ***Introduction***

Given the voluminous nature of material gathered during the interview process I have presented the findings in the following three chapters in an effort to organize the information in a logical and understandable format. These findings are a result of the interview process carried out in this research and represent common themes across most research participants.

#### ***Research Questions***

The purpose of this study was not only to examine how transformative learning takes place in the lives of participants who are in the MS community but also to draw along side to understand and become a part of the lived experience of the individual who has been diagnosed with the disease of MS. If this is accomplished it will lead to a better awareness of the struggles associated with living in a society that places this community of individuals on the margins and edges. Here I describe, in depth, the interviews and the insights offered by the participants in this particular MS community.

The interview questions cover five topics: the meaning making process, factors that were influential in the participants' understanding and coping, the subsequent life experiences that have altered the participants' perspective, the factors that have hindered the participants' ability to effectively cope, and the relationships of MS participants.

## How do participants make meaning out of the diagnosis of MS?

To begin to understand the members of this community, it was important to obtain an overall view of the participants' lived experiences. In an attempt to find this answer, the participants were asked to explain what being diagnosed and living with MS means to them physically, emotionally, socially and spiritually. Many within this community chose to refer to what they have *lost or given up* as a result of MS in response to this question.

### *Physical Aspect*

Brenda did not talk about her physical difficulties in response to this question; she talked in terms of which activities she could no longer participate in as a result of her struggle—

*To go ahead and be on—in—all the associations I was in, the boards that I served on. Because no one can go with me. And so when I'm by myself is my worse time.*

Connie, like Brenda, spoke of things she could no longer do—

*It was really bad and depressing because my first husband was very athletic and we had just bought new bicycles, and I could no longer balance on the bicycle. And he was an avid hiker and I could no longer hike. And as a young girl, I was never very athletic, but the one thing I could do was run and walk fast and all of a sudden that was all gone.*

Cathy opened up this discussion with the statement that she had lost a great deal and then preceded to talk about her experiences—

*Just to think about where you're going on vacations because I can't walk long distances. Just going in an airport . . . You can't travel.*

Dick loved to run but the clinic said he would not be able to keep up his vigorous running routine. But Dick was not convinced—

*I had to give up a lot of things that I like to do, but even the things that I should be doing, work was going downhill. And of course, that got to me. When I went to this clinic, they diagnosed me, they went over my whole exercise routine, and they said, Do you know what you're doing? Because you're exercising way too much. And I said, and of course being in denial as well, I said, I'll be able to get back into it soon. And they said, No, you're not going to ever be able to get back into it. They said, you need to cut way back. I had to give up running. I had to give up skiing. But I can travel.*

Danny, who must use a motorized wheelchair at all times, had this to say about his physical limitations—

*I used to like to ride bikes and run. Most of the stuff I used to like to do were outdoor activities. Until they make one of these [a wheelchair] that's a four-wheeler, I'm sort of limited there.*

Even the little things must be considered for Nancy—

*In a sense. There's some things that I . . . I'm not good on high heels anymore. So certain things that I have to dress up for, I'm very judicious as to what I accept. I have to cut back on that.*

### ***Emotional Aspect***

Emotions play a very important role in the life of the MSer. The MSer's lived experience in this research seems to reflect a continual struggle to balance the positive and the negative sides of the mysteriously unpredictable course of this disease.

Brenda must be careful to work her daily plan in order to get a good night sleep—  
*Because I was the most independent person in the world, I was raised to be very independent. Now my state of mind, when I'm by myself, is when I have my grieving time over the life that I lost. My mind is my worst enemy. I don't go to bed until I'm ready to fall asleep. There's no just—there in the bed and just think.*

Cathy looks at the bigger picture when she thinks about living with MS—

*Twelve people have something worse than you do. No, I have no—I'm very blessed. Very, very blessed. Every now and then you get tired and you're worn out with it all and you just have to count your blessings and that's how you face that? Start saying the things you have.*

Danny even after thirty years still remembers the day his coworkers were told of his having MS—

*That was a very sad day in my life. I remember going back to my office crying. And the people I worked with told me about one of my fellow workers who had MS. And we became good friends, or I became good friends with this guy. So whenever I called him I told him I had joined his club. Of course, he didn't have any idea what I was talking about. He said, what do you mean? I said, I just got diagnosed with the same disease you have. He says, Oh no. That was what he said. So that was a . . . Well, that was the start of my depression. You're starting with . . . you're taking a person that's totally active and telling them they can't be active anymore. Yeah, that's hard.*

Danny goes on to talk about his more recent difficulty of getting a handle on his emotions—

*It's been tough. But you just have to suck it up and keep going. I've found that one of the problems I've run into with—and I assume MS is causing it—is that I'm more emotional than I used to be. Watching a movie on TV or something like that, I'll get all teary-eyed and I never did have that. And I've read that that's a possible thing that MS can cause. But as far as the relational aspect of it, I've sort of got by that. The first 10 or 15 years I had it, you've just sort of got to accept it.*

An attempt to connect with other MSers during Kate's early years living with MS brought her emotionally face-to-face with her possible future —

*I tried going to a support group. I went twice. And the second one I went to I was so emotionally beat up by the time I got out of there, and I beat up myself because when I got in there, I felt so guilty because there was people with braces on their legs or people that couldn't swallow or had vision problems or were in a wheelchair or had the arm braces on and here I bounce in and I go hey, let's get this party started, oh, my God, I feel—I felt very guilty for doing so well. I felt, and I said, I can't go back there. It made me feel, it made me feel depressed. It was sad. I didn't know how to cope with that.*

Even though Nancy had no control over her being diagnosed with MS, she still can't shake the feeling that she was partly responsible for her husband's health issues—

*I feel guilty unburdening myself to him because I believe I contributed to his heart attack. I know that's an emotional response. It was going to happen. I realize that. He has a lot to bear, but his personality is, he never wants to be left out of anything.*

### ***Social Aspect***

Failure of the society to include or integrate the MSer usually translates into the loss of or difficulty to access a place in society. This leads to the ultimate marginalization of the individual with MS. While most of the participants in this research spoke with sadness about the abilities they lost, they were just as quick to point out that there are still ways to successfully participate within their communities.

Brenda pointed out that she has limitations, but notes that with the help of her daughters she can continue to go on the quilt trips that she loves—

*I can't go on all the trips I used to go on so one of them has to go with me. So I know my limitations—and they know not to ask me to do anything. They'll go ahead and do it behind my back. But they know not to help me unless I ask.*

Cathy cannot do the things she loves when her friends do various types of physical activities, but that does not mean she has to stay home—

*Our book club went on a two-day hike and we stayed in a stop. Well, I went but I stayed and read a book while they were all hiking. And I'm a hiker. I would have wanted to do that. That was hard.*

Dave is quick to point out that he is now comfortable with his social difficulties; people just need to get over it—

*It's like, Hey, I've got these limitations and if you can't accept those limitations, I don't need you as a friend. I've come to accept that and it's not a problem for me anymore. Well, that makes for sometimes a limited supply of friends. Fortunately, my limitations aren't as much as some other people.*

Donna is still struggling with how to deal with the unexpected difficulties brought about by MS in an unfamiliar place—

*It's terrifying going to a place you don't know, you don't know how to navigate.*

*But then if I don't walk very well and, you know, I just think of those things and I don't know—I'm not sure how to get over that.*

Socially Danny didn't feel he wanted to face the unknown and possibly scary reactions he might receive when his coworkers found out that he had MS—

*I didn't really tell anyone at work until the deficit got so bad that there was no question I had something wrong. And that was only probably 2002 that it started getting that bad. So prior to that I didn't really say anything to the people at work and that was because for one thing, I didn't want them saying, poor old Danny.*

### ***Spiritual Aspect***

When an individual learns that they have a MS, often they see this diagnoses as a time to look within and ask deep and often confusing questions. It is an opportunity to clarify values and discover who you are and what makes you a unique person. It is also a time when some MSers attempt to answer the question, “why me?” Some of the participants in this study found that it was necessary to explore this issue; others felt that what they deemed as a spiritual aspect of disease management unnecessary to their coping strategies. Others expressed that they were uncomfortable addressing this issue.

Connie did not take the time to explain how or if she relies on a spiritual source within or without to cope with her 44-year battle with MS. Instead she talked about how MS alone helped her come to a decision about her future—

*People that claim to be spiritual or spiritually minded aren't being the kindest people. I would wish for them to be. Especially since they are Unitarian Universalist, but . . . Well, it's certainly changed my view of death. I'm no longer afraid of death at all. Death can come at any time. It won't bother me. What I am afraid of is not being able to take care of myself. Much rather pass on versus live in a state of . . . with that much help and inability.*

Dick did not feel that spiritual acknowledgement played any role in his lived MS experience—

*I'm a very scientific person. And I have a perfect understanding of evolution and of humans and religion is not a part of it.*

Donna places great importance on the strength her spiritual outlook to bring comfort and understanding to her life with MS—

*I try to be as more optimistic. I think my faith helps a lot. I was a spiritual person before, but I do think it does sort of cause you to rely on your faith or I do rely on God and think about—I never was, I never questioned like why, or why me, because I don't think of that luxury or should even do that because why should it be somebody else or why should it be anybody, you know. I don't know that, I just don't have that thought that way of—I don't understand a lot of things like disease and, you know, injustice and things, but—so I have questions, but I don't really think, it's not about me, you know, either.*

Danny states that connecting with his spiritual side helps him to get a perspective that motivates him to endure the difficulties he faces on a daily basis—

*It's not that I don't talk to God. I've still got my problems. A lot of times I'm just thanking Him, simply because there's other people worse off than I am. But there's also times that I've cussed him. The way I look at it is, God's not going to give you any more than you can handle. I sort of talk to God more than I used to. I don't really go to church anymore. I used to. But it increases my spirituality I guess if you want to call it that.*

Doris's faith helps her to accept and not question her MS diagnosis and struggles—

*I'm LDS—I'm a member of the Church of Jesus Christ of Latter Day Saints and when I was being taught about the church, one of the things a missionary said was that before we were born we knew the kind of problems we were going to encounter. And we chose to buy into them and to come to this earth in a body, do what we had to do, learn. I look at coming from the preexistence to earth how can I get upset about my problems. I knew and agreed.*

Jane's spiritual awareness brought a mixture of blessings and struggles—

*I felt like a failure to God, too. I was trying, trying, trying so hard. I would recite that Footprints story to myself so often and say, I know that this is when I'm being carried. And I didn't feel like a complete failure just because of that. It's just that I was leaning very heavily on my Christian faith. If I were not raised a Christian, I wouldn't be here right now. That's how desperate I felt. It's not necessarily that I would have done something myself. I wanted to die. I wasn't necessarily going to take the steps to do it, but I really gave it thought. And I have not admitted that to—I think, I admitted it to my husband one time. Because when I was at my lowest I wanted to die.*

After seeking to get the overall view of the participants lived experiences in order to discover how the participants derive and make meaning out of their MS diagnosis, this study sought to identify and understand in what way they perceived that they have *changed* as a result of having to deal with the physical, emotional, social and spiritual side of having to live and deal with MS. The questions asked was: How do you compare to yourself to the person you are now with the person you were before being diagnosed and living with MS?

This question was answered by some participants and ignored by others. Most all the individuals that did choose to answer this question spoke in terms of what they lost and how what they have done to compensate with their loss.

Brenda answered this question by not only identifying what her passions are but also includes the steps she has taken to adapt—

*It's the thing I can do on my own [go to quilt retreats]. But I always make sure there's at least one or two people that's known me for awhile or that has somebody in their family that has MS or something so when I need help, they're there. I plan everything out. It's not spontaneous anymore. To jump in a car and say, Well, I'm going to the mall. Everything's planned.*

Cathy takes the time to explain the type of life she had before she experienced the effects of MS and then tells how she still tries to do some of the things she use to do—

*You know when you first get it you go, Here's what they say is going to happen, but I'm not going to let that happen. But how . . . has it really changed your life dramatically? How has it changed it? It's just emotional. You just mourn the loss. Being that very active person that I was. I pulled out a running calendar the other*

*day and I was running 26 miles a week. I was doing some things just recently. I was swimming on Sundays. And I really like that. I meet a friend over there. And they were doing yoga down at the church so I did that. And this particular year school started to catch up with me, so I haven't done as much.*

Donna states that her struggles with this disease has made her a stronger more assertive individual—

*I think that I just kind of try to just have more power as a person and not be afraid of other people, or maybe afraid is not the right word, but you know, intimidated or try just to be more powerful and that, you know, who I am and be okay with, try to be okay with that.*

Donna also feels that this disease limited her future employment plans and would certainly guide her future employment choices—

*I might have gone back to school or felt like I had more energy to do that. I may have gotten more education in something that I'm interested in, but, I don't know if I would have really, you know. There's certain things I know I couldn't do, standing up even. I couldn't be a nurse. I don't want to be a nurse, but I couldn't be a, I would like a nurse practitioner or physician's assistant or something, but I don't think I could stand that long. I couldn't be a teacher. I couldn't be, I know—I feel like God's put me where I'm supposed to be for a reason.*

Jane, who by her own admission has experienced few long-term effects of MS, stated—

*I can't really see where it's changed me a lot except that I'm taking the medication, and that's not really a big deal.*

The second overarching question in this study examined the influences that played a part in the coping strategies of the MS participant. The question was:

**What factors were influential in the participants' understanding and coping with this disease?**

Through discussions with the MS participants this question went in three unforeseen directions. A couple of the participants chose to point out that what helped them grow in their understanding of the disease derived from the reality that they could no longer do some of the activities that brought them joy and a sense of fulfillment in life, things I have identified as “life style choices.” Secondly, all the participants felt it necessary to discuss what I have called their “journey to diagnosis.” All had very strong feeling on this subject. In fact, no one refrained from dialoging about this topic. Each participant felt that this story and/or topic must be told in a effort to make “outsiders” not only aware of the difficulties at the beginning of this lifelong struggle but also demonstrate that they were correct in their choice to push on to eventually receive the conformation of their suspicions. To tell their story seemed to bring validation to their lived experiences. The last direction of this question spoke to the large role stress plays in the life of the MSer; I have simply labeled this as “stress” later in this chapter.

***Lifestyle Choices***

Brenda said that she knew things would never be the same when she could no longer share her expertise with the students at a local high school—

*I choreographed a majorette chorus. Believe it or not, I was an award-winning twirler for [a local high school]. I taught twirling. And there was so many things I*

*did and now having to ask somebody to go out and get something for me on certain days. Yeah. I was raised as an independent person.*

Connie's realization came when it became apparent that her plans for a future family had to change—

*I would have had children sooner and maybe tried to have more children.*

Danny love for the outdoors had to be modified due to accessibility—

*I used to like to ride bikes and run. Most of the stuff I used to like to do were outdoor activities. Until they make one of these [wheelchairs] that's a four-wheeler, I'm sort of limited there.*

Cathy is at the point where she must choose where to invest her time. MS is making it difficult to do everything she would like to do—

*My sister-in-law doesn't work and she said on Friday they were going to do this and on Saturday they were taking ballroom dance lessons, on Sunday they were going to meet her son at his college for a basketball game. And I thought, Wow, she has the energy to do all of that? So maybe I have my priorities mixed up. So I'm kind of in the process of re-evaluating . . . I have to take care of me.*

### ***Journey to Diagnosis***

The entire group of participants in this research expressed a sense of relief once they finally received the news from their attending physician that they had a definite clinical diagnosis of MS. For these participants, the struggle to obtain a concrete diagnosis of MS was a long drawn-out process of elimination due to a number of factors, ranging from the elusive nature of the disease itself and the availability of diagnostic equipment. In this community the MSer had to interact with a number of doctors in order

to establish a diagnosis of MS, and along this journey there was nowhere to turn even for temporary relief. Often the MSer was left to his/her own devices to cope alone with the disturbing symptom that brought them to the doctor in the first place, hoping to find help at their next appointment with a new physician.

Early multiple sclerosis diagnosis is especially important because early treatment can help slow the progression of the disease. In fact, early treatment can help even without visible symptoms of multiple sclerosis. That's because the disease often progresses silently, causing nerve damage before you're even aware of any problems. One of the few options used to diagnose this problem involves the use of a Magnetic Resonance Imaging (MRI) machine. It creates a magnetic field to create "cross-sectional images or scans" of the brain and spinal cord. These scans reveal damaged myelin and scar tissue associated with this disease and can eliminate the prospect of the patient having a number of other neurological disorders and diseases (MSActiveSource 2008). Yet some of the newly diagnosed MS patients in this research still stated that they had difficulty getting their physicians to have the test performed at their local hospital, citing that their symptoms could possibly be from other causes.

Even though this statement may be plausible to individuals outside of the MS community, the fact is that most MSers, in an effort to bring understanding to their puzzling journey, usually over time go to a number of places (libraries, the Internet or other MSers) to find an answer to their problem. This diligence often results in the patient's own confirmation of having MS long before the physician makes the diagnosis. Armed with this knowledge, many prospective MS patients try to make a case for an MRI

scan, only to have their suspicions dismissed or ignored by the attending medical professional.

The participants in this study look back on these experiences with the medical establishment as extended times of unnecessary stress and cruel, unfounded questioning about their mental stability, all in the quest to understand their physical condition. This was the case for most of the eventually diagnosed MSers in this study; the physician and office staff were viewed as obstacles to the patient's care. Most participants in this study expressed an overwhelming sense of paternalism and disempowerment when in the doctor's office. Interactions with the physicians and their staff are one of the most often cited instances in which the MS community's voice is often dismissed.

Brenda, a local shop owner and civic activist, spent a number of years going to various doctors only to receive any number of other reasons for her difficulties. She began telling me about her struggles and frustrations—

*I have been diagnosed with everything. You have this, this, this and not this, this, this. So I then would wait—okay, I found an answer to my question until I would go to the next doctor. So every time they'd tell me I had a disease, I would go into the library and do some research on it. Anyway, that's how I found out [I had MS]. All the diagnoses and everything they gave me and all the different diseases—I became very anxious. Now I still have anxiety attacks.*

Now through her personal research she had a disease that she thought fit her experiences, but the steps to diagnosis meant—

*Finally, I lied to the doctor. I told him I was having violent headaches; I didn't know what I was doing. I couldn't see. So that's when she sent me to a neurologist*

*and they did an MRI. And that's when I found out. That's how I did. That's the only way I could get them to do an MRI. So I lied. Well, sometimes when there's a will, there's a way. When you want to know something. Because I had done so much research that an MRI would tell them—they would see it on an MRI. But I had to have a reason for them to order an MRI.*

Similarly, Donna who directs and leads a community organization that helps to feed and clothe needy families in a small community found that her experience to get answers for her vision problems received belittling remark and tone—

*I lost the vision in my left eye, and it was a total loss for a couple of weeks. I just went to one eye doctor and the man was like what do you mean you can't see? I said, I don't know—I was 26 years old. Hold on one second. There was a decrease, just vision, there's something wrong. And, yeah, I remember him and can't see. And I was terrified. But I just felt like—I didn't go back. They said, well, come back in a couple of weeks, you know.*

Although Nancy is a woman who holds high credentials in the field of science and teaches in a major university, she felt that her voice was being silenced by the quick dismissal of her opinions—

*I have an internist whose wife actually has MS. And I've been going to see him for years and years and he never picked up on what was wrong. I mean, I also started having weakness on one side. He never picked up on it. I contacted my internist [to discuss her suspicions of MS] and he really wasn't . . . he was like, I don't think that's going to happen.*

Nancy's next experience with the medical establishment was even more revealing—

*I went to a neurologist, just over the river and he was very dismissive of my symptoms. None of the physicians down here seemed to want to take it seriously. I started feeling like female . . . I'm moving into that age . . . I felt that's was how I was being perceived until I got that diagnosis [of MS using the MRI scanner] that gave me a stamp of approval.*

Kate, who is a circuit judge and has a larger-than-life personality, took the opportunity to tell me about her long road to a diagnosis of MS and the unusual method she felt compelled to use in order assure that her voice was not silenced—

*I just remember once or twice a year I would have to go to the emergency room, I didn't know what was wrong with me. And they didn't know what was wrong with me. It was like okay, nothing's working right. I just feel, I just felt like I had fallen apart physically. I had been feeling really bad. I mean just couldn't figure out what was wrong with me. Just felt like I had the flu all the time. No energy. It felt like a balloon with the air let out of it. So eventually I called my family doctor and [after discussing my symptoms] he says, well you need to see a neurologist. Well, he gave me the name of several and every time I'd call, they were like we're full up or we're not taking new patients. Well, I finally found one and they literally said well, there's a waiting list of three months or whatever. Well, I don't take there's a waiting list for three months very lightly, so I said, fine. I will call you every day, multiple times, until you can fit me in or there has to be a cancellation. And I will take it. So, for seven days, or seven working days in a row, seven working days, I called them three times a day and I would literally, they knew it was me. I'd go, "It's your favorite hemorrhoid. I know I'm a pain in the butt. Do*

*you have a cancellation?” No, we do not. Finally, I guess they thought she’s not gonna quit and they said tomorrow we have a cancellation.*

To Doris all the pieces fit when she finally received the diagnosis of MS. Her intuition, the symptoms, and the results of the MRI scan only gave credence to what she had been trying to tell all the physicians in the past, if they had only listened and not shushed the obvious—

*But all of these years I have suspected it. I’d go to the doctor and the symptoms were like, use the trunk of the elephant. Here’s the tail of a camel and when he said you know what I’ve got to tell you, it was a relief. [The doctor] said he had never heard anybody cheer for an MS diagnosis. I said but I have a diagnosis. I now know what is wrong. And it’s a relief to know what’s wrong. Because then you can deal with it. I had been telling doctors how bad I had MS and they would tell me it was all in my head. Well, in my case, it’s all in my spine—I just, all I could think of was here I go again with another year trying to get somebody else [to listen to me].*

Jane is employed as a secretary in a busy legal office in which her job description requires her to travel between two job sites. Her road to diagnosis was much shorter than everyone else in this study, but even in just a few months to diagnosis, Jane had to face the same stereotyping—

*One eye started to look like I was looking through a screen—half of a screen. And I didn’t really give it a whole lot of thought until it didn’t go away for like three weeks. And I just—it still wasn’t bothering me. It was just kind or weird, so maybe I should call the eye doctor. And they got me in immediately. Oh my gosh,*

*you're not supposed to have—you should have called us long before now. And he did the exam and he didn't find anything wrong, which you probably wouldn't. He sent me to an ophthalmologist who did the exact same exam the next day. He wanted to wait another three weeks. Then when it didn't go away, that's when they did the MRI. And both of them were floored. They said that they could not believe that I had MS. Don't just dismiss anybody—in a way they didn't believe, I guess, because if they can't see anything wrong, you must not have anything wrong with your vision.*

The relationship between the medical establishment and the MS community has never been a smooth road due to what is perceived as the hierarchical nature of the medical profession. Given the above examples of the participants' journey to diagnosis, many in this community relate to the statement of Joshua Malinga, the secretary general of the Southern Africa Federation of the Disabled, when he addressed what he saw and experienced in relationship to the attitudes and actions of the present day medical establishment toward the disabled:

The point is that they [members of the medical establishment] believe that they have solutions to our problems. They do not see us as belonging to society, they think we belong to them, they have to keep files on us throughout our lives, and decide when we should see a doctor and so on (Coleridge 1993, 74.)

### ***Stress***

The last topic discussed by the participants in relationship to understanding and coping with MS addressed the issue of stress. Individuals with MS believe stress makes their symptoms worse. Doctors at the Behavioral Medicine Research Center at the University of California, San Francisco examined all major studies of MS and stress and concluded that stressful events worsen MS symptoms and can offset the acquired benefits

brought about by an effective MS drug treatment regiments (Mohr 2004). How the MSer relieves and deals with stress frequently finds its way into the lived experiences of members of the MS community, and five out of the ten participants in this study thought that stress did affect their overall well-being.

Brenda finds that it helps to stop focusing on your own troubles and seek to relieve or comfort another person in the midst of their problems. This way you are able to see the bigger picture—

*Come back with an encouraging word for a person that feels gloom and despair, then I think you'll help yourself. Then, get off yourself and get on to other people and other things. Hey, look! Oh my goodness, everything's positive if you look at it.*

Cathy's escape mechanism is to participate in activities that calm the spirit—

*I do massage therapy and the yoga and some of the meditation tapes. I would love to do the acupuncture but I just haven't got there yet.*

Dick found that the responsibilities of his job were the catalyst for his issues with stress. Upon recommendation from his physician, he chose to apply, and did receive, disability. The removal of the demands of his job allowed him to become a calmer, more centered individual. Dick expresses it this way—

*I got rid of the work and I have a life again. And it's a good life.*

Both Donna and Jane felt that they needed to take an active role in their stress management. Donna makes her point this way—

*There's certain stresses that you just can't avoid and I don't care what you have or don't have. Sometimes I, you know, don't know, I don't deal very well with it.*

*You know, you just feel like oh, but you know, but I laugh and joke about the things, you know, don't take it maybe too seriously.*

Jane loves the outdoors and relieves her tension by—

*I go out for a walk, get outside, something like that. I do still have panic attacks. So, I tell you, if I get outside I see that I can calm myself down. So I use that, going outside, walking the dogs, something like that as an escape.*

The third over-arching question in this study investigated in what ways has their lives continued to change after their diagnosis of MS. The question was:

**In what ways do subsequent life experiences alter the perspective transformation that resulted from the participants' diagnosis of MS?**

This question addressed how the MSer digested, absorbed and *moved beyond* their initial diagnosis of MS, and it is also a look at insider's perspective of the daily lives of the individual. This led to a discussion about the *positive* and *negative* aspects of this disease. Acceptance is at times a very difficult thing to do. To the MSer it is the realization that things are not going to work out the way originally planned. It is to admit that you may have little control over your future. Some, even after substantive diagnosis, wanted to believe that the evidence was incorrect, citing that at the time they were not having any level of physical or mental difficulty that would warrant making any type of adjustment in their activities and desires. That line of thought would substantiate the possibility of a misdiagnosis. Later when the disease had made some type of impact on what was perceived as their normal "quality of life," some of the participants began to realize, accept and create a lifestyle that accommodated the disease of MS.

## ***Moving Beyond Diagnosis***

The way individuals view the world is the result of their knowledge and interaction with the world. Many of the participants of this study spoke about their struggle to find the answer to their mystifying physical difficulties. Just what was *their* particular life with MS going to look like?

Jane expressed how difficult it was for her to come to grips with her MS diagnosis—

*I was climbing all over rocks and hiking and all kinds of stuff. And I said, I can't believe that somebody thinks I'm sick!*

Jane described her adjustment to having MS—

*School was my salvation. But I just—it wasn't enough. I ended up having to see a counselor, which killed me because I'm the type of person that I shouldn't need help. And then I was put on medication for that. But there are some times that you just cannot handle everything. You're not superwoman.*

Now Jane no longer questions her MS diagnosis but relies on the following insights to bring guidance and direction—

*God does give you a lot strength, but God gives you strength in helping yourself, too. That's part of what he's given you. It's not the end of the world—not in those words. But you basically have to tell somebody, it's not the end of the world. This is not as devastating a disease as maybe you think it is. Yes, it can be. It can be very debilitating. It can be very draining, but your attitude is just going to judge how you handle it too.*

Danny, in his discussion about his journey to acceptance, said—

*Initially, I didn't believe I had it because after I was diagnosed back in 1978–79, I really didn't have any noticeable deficit after the numbness went away. Until I started having some permanent deficit, it really didn't impact my life that much. I just figured I'd get on with it and if it gets worse, it gets worse. But when I started having some deficits that stayed with me after the exacerbations, it made me sort of sit back and think a little bit more. Every day that's above ground is a good day. You can boo-hoo about that all you want and that's not going to change anything. You have to get on down the road and do what you can do with what you've got and let it go at that. I'm still able to get around with the wheelchair and my mental skills are still half-decent. I have problems with fine motor skills in my hands and stuff like that, but to me—and again—that's a problem that you just have to find a solution to. That's what I've tried to do. Find a way to work around whatever deficits I've got; doing everything I can to impact the disease.*

Dick's interview quickly suggested that he went through a time of significant struggle before accepting the diagnosis of MS—

*I went and did this triathlon and after the thing was over, well I knew during the event, while I was running something wasn't right. So after the event was over, some guy that passed me during the run came up to me and goes, Is something wrong with your leg? And I said, There's nothing wrong with my leg. I was just real dizzy. And he said, No, there's something wrong with your leg. I went back to my doctor and I told him I did this triathlon. [The doctor then suggested that Dick have an MRI scan done at the local hospital]. The MRI came back to be a demyelinating disease. [MS is often described as a demyelinating disease]. And I*

*got a book on neurological problems and looked under demyelinating disease, and they had listed seven things and I read them all and I said, No, I don't have any of those. After I went and saw him [the doctor] the next time, I said, Well, that's not listed as a demilating.disease. And he said, Yeah, that's the most common disease in the list. So I got my book out and looked after I got home. Turns out it was the first thing on the list, and I missed it. So, I was already in denial and didn't even know it. Didn't know that you had read it and just kind of brushed it over. I was in denial for about six months, didn't know it, of course.*

Dick came face-to-face with his denial on the way home from a doctor's appointment at an MS clinic—

*After this clinic . . . well, I was driving home from the clinic and it hit me, like, yeah, because one of the things they did towards the end of the clinic was talk about denial, and the likelihood of getting better, which is just about zero. And so all this hit me on the way home and I was crying for almost the whole trip home. Two days.*

Shortly coming to the realization that the life he envisioned would never become a reality, Dick began a long battle with depression—

*I had been seeing a therapist for my depression for like four or five years and wasn't really getting anywhere. And then, after no therapist for like a year, I said, I've got to do something. So then I went and talked to the people at the MS clinic in Baltimore and said, I've got depression problems. I need to talk to someone who's well-versed in MS. And they connected me with a woman who does therapy for the chronically ill.*

Throughout the years of dealing with MS, Dick believes that his ability to accept and adapt to a life with MS comes about by him being able to—

*Put everything around the MS, so that I deal with the MS and then I have a life on the side. Whereas before, I had work and the MS and that was it. When I was first diagnosed, I would go to doctors to find solutions. And now that I've read a lot about MS and I've been to doctors a lot, I don't look to answers from doctors anymore. You have to make up your own learning and transform the way you do things, the way you live.*

Donna just didn't want to believe that what the doctor suspected was really true—

*A doctor in the emergency room suspected MS. Once [the vision difficulty] went away, it took maybe a month or maybe four or five weeks before I felt stronger and better. After that, I told myself that I was fine I didn't really . . . I don't really have this. And people were giving me all this stuff about MS and I just didn't want to know. I denied and put that stuff away. Then about a year later I had another problem with numbness in my hands or one of my hands. It came and went and the neurologist did some tests and he identified that I had symptoms or the spots in two different places—my brain as well as my spine—with another MRI. But I never saw the MRIs and I still . . . I was young and I felt good. And I said, Do I really have anything really? So I'm like, I'm fine. I think I went through the denial. No, I don't really have that. I didn't see it. I think I was just, it was just my personality then. I was just too young.*

Eventually in the course of our conversation, Donna admitted that just having time to think things through before she was willing to entertain the thought of having MS—

*It just was a real shock and I think I got a little depressed at first. So I think it just took me awhile to adjust. Sort of a situational thing.*

With the effects of MS looming, Donna felt pressed to rethink and meditate upon her position as a possible member of the MS community—

*It's definitely slowed me down and caused me to, you know . . . have to have more time to kind of internalize or think than say maybe I would have. But then again, I don't know. I just don't understand a lot of things like disease and injustice and things. So I have questions. I get really mad or upset when I have an attack. That's when I'm mad. I'm okay today. Because I'm mad when I can't do what I absolutely want to do no matter what. But I'm angry when I have an attack. I think I have a bad outlook whenever I'm in the middle of an attack. Because again, you get scared . . . then I get scared and get, Oh gosh, what if this doesn't go away? What if, what if?*

But Donna's outlook is changing; it is evolving in ways she never would have imagined from accepting to embracing—

*It just takes time, I think. Or it did for me. It just takes time. And you know, it's not . . . I wouldn't say it becomes a friend, I just becomes a . . . It is part of you. And like it or not, you have to address it and you have to . . . You can either hate it and cause yourself more stress and more problems or you can accept it in a way that you try to be the stronger part of . . . You're stronger than that is and don't let it take you over.*

Yet there are some things that according to Donna you cannot get back—

*I think after I lost my eyesight and my vision came back, I never looked at myself the same. I don't know why. I just saw something totally different. I don't know, I think there was something that one day look up and I wasn't, I didn't feel as pretty, I didn't feel as strong, I didn't feel as all the things I did when I was 25, you know. I think, you know, you feel like, I think you, when you're young you have that anyway. You're invincible or whatever. I just lost that. And never completely, you know, got that back.*

Cathy was told by her doctor after a number of visits and an MRI that he was 99 percent sure she had MS, but Cathy was not ready to accept the diagnosis—

*I was having no symptoms. That mouth thing finally went away. I was running four miles a couple times a week, or three or four and life was great. And so I said, I'm not going to let this get me down. I'm going to keep running and doing everything I do and I don't tell anybody and so, Gee, I don't really have it.*

After another visit to her neurologist, Cathy's doctors made a very strong case that she did in fact have MS. So Cathy decided it was time to move forward and include her husband on her thoughts about the future—

*I left the building. I came home. I think I called my husband. And I sat and cried for a couple of hours. And then like I said, I chose to ignore it. I wasn't going to have it. I was going to keep running and exercising and doing everything I did.*

Cathy's denial was short lived, as she was forced by difficulties brought about by the disease to come to terms with the reality of having MS—

*It took a long time to say it to myself. I still wanted to be who I was. I still wanted . . . if somebody needed a job done, I wanted to be considered. And you know,*

*she's got MS. Don't ask her. And I couldn't say it to myself. That summer that I had a real bad experience, I didn't have any choice. It bit me in the butt. [The MS] creeps up on you very slowly. It doesn't like slam you, but it creeps up.*

The members of this study all initially did not want to acknowledge the fact that they had MS. Some were not given the luxury of time to get used to the idea because the disease itself had interrupted their daily routines in such a way that denial was no longer possible, but all participants in this study expressed the conviction that they *had* also adjusted to their illness. They were pondering the issues created by the disease and finding a way to circumvent present difficulties, while at the same time not wanting to entertain what their future struggles with the disease may be if the MS progresses to what is perceived as a higher degree of difficulty (loss of control).

Many in this community expressed that they had accepted and made adjustments to accommodate a life with MS, finding information that will help with present difficulties through various venues (Internet, doctor and publications). They still find it difficult and unnecessary to enlist the advice and support from those who have the same disease but at a more advanced level of disability.

Jane, who has had the disease for ten years, states—

*Everybody's at a different level of disability or ability and I don't want that. I don't need it. It's not a supportive thing for me. Some people that is support. If you can all prepare notes and boo-hoo and complain and all that kind of stuff, that's fine. And if I ever were at that stage, if I ever get to that stage, I might need it. But I really have always felt like I've got the support I need from within, from my family and all the friends I've had.*

Brenda believes that it is vital to adapt to change, but only as necessary. Possible future difficulties are left truly in the future—

*If I went to their counseling, their support groups and everything, then I'd want to know [if the MS is getting worse]. Then I'd know what stage I am in. I want it to creep up on me. To me, if it creeps up on me, then I can make concessions gradually as I go. But if somebody is going to say, Okay, in 18 months, you're not going to be able to feed yourself, then I would freak. But if I know that it's—if I don't know it and I slowly lose control of doing a function that I'm used to doing, then I will slowly compensate some other way—if I have to lick the darned plate. But I will work my way up to it.*

When the conversation turned to how Connie feels about the past 44 years of living with MS and her possible future lived experiences she stated—

*I've had it for too long to think of me in the previous sometimes; it's certainly changed my view of death. [How so?] I'm no longer afraid of death at all. Death can come at any time. It won't bother me. What I am afraid to death of is not being able to take care of myself. Much rather pass on versus live in a state of . . . with that much help and inability.*

Danny, who has had MS for 30 years, is having a very difficult time managing the devastating effects of this disease. When asked about his present and future condition, Danny is trying to be very optimistic about his future—

*I'm sort of borderline right now. If MaryAnn [wife] were to go somewhere and stay away for a week or something like that, I could probably handle things okay around here. But I'm at that point where . . . Now I'm getting to the point where I*

*don't have a choice. Once it gets to the point where I have to have somebody helping me I think that's going to have a negative impact on me. I'd love it if it would just stop here. Even having the deficit I've got, if it could hold right there, that would be fine with me, but I don't know. I don't know what the future holds. I'm just sort of living for the day. You just have to . . . It's a battle every day, you know that. You just sort of have to kick yourself in the ass and get moving. You don't have any choice. I'm hoping that three, four, five years down the road, they'll come up with a—maybe not a cure—but something like a diabetic takes insulin—I'm hoping they can come up with something like for MSers where we can take a shot and we don't get any worse.*

The participants in this study defined acceptance as not only the ability to accept the fact that one has MS but also going beyond acknowledgement to make the most of what abilities remained. In this community transformation is more than just having embraced one's diagnosis of MS and accommodating one's lifestyle. It is also involves the reunifying the needs of the body with the self and/or soul in such a way that makes sense to the MSer. It is a life defined by a fine line between independence and support. This life is the balance between what is lost and what one has. Charmaz (1995) states: “[Successful] living with chronic illness refers to adapting to the situation by altering life and self to accommodate to physical losses and to reunify body and self accordingly” (657).

### ***Positive Outcomes of the Disease***

Another aspect of the above over-arching question was the exploration into the positive and negative aspects of living with MS. The first voices express how he or she

has become a more rounded and complete person due to the traits one must acquire in order to successfully deal with the day-to-day workings of this disease. Secondly, you will become acquainted with some of what I choose to identify as the consequences of having MS. Many in this community, when describing positive outcomes, could quickly identify a trait that has expanded and grown as a result of living with MS for a good number of years.

Brenda stated that—

*Everything had to go my way. I think that was the hardest thing for me. My whole world has always been my way. Now my whole world has to be adjusted to another way. So it was hard. But that's in the past now. But as far as what lessons came out of it, I never thought that my children would be 40 and in their early 30s and I would be as close to them as I am.*

Connie says that she has a better—

*[U]nderstanding of people with handicaps. That's a plus. Because if everybody understood handicapped people and other people that have difficulties like you did, it would be a totally different place. So I think that's a good thing.*

Dick expresses a greater acknowledgement and understanding of others—

*I've become very empathic. Suddenly, I look at other people that are having health problems, totally unrelated to mine. And I like to look at them and think about how it's affecting them. Whereas myself, and all the other people, never think about that. So it has opened that whole new side of me. You see someone that's different or someone that's having a struggle. Someone else might not see it, but you see it. And I feel sorry for them.*

Donna not only sees her ability to understand the difficulty of others, she also uses her knowledge to encourage others to reach to a higher level of self resourcefulness—

*I think that helps you as a, you know, to be more sensitive, I think. I'm more sensitive, much more sensitive to other people. I hold people a whole lot more accountable. They can't just say well, I hurt somewhere, because—that's why I can't—when they come in here for some kind of assistance they may not know that, but I think you can, you can do a whole lot more than you think you can. Don't be limited just because.*

Danny is more understanding of the difficulties of others and wants to make people aware of the plight of those with physical difficulties when it comes to getting around in our communities—

*I was going to say maybe more understanding of people with disabilities, and it's also made me aware that there's a whole lot more that can be done to make it easier on people in wheelchairs.*

Nancy simply looked into someplace far away in her thoughts and said—

*I think I'm a nicer person. I think I'm more patient.*

Cathy who has had this disease for 18 years stated that having MS makes you—

*Humble [and makes] the whole “why me” thing a smaller issue.*

Katie found that MS has taught her lessons in the struggles of others—

*I'm more understanding of others and their afflictions be it the color of their skin, their religion, their sexual preference, their socioeconomic status, I mean, it's made me realize that the physical body is not the total person. It's made me a better listener.*

### *Negative Outcomes of the Disease*

When we discussed the negative aspects of the disease, the answers covered a broad spectrum of what it means to live with a chronic disease. Yet if you take time to hear beyond the words, each participant referenced his/her fear of the unknown future with the devastating effects of this disease.

*Cathy is tired of the daily grind associated with MS and states—*

*I'm not quite the fighter that I was maybe at one time. [I'm just] accept[ing] what's happening. Or not as verbal about it as I once was. I've heard him [husband] say . . . you just get depressed with it.*

Donna, who is recently divorced, has become more aware of the greater pressure placed upon her to meet the family needs and wonders about what the MS will do—

*When I have an attack, I think is this the time I won't be able to come back, you know. And now, it's like we rely on my income, you know. So, that kind of worries me a bit. But, we've always, you know, my insurance is good and we've always used my insurance, so, I don't worry about that because I—there's all kinds of children's insurance programs, but what would I do if I couldn't work and what if I don't bounce back.*

The fourth over-arching question in this research dealt with the MSer's recollection as to what have been the major areas of frustrations throughout the years. Most would readily point out there have been a number of frustrations, but they expressed a desire to avoid discussing this issue at great length, and when pressed for a response they attempted to identify their most recent or most trying episodes or experience. The question in this section was:

*What factors have hindered the participants' ability to deal  
effectively with their MS?*

A number of the participants chose not to dwell on the negatives of having MS. Instead they chose to use their voice to express how they have become a more rounded and complete person due to the lessons learned through the trials in dealing with the day-to-day workings of this disease. Secondly, you will become acquainted with some of what I identify as the consequences of having MS expressed by other participants of this study. Much of this dialogue accounts for what has been “lost” in the mind of the MSer.

*Consequences of MS*

When we discussed the negative aspects of the disease the answers covered a broad spectrum of what it means to live with a chronic disease. Danny has not been able to slow the downward physical spiral of the disease; the medicines have made little, if any, improvement in his situation, which makes him wonder what his next options are—

*I'm not to the point yet—but I'm almost where I'm not able to do, like dressing myself and that kind of thing. Once it gets to the point where I have to have somebody helping me do that, I think that's going to have a negative impact on me. There's a whole lot of stuff that I can't do anymore. I understand that. But there's also a lot of stuff that I can still do. And that's hard for me to say Okay, you've got all this stuff that I can't do. And it's hard for me not to look at that and focus on the negativity and not all the stuff that you can do. I'm working on that.*

Kate's mission is to help her students succeed in the educational endeavors and she expressed that the only thing that would devastate her would be her inability—

*[T]o give 100 percent in the classroom.*

Nancy, just like other MSers, finds it a struggle at times to deal daily with MS because—

*It's so elusive. There's no actual . . . it changes from day to day as to how you feel. There is that fear. I'm not sure if that goes away too often. I'm fearful of what the future has. I want to be encouraged. And I am encouraged by how well I'm doing. But I am fearful.*

Nancy is also worried that there will be long-term discrimination against MS patients.

She believes that—

*We really have to fight that. That's what is going to get me politically involved in the MS fight. Now I support the MS . . . financially I try to support the MS Society, but I haven't been open . . . I don't feel comfortable participating in the walks, for instance. You know, it's like, Why are you doing that? I have MS. And I don't want to go there.*

The final section of this research explores the effects relationships have upon the MSer's lived experiences. The over-arching question in this section is:

### **What role did relationships play in their transformation?**

#### ***Help and Hindrance to Transformation***

Many in the MS community are reluctant or feel powerless to ask their family members and friends for help. Yet MSers make efforts to be socially engaged and avoid isolation; many individuals with MS take on the task of educating friends and family about their condition. Within this community there was a mixed response to the individual's effort to include friends and family in their lived experiences as an MSer.

Donna's story relates finding a fine line between the expectations of others and herself—

*The things I struggle with telling my family now is when I don't feel good because I'm supposed to be strong. I feel like I should be strong. Because they are very strong, hard-working. Even when you don't feel good you do it anyway. There is no pressure from them. It's all me. But I don't want them to worry. All that kind of thing. So I don't tell them unless it's really an attack. Unless it's really bad. I've been judged in some ways like, You can do what you want to do, but you can't do maybe what they [husband's family] wants me to do. Yes, I can do what I want to do a lot of times, but I have to really plan and conserve my energy to plan in order to be able to do anything that I really wanted to do. And then I have to plan to be a day or two, whatever it's going to take to recuperate. And I think that people don't really understand that because they say, Oh, you look just fine.*

Brenda met with an outright refusal to participate in her newly rearranged life—

*We [husband and wife] even went to a marriage counselor and the marriage counselor had MS. And so he was told to get the MS for Dummies. I was the only one that read it. He started it, but he said he didn't have time. Not with his obligations. He pushed me through a wheelchair one time—in a wheelchair—and the only remark I got was, that felt funny. So I never asked him to do it again.*

Connie's attempt to include her husband in her life brought out various emotions—

*He is very supportive in the abstract. He is not always as—what's the word I want—cognizant of what I'm going through in the concrete. [He doesn't] pay attention to the fact that you've moved your chair out into the middle of the room*

*so that I can't get past with the walker. My husband and I don't always get along. Well, I don't know anyone that does. But I don't think either one of us has enough ambition to . . . start again with someone else?*

Dick's effort to educate his mom and dad about the problems he was having with MS brought about a revelation—

*I had to educate them about MS. Nobody understands MS unless you have it, as you well know. When I explained it to my parents they would kind of shake their heads like, Yeah, we understand but, then they went to this MS clinic with me. My parents came home from that saying, We can't believe all the complaints, we heard the same thing from you. I heard my parents talk about that and suddenly realize that yes, it is tough on them.*

Dick also faced a very different reaction from his wife—

*As my wife said at the time, It's not because of the MS, but the MS is the final straw. Yeah, there were problems prior to that. I can remember her constantly berating me for not remembering the names—we had a rental property. She was always berating me for not remembering the names of our tenants. Just things like that. And as you now know, I have trouble remembering people's names. About a year ago, I couldn't remember my ex-wife's name. That was a very positive revelation.*

Cathy found that a difficult situation was only made more difficult with the added pressure and stress of having a disease—

*He's a good person in a lot of ways, but there's just not a lot of support of . . . Let's do things to help you not get worse. I think it was more he's going to do*

*what he wants to do in case some day he has to take care of me. That kind of attitude. And that's what I was told over and over. That he was . . . it's about him now and someday when I can't walk, then I'll take care of you. If I was sick, he was sicker. But it wasn't more of a team approach. When I had attacks, my husband just never would watch our daughter from day one.*

Danny expressed that the disability brought about by this disease limits who is in your circle of friendship—

*My family has been real supportive. My sisters, if they hear about some kind of a treatment or something like that, then they'll call and tell me about it. The people who were friends of mine at work, when they found out about it, they were sort of supportive, but without much—I don't have much to do with them anymore so I can't really get any support there. Of course, my wife MaryAnn, she's just been really super, especially since it's gotten to the point where I have to use the chair.*

Doris's life with MS brought about feelings of mortification and rejection—

*I was so embarrassed to have to park in a handicap spot, but at least I could, if I did that I could manage to struggle two blocks to where I worked. But, it was a struggle. And there were things about it he [husband] accepted. And some he couldn't.*

Kate and her family have a very close and loving relationship, but her parents' reaction to her MS was surprising—

*My dad and mom thought that MS was contagious, and I'm gonna get emotional again, but I tried—they, for the first maybe six months until I got from a book on MS, my parents and I have a real loving relationship. We always kiss on the lips*

*when we see each other and we always kiss on the lips when we leave. It's a little mu-ah, peck, that kind of thing. And I noticed that my parents stopped kissing me on the lips. And I noticed that my parents stopped hugging me. And I was like, what the hell. Okay, you need some education. So finally, I started getting the magazine from the MS Society.*

Her dad also offered to step in when and take matters into his own hands if the stress and strain of living with MS became too much to endure--

*When he first found out he said something to me just blew me out of my chair. He said now, Kate, I know you, you're an active person and you're energetic and you're Miss Go, Go, Go, and do for others first and do for yourself second. And I'm like, well, yeah, mostly. He goes what happens when it gets to the point when you're in a wheelchair. And I laughed and I said well, daddy, I guess you brought me in this word and you can take me out. And he said I'll do that for you. I would like to. Oh, God, you were so quick to volunteer. Great. I've got an out. But, he was just, whatever you want. You're my daughter. And I'm like, oh. I just thought that was strange. Instead of hesitation or don't talk that way. I didn't expect that.*

Nancy's husband stayed with her through the diagnosis, but as all MSers will acknowledge, the disease brings a high level of stress into the family relationship that unfortunately brings at times a sense of self-imposed, unwarranted guilt upon the MSer—

*He [husband] was relieved that I was relieved. He certainly wasn't happy with the diagnosis. And probably a year, maybe two years after I'd had the diagnosis . . . and for awhile I started going downhill. These symptoms were coming out that people were seeing. It was getting really problematic. He had a heart attack and I*

*feel my condition contributed to that and the stress of what was going into that. So I do feel that he internalized a lot of things.*

### **Summary**

Each of these participants has accepted their MS diagnosis and has spoken of moving on to embracing this disease in such a way that would bring about a successful union and connection between the patient, the family, the culture and the community. Many in this community may not be disabled in physical terms to the extent that they need medical aids to get around, but the mere outward acknowledgement of illness brings societal barriers: “We [may or may not be] disabled by buildings that are not designed to admit us . . . the disablement lies in the construction of society, not in the physical condition of the individual” (Brisenden 1986, 176).

The next section of this research will discuss the findings drawing from these research conclusions, implications and recommendations interpreted from the questions originally raised in this study, which underpin its purpose. Accordingly, I will discuss and interpret the questions using transformative learning, constructivism and critical ethnography as the theoretical frame.

## CHAPTER 5

***Findings: Mezirow and Boyd & Myers Transformative Learning  
evident in the MS community; Integration of both theories  
necessary to the development of coping strategies within the  
MS community***

This research study was an effort to acknowledge my own membership in the MS community, but more importantly it was also an effort to help you, as the reader of this research, to come alongside and take part in this unique and transformative community of strong, intelligent individuals held in the grip of this elusive and mystifying disease. It has been the desire of this researcher to encourage all of us to take the time to become informed, concerned and pro-active participants in the victories and struggles of the participants in the MS community. It is critical that we as readers and seekers go far beyond casual interest in this research. We should reach for the place where we become fully immersed in the settings and surroundings of these individuals so that we may fully discover the personal, idiosyncratic meanings behind their actions. May our findings bring us to a place of understanding and tolerance, giving space and validation to the voices of the participants in this research study and then continue to move out into other silenced communities in our society.

The findings discussed and interpreted below were framed by the five questions presented in the first chapter of this research. The research questions were as follows:

1. How do participants make meaning out of the diagnosis of MS?

2. What factors were influential in the participants' understanding and coping with this disease?
3. In what ways do subsequent life experiences alter the perspective transformation that resulted from the participants' diagnosis of MS?
4. What factors have hindered the participants' ability to deal effectively with MS?
5. What role did relationships play in their transformation?

These questions led to the creation of this study, and they illuminate findings that require discussion and explanation. This will be approached through the theoretical framework used in this study: transformative learning and critical ethnography.

In the previous chapter I connected the participants' opinions and statements to the five overarching questions above. In this chapter, I will first discuss the findings that relate to the transformative nature of learning in the lives of the individuals in the participants of this MS community. Also, it will be important to identify the coping strategies and motivational factors that were influential and vital to their transformative experience. Next, this research will explore the lived experiences, meaning and consequent changes in the lives of the research participants that followed the realization that they each seek to be a fully participatory member in their communities and society at large.

### ***Mezirow's Transformative Learning***

Part of the daily requirements of an adult in our society is to be able to understand, to make sense of, and to establish meaning in our lived experiences.

Fulfilling this requirement helps us to avoid the threat of chaos in all areas of the adult's life. Transformational learning speaks to the idea of a type of learning that produces change that has "a significant impact on the learner's subsequent experiences. . . . it shapes people" (Clark 1993, 47). Such a dynamic concept that seems to explain and promises to transform learning has been the hot topic of discussion for a number of years in a variety of articles, books, conferences, higher education courses and online discussions (Taylor 1997a, Mezirow (1994) defines transformative learning as "the social process of construing and appropriating a new or revised interpretation of the meaning of one's experience as a guide to action" (222–3). In other words, "meaning exists within ourselves rather than in external forms such as books, and personal meanings [are] acquired and validated through human interaction and communication" (Mezirow 1991, xiv). Interpretations of life experiences are individualistic in nature; one's view of the world is a result of his or her lived experiences. Transformative learning is "a process of examining, questioning, validating, and revising [personal] perceptions (Cranton 1994, 26).

Adults come to expect certain outcomes throughout their lived experiences based upon what Mezirow calls *meaning perspective*. These perspectives are the direct result of the way one grew up, the culture in which one lives, and what one has previously learned (1991, 4). Meaning perspectives "provide [the individual] the criteria for judging or evaluating right and wrong, bad and good, beautiful and ugly, true and false, appropriate and inappropriate" (Mezirow 1991, 44). A meaning perspective is the way an individual sees the world (Cranton 1994, 42). When an individual is confronted with an experience that cannot be reconciled into his or her meaning perspective, the experience must be

rejected or the individual's perspective must change to accommodate the new experience (Taylor 1994, 158).

Mezirow identified 10 phases of perspective transformation (transformative learning) based upon his in-depth interviewing of 83 women who participated in an academic reentry program after a long break from school participation (Mezirow 1978). According to his findings, the journey to transformation begins when the individual experiences what Mezirow calls a disorienting dilemma as a result of an acute personal crisis, such as a death of a spouse, divorce, loss of a job or illness, and continues to the final stages where there is a building of "competence and self-confidence" (1991, 169). Mezirow (1995) listed the following 10 phases of transformation (50):

1. A disorienting dilemma
2. Self-examination with feelings of guilt or shame
3. A critical assessment of assumptions
4. Recognition that one's discontent and process of transformation are shared and that others have negotiated a similar change
5. Exploration of options for new roles, relationships and actions
6. Planning of a course of action
7. Acquisition of knowledge and skills for implementing one's plans
8. Provisionally trying out new roles
9. Building of competence and self-confidence in new roles and relationships
10. A reintegration into one's life on the basis of conditions dictated by one's new perspective.

Three themes emerge in the process of meaning making: experience (e.g., a disorienting dilemma), critical reflection (questioning assumptions and beliefs based on

prior experiences), and rational discourse (assumptions and beliefs are questioned and transformed) (Taylor 1998, 8). Mezirow sees this type of transformation as irreversible, resulting in the individual having a more inclusive and discriminating worldview (1998, 11).

### ***Mezirow's Transformative Learning in the MS Community***

Many individuals in this community suggest that they knew with certainty that something was just not right, or they knew that physically they were struggling to do tasks that had previously been done on autopilot. Some in this study were not given the luxury of time to get used to the idea that they now have to live their life as an individual with a chronic disease.

#### ***1. Disorienting Dilemma***

It is difficult for people who are not a part of this community to understand the tug of war that exists within this community when you first learn that you do have this disease. Most all in this study had an inkling that they had MS and went to great lengths to receive a definite “yea-or-nay” diagnosis, but it is still quite a shock—or what Mezirow called a *disorienting dilemma*—when their physician solemnly told them that their suspicions were a reality. No one is really prepared to deal with a chronic disease. There are no classes, no aspirations for such a life. Cathy explained to me what she did and how she felt after receiving a diagnosis of MS—

*I left the building. I came home and I sat and cried for a couple of hours. It took a long time to say it to myself [that I had MS].*

Jane's world was turned upside down. Nothing made sense. She just did not realize that given time the disease would progress but for now Jane just could not get her thoughts around the fact that she had MS. After all she was—

*Still climbing all over rocks and hiking and all that stuff. And I said [to myself] I can't believe that somebody thinks I'm sick!*

Lastly, after being told by two physicians that they suspected Donna had MS, she still described her diagnosis as—

*A real shock. I think it just took me a while to adjust. You know. . . [I had] to have more time to kind of internalize it. I have questions.*

## **2. Self-examination with Feelings of Guilt or Shame**

Every member of a family is affected when one member is diagnosed with a chronic illness (Lubkin 1995, 31). Illness places stress on the family structure. When a family member becomes ill and is unable to fulfill his or her usual tasks or roles, the family must change its established patterns and roles. Bahnson (1987) describes illness of a family member as “an attack on the unconscious expectations of the existing family structure” (36).

Some members in this community view the disruption of their well-established family routine due to MS as a self-inflicted and unfair personal assault that they imposed upon their family members. Others perceive that what they face physically and emotionally is a far less burden than what others around them must daily endure. Even though Nancy knows that she had no control over her getting or not getting MS, she still can't shake the feeling that she was partly responsible for her husband's health issues—

*I feel guilty unburdening myself to him [husband] because I believe I contributed to his heart attack. I know that's an emotional response. It was going to happen. I realize that. He has a lot to bear, but his personality is, he never wants to be left out of anything [what is happening with her health].*

### **3. Assessment of Assumptions**

Mezirow described the third phase of his transformative theory as when individuals critically assess their assumptions about the world and society in which they live. Members of this study find that the effects of this disease force them to place a premium on their time. The number of hours of perceived productivity dwindles as the disease progresses. Some members of this community cite a “soulful” source for meaning and explanation to their future actions, while others in this community place a higher premium on the value of shoring up or building stronger friends and family connections to face daily crisis. Kate stated that this disease has made her—

*More [aware] of others and their afflictions, whether color of their skin, religion, sexual preference, socioeconomic status, I mean, it's made me realize that the physical body is not the total person. I've come to realize that the whole “why me?” thing is a small issue.*

### **4. Recognition that one's discontent and process of transformation are shared and that others have negotiated a similar change**

Many of the participants of this study acknowledged that part of their adjustment and acceptance to having this disease came about by looking beyond their personal struggles and realizing that they were not the first to enter into this difficult journey.

Many of the participants were to some extent acquainted with other individuals who were suffering with the same milady or a similar disease.

Dick, who spends his days in his wheelchair, spoke about living with MS—

*It [MS] has opened that whole new side of me. You see someone that's different or someone that's having a struggle. Someone else might not see it but you see it.*

He can quickly identify with others who have difficulties and wants to be of assistance to make their lives easier, even if it is just a kind word.

Cathy says that she is very fortunate—

*Twelve people have something worse than you do. I'm very blessed . . . you just have to count your blessings.*

Cathy believes that you must look at the bigger picture, which reminds her that she is not the only one who must deal with difficult circumstances.

##### ***5. Exploration of options for new roles, relationships and actions***

Living with MS leads to a variety of changes and consequences for everyday life. According to Frank (1995), “serious illness is a loss of the destination and map that had previously guided the ill person’s life” (1). Cassel (1982) stated, “personal meaning is a fundamental dimension of personhood, and there can be no understanding of human illness or suffering without taking it into account” (641).

The members of this community felt that after their diagnosis there was little in the way of materials or resources that could help in their quest for how to reposition themselves in their world. The notion of what you do after diagnosis, how you get on with your life in such a way as to accommodate possible future disability, can be overwhelming. Many in this group have chosen to not think too far ahead at the possible

worst scenarios but strove to look to today—let the future remain out there—distant. Even with this mindset, it becomes quite evident to the MSer that some things must be faced. Most in this community have taken steps, some ever so little, to establish a future plan of action. For the most part, though, life is getting through one day at a time, for no one really is sure of the future. Why stress over what may not come to pass? I believe this view can be a lesson for all, whether you find yourself within or on the outside of this community of MSers.

Cathy found that many around her had ample energy to work and play and she wished she could participate in all the activities herself. Then it dawned on her that maybe she should rethink her commitments and responsibilities—

*My sister-in-law doesn't work and she said on Friday they were going to do this and on Saturday they were taking ballroom dance lessons, on Sunday they were going to meet her son at his college for a basketball game. And I thought, Wow, she has the energy to do all of that? So maybe I have my priorities mixed up. So I'm kind of in the process of re-evaluating . . . I have to take care of me.*

Donna, who is presently seeking a divorce, has taken time to consider her options if she were not able to work full-time with her present employer. She has come up with a number of creative options—

*I'm the kind of person who can always find something to do. You know, I like to scrapbook, I like photography, I like a lot of things like that, that I could even do without me going nine-to-five working somewhere. I would like . . . a little side businesses. I would like to do community work and would . . . try to stay on a couple of boards or whatever that I'm on, like domestic violence kinds of*

*advocacy, and there's certain things I think I could still do, you know, even through the telephone, so I think I would have to probably kind of rethinking that and figure out how I could still be involved. And from home, even as a volunteer in some level, of some—we do a lot of, a lot of our job is collaboration with other organizations and other people, so, you know, you meet all of these people who are affiliated with lots of different things. I mean, there's always ways to, I think, stay connected. But, I mean I think it would be probably an adjustment at first. My daughter, who's going to come first, and my, you know, my health would need to come first. And I think, I think I am comfortable enough letting go of what maybe needs to be let go of.*

#### **6. Planning of a course of action**

Many in this community spoke of future possible changes in their routines and actions. One such participant was Brenda, who found that she could at this point in her journey still do some of the things that she used to do before MS affected her life like her beloved quilting retreats—

*It's the thing I can do on my own [go to quilt retreats]. But I always make sure there's at least one or two people that's known me for awhile or that has somebody in their family that has MS that I can go to for help if I need them [while at the retreat].*

Because of the physical difficulties Cathy experiences with MS, she can no longer go on two-day hikes with her book club, so in order to still be a part of the group she came up with an alternative plan. Cathy told me of an occasion when her fellow club members

planned to participate in an outdoor activity in which she could not participate due to her illness—

*Our book club went on a two-day hike and we stayed in a stop [hotel]. Well, I went, but I stayed and read a book while they were all hiking and met up with them later in the day.*

### **7. Acquisition of knowledge and skills for implementing one's plans**

Since the effects of MS differ from person to person, most all of the participants of this study turned to multiple sources to find explanations, insights and suggestions for dealing with the symptoms that they now face due to MS. The most sought-after material usually answers or helps to answer the MSer's present struggles. This being said, one day the information needed may discuss better ways to manage time in order to conserve energy. Another day it may be the dosing information about a prescribed MS medication. Today there are numerous ways to locate information (e.g., libraries, societies and the Internet).

Nancy, armed with her love for and expertise in a biological field of study, goes down to the school's library to scour their resources for the answers to her MS issues. Nancy has been in that library so much she calls it going "down in the dungeon." Donna, in an effort to find out her options on assistance, read "MS magazines" and attended an "information thing up at the Marriott." Dick, who was trying to understand and to possibly better deal with his MS symptoms, borrowed a book from his doctor. Dick feels that after extensive study of the disease of MS over the years using various resources, (e.g., books, others, doctors and Internet), he can now create his "own learning and transforms the way he does things" to fit his lifestyle.

## ***8. Provisionally trying out new roles***

Most of members in this study felt that having this disease opened their eyes to the needs and difficulties faced by other individuals with physical limitations. All saw their role as advocates for individuals with handicaps and made efforts to make their world a better place in terms of understanding, acceptance and opportunity for people whom they thought were less fortunate than themselves. While other members of this study stressed that individuals with handicaps should be made aware or reminded of the abilities they still have. Donna stated that—

*I think that it helps to be sensitive. I'm more sensitive, much more sensitive to other people. I hold people a whole lot more accountable. They [the handicapped] can't just say well, I hurt somewhere—because that's why I can't—when they come in here. I tell them you can, you can do a whole lot more than you think you can. Don't be limited just because.*

Danny stressed the need to make people aware of the plight of those with physical difficulties when trying to get around in the community and he believes that “a whole lot more can be done to make it easier on people in wheelchairs.” He would like to see a better designed wheelchair, one that could go through sand on the beach.

Connie understands what it is like to have a physical difficulty and feel like those around her think her less of a person for having a handicap. Connie looks for ways to help people understand and accept individuals who have handicaps “because if everybody understood handicapped people and other people that have difficulties like you [me, the researcher] and it would be a totally different place.”

Kate's vision for her future went well beyond just assisting handicapped individuals in society. She also addressed the fact that in her capacity in city government, her disease helped her to become more aware of the difficulties of other marginalized voices in society—

*I'm more understanding of others and their afflictions be it the color of their skin, their religion, their sexual preference, their socioeconomic status, I mean, it's made me realize that the physical body is not the total person. To look outside that box, to not prejudge somebody the minute you meet them, you know, oh, they gotta be whatever, or they gotta be this way or that way. It's made me a better listener.*

### **9. Building competence and self-confidence in new roles and relationships**

It is difficult for some members in this community to talk openly about their struggle to gain some semblance of the life they had before the effects of MS seemed to dominate their lived experiences. Yet those who do make an effort to venture out and attempt to regain and reclaim their old relationships and communities say that the effort was well worth the struggles. Donna said that she went from accepting to embracing the idea that she had to make a way to continue to live her life having MS—

*I wouldn't say it becomes a friend; it just becomes a . . . part of you. You can either hate it and cause yourself more problems or you can accept it in a way that you try to be the stronger part of. . . .You're stronger than that is [MS] and don't let it take you over.*

Danny, who has had MS for 30 years, has very strong feelings about his ability to continue on in his fight with this disease. He realizes that attitudes and actions play a large part in his dealing with MS—

*I don't know what the future holds. I'm just sort of living for the day. You just have to. . . . It's a battle every day, you know that. You just sort of have to kick yourself in the ass and get moving.*

Donna has had to struggle with the misconceptions of others in her family. She has had to find the strength to defend her actions while at the same time working to accommodate the needs of her extended family members. The disease forces her to make decisions that are at times not popular with other members of her extended family—

*I've been judged in some ways like, "you can do what you want to do, but you can't do maybe what he [husband's family] wants me to do."*

She tries to explain that due to her disease she must plan activities in advance in order to conserve energy all the while sticking to her need to plan in advance.

Dick, in his attempt to participate in his social activities, has had to come to the realization that not everyone will be sympathetic and accommodating to his situation. He quickly points out that he cannot change, and if others are not willing to shift their positions then—

*It's like, hey, I've got these limitations and if you can't accept those limitations, I don't need you as a friend. I've come to accept that and it's not a problem for me anymore. Well, that makes for sometimes a limited supply of friends. Fortunately, my limitations aren't as much as some other people.*

**10. Reintegration into one's life on the basis of conditions dictated by one's new perspective**

All of the individuals in this study are pushed in one direction or another to be active participants in the communities in which they live. Most spoke about the activities they lost and casual acquaintances that never darken their door, and then turned around and praised the individuals and opportunities that are still available to them in spite of the demands of the disease. Social support provides stability in an MSer's life and helps to promote self-worth (Cohen and Wills 1985, 311).

Danny says that relationships are what they are, and mobility issues limit his contacts. Yet Danny has accepted his limited supply of friends due to his MS issues—

*As far as the relational aspect of it, I've sort of got by that. The first 10 or 15 years I had it, you've just sort of got to accept it. Every day that's above ground is a good day. You have to get on down the road and do what you can do with what you've got and let it go at that. I'm still able to get around with the wheelchair and my mental skills are still half-decent . . . You just have to find a solution [to difficulties]. Find a way to work around whatever deficits I've got.*

Dick, who has chosen to apply for disability, describes his adaptation and re-entry into a normal life as possible by prioritizing what you want to do. He said that he—

*puts everything around the MS, so that I deal with the MS and then I have a life on the side. Whereas before, I had work and the MS and that was it.*

Both Connie and Brenda expressed the idea that they have had this disease for so long that it was difficult for them “to think of [themselves] without living with MS.” They suggested that they have just adjusted over time. The disease is simply a part of their

everyday reality; adjustment is just an everyday task. They do what is necessary to successfully get through their day, and others may come alongside in the journey.

## **Conclusion One: Mezirow's Transformation Evident in the MS**

### **Community**

It is my belief that all members of this community had a transformative learning experience using a rational discourse. Mezirow states that transformation is:

[A] process of becoming critically aware of how and why our presuppositions have come to constrain the way we perceive, understand, and feel about our world; of reformulating these assumptions to permit a more inclusive, discriminating, permeable and integrative perspective; and of making decisions or otherwise acting on these new understandings (1990b, 14).

It quickly became evident to the members of this group that the beliefs and assumptions that they used to successfully participate within their communities and society as a whole no longer helped them to make sense of their newly formed world with its different demands and priorities. All had changed. They, and others to varying degrees, no longer viewed these individuals as who they were before they received a diagnosis of MS. This change of view turned the MSer's life upside down, making it mandatory for this person to re-evaluate his worth, position in the status in society and the meaning of life with new restrictions. Doing something or believing something for the sake of old ways did no longer make sense. Roles had changed in the family and society; needs had changed; and they re-evaluated their worth and the meaning of life itself.

Evaluating old views and ways of doing things and creating new ways of seeing and doing was now the only option if they wished to re-enter their old communities and society at large. It was a very decided effort on the part of these MSers to better understand their world through their newly redefined life by critically reflecting on their

losses so as to make a plan of action that would allow their re-entrance into their social settings.

Donna pointed out that living with MS was a mental adjustment—

*It just was a real shock and I think I got a little depressed at first. So I think it just took me awhile to adjust.*

In order to live successfully with MS, Danny also believed his transformation was a conscious and rational decision. It meant rethinking your views and actions—

*You have to get on down the road and do what you can do with what you've got and let it go at that. You just have to find a solution. Find a way to work around whatever deficits I've got. When I started having some deficits that stayed with me after the exacerbations, it made me sort of sit back and think a little bit more.*

Transformative learning, according to Mezirow and the members of this community, is a process where meaning making becomes continually more clarified. The transformation was characterized by the individual taking responsibility for any actions deemed necessary due to their change in outlook. Each spoke of what had become more precious and important to them as a result of living with MS: family. They also continued to talk about how their actions toward other individuals with disabilities or weaknesses had changed due to their plight in life.

Danny stated—

*MS allowed me to live every day like it was my last. And as a result of that, I've spent more time with my boys, more time doing stuff with them, more time with MaryAnn [wife], doing more stuff with her.*

Nancy's transformation has not only been inward in nature but outward. She takes the lessons she has learned through having MS into her classroom—

*Yeah, I think I am more caring because of MS. I can't say I was always a compassionate person. But I've always had these barriers—students and teachers. And I think I've managed to melt that a little bit. I'm more willing to try. To me there are more things that I can get across to them [the student] if I try in a different way. And I'm more willing to do that now.*

Transformative learning is a process that moved the members of this research towards a more “inclusive, permeable and integrated meaning perspective” that brought the MSer to the place of making better decisions, which in turn brought about new understanding of the world in which they dwell. According to the analysis of the data derived from this study, members of this community incorporated a rational process in an attempt to understand and thrive in the communities in which they live.

Transformative learning provides an explanation for change in the way one views and directs his or her life experiences. As each individual in this community will quickly tell you, MS has impacted every area of their life. All will be able to immediately list the things they have lost because of the debilitating effects of this disease; all members will just as quickly be able to list for you blessings and lessons learned due to the effects of MS. This community will tell you that they are not the same individuals they were before the onset of this disease. In writing and reviewing the ten steps to personal transformation, it is evident to this researcher that the members of this community have entered into and have experienced and participated in transformative learning theory as described by Dr. Mezirow. The way this community views the world has evolved over

time. Their transformation was a process where their meaning making became more clarified. Their journey reflected a process that moved each participants toward a “more inclusive, differentiated, permeable (open to other views), and integrated” perspective of themselves and the world (Mezirow 1991, 155).

### ***A Call for a Mixture of Mezirow, Boyd and Myers Transformation***

Mezirow views transformation theory as a “conscious and rational” process of self-reflection that changes how individuals know and experience the world (Cranton 1994, 55). While identifying with the overall theory of transformative learning purported by Mezirow, I noticed that some aspects of my transformative learning process did not match up with Mezirow’s theory, even though I found a great deal of camaraderie and validation there. My experience has also been a process that included an emotional component brought about by my diagnosis of MS that was not given voice in Mezirow’s theory of how one makes meaning out of the traumatic experiences of life. The lack of discussion of the part that emotions play in the learning process led me to seek further discussion and investigation into what seemed to be a vital part of my transformation process.

Given the fact that MS is a highly unpredictable disease, the realization that one has little or no control over its progression leads me to agree with results from Pakenham’s research. He found that individuals with MS have a higher rate of emotional disturbance when compared with other patient groups having a similar level of physical disability (1999, 384). While Mezirow’s theory is directed toward personal development, his transformation is based on the “rational, autonomous, responsible adult” (1985, 27). This adult controls experiences rather than being controlled by an experience (1990a,

375). It is the individual's capacity for rationality that determines what is to be trusted and incorporated into meaning-making process (Clark, 1993, 51). For Mezirow, transformation is validated through a balanced discourse that will bring about one's "greatest assurance of objectivity" (1990b, 10), even though he states in his later writings that restructuring what an individual knows can be an "intensely threatening emotional experience" (2000, 6) and that adult must learn to "cope with anxiety over the consequences of taking action" over a newfound belief system (ibid.). Yet no discussion was forthcoming on the subject of how emotions enter into the learning process.

In fact, it must be noted that a common critique of Mezirow's transformation theory addresses its lack of discussing emotion adequately (Wiessner and Smith 2000, 334). So I continued to seek out other voices in an effort to validate and further explain what I considered to be one of my deepest turning points in my life, and I found a number of scholars who defined transformative learning in such a way as to acknowledge and include the emotions of the learner in the transformative process (Boyd 1991; Boyd and Myers 1988; Taylor 1997a, Dirkx, 1997, 1998, 2000, 2001; O'Sullivan 2003).

### **Boyd and Myers's Transformation**

According to Boyd and his colleagues, forceful and demanding feelings and strong emotions arise during transformative learning experiences that lead the adult's attention and efforts to seek to resolve hidden issues or concerns that play a vital role in the formation of an individual's personality (Boyd 1989, 459; Washburn 1988, 55). Boyd's work is based on the belief that the unconscious plays a strong and influential role in the formation of one's thoughts, feelings and actions throughout one's adult life. His view of transformative learning "seems to be grounded in Jung's concept of

‘individuation’ that leads to the further development of the individual’s personality” (Dirkx 2000b, 1). This notion of individuation supports the idea that emotions play a large role in the transformative learning process by using what is defined as “discernment.” This discernment calls upon extra-rational sources such as symbols, images and archetypes to assist in creating a personal vision through the transformation of the individual’s personality, which comes through resolving a personal dilemma. This brings about the expansion of consciousness, resulting in greater “personality integration” (Boyd 1989, 459). For Boyd, transformation speaks to the core of the learner’s being and plays a part in determining thoughts, feelings and actions on a day-to-day basis. It often focuses on the “emotional and spiritual perspectives of learning” (Dirkx 2000a, 82). What matters most in learning is what matters to the deep ground of our being, the psyche or soul, what is primary, original, basic and necessary (Sells 2000, 3).

The use of discernment is critical to the transformative process using Boyd and Myers definition of the adult’s learning process (Boyd and Myers 1988, 280). Discernment is comprised of three actions: receptivity (willingness to explore “alternative expressions of meaning”); recognition (acknowledgement that other ways of meaning may be valid to use for oneself); and grieving (realization that old patterns of perceiving are no longer relevant). When applied to the adult’s dilemma, this will result in fundamental change in the adult’s personality through the resolution of a personal dilemma and new growth and understanding of “self” in relationship to the learner’s world. This process of discernment allows for movement between the rational and the extra-rational, and this movement between the rational and the extra-rational is one of the most vital components of the learning process in the life of an individual with MS. It

allows the learner to recognize and develop an awareness of who they are and how they relate to others, which brings a greater appreciation for who they are apart from the social and cultural situations in which they are participating member (Dirkx 2006, p. 18).

### **Boyd and Myers's Transformation in the MS Community**

All within this MS community have admitted that the nature of this disease contributes to a continuous wellspring of emotions. No one on this planet is able to tell these patients what they can expect their life to look like tomorrow, much less a week or year from the present. Every day brings new sets of challenges, large and small. It is a disease of mystery; as Cathy so aptly stated: "It bit me in the butt. [The MS] creeps up on you very slowly, it doesn't like slam you, but it creeps up. I didn't have any choice."

Most all in this community talked about their struggle with this disease with tears in their eyes or tears running down their cheeks. During the interviews, it was common to hear each struggling for words to express their difficulties and victories. Words like the following were peppered throughout the interview process—"grieving," "sobbing," "bawling," "afraid," "frustrating," "screaming," "depressed," "laugh," "hate," "heart-broken," "relieved," "funny," and "panic attack."

Rationality or "reason" is the ability "to analyze the objective, visible world" in order to draw conclusions and form a worldview (Murphy 1999, 45). Imagination allows the mind to see what is "not present or accessible to the senses" (ibid.). Human beings are emotional creatures, and while it is almost impossible to explain our emotions or how we feel, all humans know and have emotional experiences (e.g., sadness, love hate, fear and happiness). Partly because of the above experiences, I feel failing to acknowledge the part emotions play in the MS community would tell an incomplete story.

Boyd (1991) suggested that transformation is not totally a rational approach to understand and make sense of one's world. He believes it to be an inner journey leading to an investigation into one's uniqueness that leads to the development of the individual personality (Cranton 2008, 35). As noted above, researchers Boyd and Myers (Boyd 1991; Boyd and Myers 1989) explained transformative learning as a process understood and achieved through what they described as *discernment* (Cranton & Roy 2008, 35)—a holistic orientation including receptivity, recognition and grieving (Cranton and Roy 2003, 90). These will result in fundamental change in the adult's personality through resolving a personal dilemma and allowing new growth and understanding of "self" in relationship to the MSer's world.

### ***1. Receptivity***

Receptivity implies that the MSer, in an effort to understand their personal situation, is willing to see a need to explore new ways to find meaning, navigate and understand their life and lived experiences. This acknowledgement is settled and considered a must in order for the MSer to realize their goal of reintegration into their society and community. Members of this study voiced the notion that they had to move on with their lives, reconnecting with what they viewed as their normal daily practices before feeling the effects of MS, all the while realizing that "normal" will mean adjustment and doing things a little differently from the past.

Cathy led a very active life before MS symptoms took a toll on her plans. She realizes, like others in this community, that changes in one's lifestyle are inevitable. Cathy is now coming to realize that the demands of her teaching job might be placing undue stress and fatigue upon her life. She is now reconsidering her options—

*I think maybe I could get—if I could spend some time doing some things—exercise stuff and yoga stuff—doing some things, I might be able to get in a little better position than I am right now [physically]. I do love my work and I really thought I got a lot of energy from it, but this year . . . I need to just re-evaluate some things.*

Cathy has moved past diagnosis and on to searching for alternate ways to find meaning in her life. Maybe less work commitment will bring about the time and energy needed so that she will be able to reconnect with her hobbies and friends.

Donna, after being told that she had MS, has recently found herself in the position to become the sole supporter for her daughter. She felt that she needed to think about what job possibilities she would have if her MS progressed to the point that her present employment was no longer an option. She was clear to point out that her possible future employment would have to be something that was of interest to her. During her interview she explained to me that she was exploring what she would and would not do if a career change were necessary. “There’s certain things I know I couldn’t be, like a nurse. I would like to be a nurse practitioner or physician’s assistant or something.”

Brenda found that some the activities that brought her a great deal of satisfaction were no longer possible, so she explored other options to fill the void she was experiencing. The ideas that seemed most promising to her were setting up a business on eBay and opening a quilt shop, both of which would still help her keep active and interacting in ways that will help others accomplish their goals.

## **2. Recognition**

Recognition is the step that acknowledges other ways of meaning may be valid to use for oneself. This second step moves beyond the identification of options to actually attempting to take action on one's plans or options created in the first step of the transformative journey.

Whether Brenda is thinking about how to get to the next room or how to get to a quilting retreat, she finds a way. She uses anything at her disposal to get her tasks done in her quilt shop; I just “slide along the wall” when working alone in her quilt shop and depends upon family members to facilitate her participation in quilt retreats. With planning, many of the old activities were still possible—

*I know my limitations so I depend on one of the girls. I know I can't go on all the trips I used to go on so one of them has to go with me. It's the friendship, the fellowship, the people you meet. It's the thing I can do on my own—the quilt retreats. It's the thing I can do on my own. But I always make sure there's at least one or two people that's known me for awhile or that has somebody in their family that has MS or something so when I need help, they're there.*

After much soul-searching, Brenda's dream of opening a quilt shop and starting a business on eBay became a reality—

*I make no profit. But it's worth it. Everything that I make I give to her [her daughter]. I mean, this is my quilt shop but she makes every penny off of it. That's one reason that I list things on eBay for people because that's one thing I can sit and do.*

Donna still wants to make a life for her and her small daughter. One of the things she loved to do was to go to new places. So even though the MS makes it impossible for Donna to go on long trips like going to the beach or New York, she goes to places closer to home—

*There are things that I don't do like vacations. I used to go all the time. I want to take my daughter to the beach. She's been to the beach once but I don't have as much, I don't know—courage. Like, if I want to go to New York. It's like, that's a little terrifying to me if I want to go to New York. But then, I don't walk very well. You know, I just think of those things. I'm not sure how to get over that. We do short trips which is not bad.*

### **3. Grieving**

In Boyd's and Myers' learning process *grieving* is the final action in transformation. Grieving speaks to the participant's realization that their old patterns of perceiving are no longer relevant, which then leads to new growth and a better understanding of one's self. When interviewing members of this community, all felt it was important to tell me (the researcher) what abilities, physically, emotionally or socially they had lost. Some participants cried while listing their losses, others seemed to be looking far back into the past as if wanting to relive their missing abilities.

Connie, who has had MS for 44 years, has seen a great number of changes in her life as a result of having this disease, including the delay of family plans and divorce. Given the difficulties she faces as a result of disease and aging, she told me that she does not view death as a foe to be shunned—

*It's [MS] certainly changed my view of death. I'm no longer afraid of death at all. Death can come at any time. It won't bother me. What I am afraid to death of is not being able to take care of myself. Much rather pass on versus live in a state of . . . inability.*

Donna has not been diagnosed with MS for very long and has lost very little physically compared to a number of others in this community, yet she is a reminder to all within and without this community that no one is left untouched by this disease. Her outlook on life changes—

*After I lost my eyesight and my vision came back, I never looked at myself the same. I don't know why? I just saw something totally different. I don't know. I just think there was something where I . . . one day I woke up and I wasn't . . . I didn't feel as pretty. I didn't feel as strong. I didn't feel as . . . all the things I did when I was 25, you know, I think I felt like . . . You know, I think you feel like when you're young, you have that anyway—you're invincible or whatever. I just lost that. And I never completely got that back. I think that's something that's changed me more than I realized.*

## **Conclusion Two: Boyd and Myers's Transformation Evident in the MS**

### **Community**

Emotions did play a large role in this community's transformative experience. This group of individuals spoke of spending overwhelming amounts of their emotional make-up trying to come to terms with their losses (physical ability, independence). According to Boyd and Myers (1988), emotions lead to a more personal journey that brings personal illumination (274). Boyd and Myers's transformation places significance

on the further development of the individual's personality (Dirkx 2000b, 1) leading to a better awareness of who they are and how they relate to others. This in turn brings about a greater appreciation for who they are apart from the social and cultural situations in which they are a participating member (2006, 18).

The MS journey is one that is unique to each member of the group. No two individuals have the same symptoms or difficulties; that is just the nature of the disease. This fact alone forces the MSer to look deep down inside for answers to difficulties no one else has experienced and confront demons real and imagined when they contemplate a life lived with MS. MS forces the individual to take a long, hard look at their victories, failures, goals and dreams.

None of the individuals in this study dialogued with me about their life with and before MS without shedding tears. To some, voicing their struggle to another person with MS (myself) brought a sense of validation. There were times in during our dialoguing that no words of explanation were needed—a look into each other's eyes told the whole story and brought a closeness that I will never forget. Others seemed to be letting go of built-up tensions they have held on to for a long, long time. The word *loss* or some derivative was in every conversation.

Lest you think that our conversation was all melancholy, I have to say that the members in this group at times cried for joy as they relayed to me some of the precious things that they have gained as a result of having MS. Most of this dialogue alluded to the depths of relationships they had formed over the course of this disease: family members who are so committed to the well-being of all in the circle called family; friends who haven't forgotten them after a long absence from the old haunts. The list could go on for

quite a while. Each spoke with pride in reference to the strides they have made personally in an attempt to get back some of their familiar routines.

Living with MS is an emotional roller coaster! Some days are good and some days are bad. It comes with the ebb and flow of the disease. This transformation involves coming to terms with deep and hidden things; this transformation calls for exploring feelings of discomfort and disorientation (Boyd and Myers 1988, 280).

All members of this group displayed the three components of Boyd and Myers's transformative theory: receptivity, recognition and grieving. Each of the MS members made extensive efforts not only to understand their situation but also to be willing to find new ways to dwell in their communities and families. Because of the uncharted waters each experiences due to the nature of this disease, all participants were open to trying new things or accept alternate views on issues that they thought might prove to be of benefit to their coping with MS. All expressed not only a desire to find new ways to look at difficulties but also mourned their old habits and ways of doing things which at times still seemed so "natural" to their existence.

Armed with the analysis of this research, I feel that this community of MSers did participate in the transformative learning espoused by Boyd and Myers. Transformative learning is an "evolving integration between two journeys, an inner journey into 'self' as well as an outer journey into the existential world" (Boyd and Myers 1988, 280).

### **Conclusion Three: Evidence that Both Transformative Learning Theories Coexist and Complement Each Other in This MS Community**

Given the overwhelming data provided earlier in this chapter, I believe it is possible for both Mezirow and Boyd and Myers transformative learning theories

successfully to coexist in this research study. Transformative learning has two sides: the rational and the emotional. Both have a role in the transformative learning of this MS community.

At first glance, Mezirow and Boyd and Myers's views about transformative learning seem too far apart to coexist or enhance each other in a study. Mezirow's theory employs a rational approach to learning, whereas Boyd and Myers' theory is expressed in emotions and feelings. Yet a number of similarities appear in both theories. Both use a rational roadmap to reach their goal of transformation—Mezirow has ten steps and Boyd and Myers have three. According to Grabov (1997) the two theories have a great deal in common: “humanism, emancipation, autonomy, critical reflection, self-knowledge, participation and discourse” (90).

Mezirow's theory focuses on conflicts experienced by the individual's connection with culture; Boyd and Myers focuses on conflicts within the individual's mind (Taylor (1998, 14). I see both theories as compatible with each other. First, all the participants took rational steps that led them to a place where they were able to become more inclusive, discriminating, open to other points of view, emotionally capable of change and more reflective in an effort to solidify beliefs and opinions to guide future actions. Second, rational thought and action is only part of the equation for a MSer. Humans are emotional creatures. We cannot overlook this aspect of our being; individuals with a chronic disease will never be able to stray far from their emotions. With the combination of the stress and the unknown associated with this disease, these MSers are continually striving to understand their innermost feelings. Understanding of emotions or *self* is vital to this community's ability to be grounded in what they believe and the actions they take.

The coexistence of both these learning theories in this MS community allows the freedom necessary to function in their world.

### ***Coping Strategies and Motivational Factors in the Transformative Learning Experience***

Attempting to adjust to living with a chronic illness introduces new problems of gigantic inconsistencies and irregularity, which are strongly linked to and influenced by the patient's social and environmental settings (Bury 1982,176). The initial impact of being diagnosed with an illness can include feelings of fear, shock and even relief, depending on whether or not the diagnosis was expected (Glacken, Kernohan and Coats 2001,109). Following this initial period, there seems to be a movement toward acceptance and modification of one's life in order to deal with illness (Sutton and Trelor 2007, 338). According to Pakenham's (1999) study that examined stress and coping models relevant to MS patients, overall adjustment to life with a chronic disease improved over time (390). It has been suggested in the past that this adjustment period is seen as a opportunity by the individual to begin to rethink and rearrange their self-concept in the new situation and reassess plans and expectation for the future (Bury 1982, 169).

One goal of this research was to identify and understand what coping strategies and motivational factors were influential and vital to the MSer's lived experiences. The diagnosis of a chronic illness like MS provides little likelihood of a complete return to the pre-illness state. Because of the illness's long-term nature, major changes must be made in the way life is conducted and lived. Here is a sampling of what was discovered.

## Ways of Coping in the MS Community

Coping strategies are activities and thoughts that aid the person in getting back to life and adapting life to accommodate illness. Some participants in the study *reframed their illness in a positive light*. Many of the members in this community made comparisons between themselves with MS and other medical conditions. Others spoke of how lucky they were not to have what they perceived as more challenging symptoms associated with MS. In all cases the MSer made the remark that they had gotten the better hand in each of the situations they described.

Since Kate displayed no symptoms of the disease until she was in her forties, most physicians did not initially think she could possibly have MS. (Symptoms of MS usually display themselves at a much earlier age). It was through her determination and persistence that Kate finally “had a name” to attach to her problems, which brought a sense of validation to what she had described for years. Kate told me in her interview that she was relieved to find out she did not have “Lou Gehrig’s disease, because it’s so closely related. Lou Gehrig’s disease kills you. MS doesn’t.” Even though the diagnosis of MS is hard to receive, Kate was relieved in a lot of ways simply because she had imagined the possibility of a disease that “kills you.”

Danny is an MSer who has not been able to slow the progression or course of his disease. He has tried every therapy available and is showing no sign of remission or slowing of the disease. His solace was to realize and remind himself that he “could be in a hospital bed. I could be in a nursing home or whatever” instead of being just in a wheelchair.

Another way individuals in this community cope with MS is to *play down the threat of the illness*. They saw their illness simply as a problem. This down playing of one's illness was paramount in the conversation I had with Jane. In this study, she had been diagnosed for shortest amount of time and had the least amount of physical deficits compared to others in this study. To Jane, her MS was viewed as "a very minor thing" that had not caused her to change a large aspect of her daily routine or change any long-range plans.

A different way that an MSer uses to face the day-to-day challenges of this disease was the use of *humor*. In an effort to ward off any visible signs of pity on the behalf of her co-workers, Jane created a funny, visual picture of how others could assist her in the future. She told them, "If someday you happen to see me on the floor, just sort of pull me over to the corner and put some parking cones around me and I'll be fine."

All in this community found that their illness helped to *create a stronger bond and thankfulness for family and friends*. Again, Jane related a story—

*All of a sudden I couldn't do it [inject her medication into her leg]. I would sit there with a needle over my leg for an hour, literally, willing myself to stick it in. [Her daughter] happened to be there one time and she kept saying, "Mom, you have to stick it in." And she sat there crying. And my heart broke for her, because I knew I was doing it for myself and she knew I was doing it for my own good.*

Some members of this community felt that having MS *forced them to refocus their outlook on life*. Donna came to realize after years of dealing with MS that she had to somehow come to terms with having the disease and find a way to coexist. Donna said that she had to choose—

*Either hate it and cause yourself more stress and more problems or you can accept it in a way that you try to be the stronger part of [the relationship]; you don't let it take over your life where you feel like you're not you anymore.*

Dick came to accept that there would be people who did not understand some of the decisions he made in order to better cope with his MS issues. He pointed out that he had “limitations and that if someone couldn't accept those limitations” then he did not “need them as a friend,” fully realizing that his attitude would “make for a limited supply of friends.”

A further technique used to cope with MS is *distraction*. Everyone needs to relax and get their mind off their struggles at times. Some ways this community stepped out of the daily grind of their MS world include long walks, walking a dog, watching television, reading a book, doing embroidery work and bird watching from their windows.

Even with the fact that no one really knows how this disease will affect any individual, all in this membership *expressed as hopefulness for the future* in varying ways. Dick sees himself as one who is “taking advantage of the system and doing very well.” He feels now that he has had the ability to go on disability and does not have the responsibility of going to work every day that “life is good again.”

### **Coping with Losses in the MS Community**

To the members of this community, remembering and discussing their losses includes not only embracing a diagnosis of MS but also accommodating a new lifestyle. It also speaks to reunifying the needs of the body with the self and/or soul in such a way that makes sense to the MSer. It is a life defined by a fine line between independence and support. For example, they focused on special meaning of what had happened, all the

while reliving past roles and routines that they had lost. This discussion brought out a great struggle of emotions; some were crying, others had eyes moist and glistening when they spoke of their physical losses. To a few of the members of this study their physical changes created body image changes. Upon finding out she had MS, Jane left the office and immediately went home and told her husband that she was “damaged goods.” I am happy to say that Jane went on to say that her husband got upset with her for making such a statement and reminded her he was there for her, no matter what.

Donna was very young at the time of her diagnosis and felt that she could take on the world; there was nothing she could not do. Then one day shortly after her diagnosis Donna said she woke up and “didn’t feel as pretty. I didn’t feel as strong. I didn’t feel as . . . all the things I did not feel you’re invincible or whatever. I just lost that.”

Others in this community were quick to let me as the researcher know what their losses were due to the MS. These individuals went out of their way to make me aware of even though they were resigned to a life with physical, emotional and cognitive issues, their resignation was not a sign of surrender. Each of their losses invoked sadness and anger in the individual. All in this community of MSers spoke of slowing down and being angry “when they have an attack.” That they were “mad” when they could not do the things they wanted to do because of the disease. Cathy described a problem she had to face due to her loss of being able to lift her right leg and foot—

*I went to a physical therapist because I have one particular pair of shoes that are really the only pair of shoes . . . and I’ve bought 40 pairs of shoes trying to duplicate that pair and I can’t do it. And she makes insoles. So I went to her. And she said she couldn’t help me, but she said, You look like you’re doing great.*

*You're just doing so great. And I was like, This isn't great. Go sit in the parking lot at Wal-Mart. Every 80-year-old woman is walking better than I am.*

## **Creating New Approaches to Living with MS**

When attempting to make sense of and create workable ways to adapt to a life influenced by MS, three areas of acceptance seems to be necessary: the emotional, behavioral and cognitive adaptation of the individual's view of life. The *emotional adaptation* aspect of coping speaks to the MSer's ability to incorporate a positive approach to their lived experiences. This does not mean that there are no low mood shifts; it is the idea that the individual may truly experience highs and lows but does not live in the valley on a constant basis. Danny tries to keep a balanced outlook on his lived experiences. He has come to view his struggle as a challenge that was meant to be overcome. After living with MS for over 30 years, he states that he is "still cooking" and that he is going to "keep on trucking."

Kate believes it is important not to focus on what you can't do but "enjoy what you can do." Kate told me during her interview that giving up her two passions of running and skiing was difficult, but she is more than happy to replace these passions for a new passion of travel.

The *behavioral adaptation* aspect of coping explores the MSer's attempt and desire to do what is necessary to perform whatever tasks were deemed necessary to stay at their present level of health in spite of the disease. This type of behavior in various circles of inquiry has become known as self-care, which is a course of action whereby individuals work on their own behalf in promoting their health and in preventing and treating disease (Levin, Katz, and Holst 1979). Danny told me during our interview that

he attributes his sustained degree of mobility to the fact that until six or eight months ago he use to work out on a regular basis. He is happy to do whatever it takes to “impact this disease.” In fact, he was happy to give himself his daily shot because he felt it was a “striking blow against the disease.”

Kate has been giving herself shots for years in an effort to slow down the disease and has thought up a way to lessen the stress of giving herself shots by calling it her “MS Macarena” routine. Kate keeps a log everyday of where she “shoots” herself singing, “arm, arm, stomach, stomach, leg, leg, stomach, stomach, arm and arm.”

The *cognitive adaptation* of coping speaks to the MSe’s ability to look beyond the required tasks of the day. Cognitive adaptation brings the absence of worrying thoughts about the illness or possible future difficulties. It is not a denial of the real situation, but rather an acknowledgement that one is able to confront problems as they arise, and successfully freeing the present. After going through the roller coaster of an MS diagnosis, both Doris and Jane have tried to get a realistic and balanced outlook on having a disease. According to Doris, who has had MS for a great number of years, “It not a handicap; sometimes it’s a nuisance. MS isn’t any more to me than a kind of nuisance.” Jane tries to see this disease in a positive light and does not view herself as an individual with “any kind of debilitation.” But she is very willing to help others who have not been as fortunate as she.

Another important aspect to successfully dealing with an illness is the move toward a lifestyle that acknowledges and accepts MS as part of who they are as an individual. It therefore must be part of the defining qualities in their relationships. It is not ignored but included and accepted in every situation and in every relationship. Most

everyone in this community felt that having MS forces you to become a more “outgoing person” because you did not have a choice. It was either become more outgoing or walling yourself up in your house. They believed that becoming an outgoing person was a direct result of trying to get those without MS to “pay attention to them,” because sometimes the MSer had to resort to poking, yelling or other actions to get others to pay attention to what they had to say.

#### **Conclusion Four: Coping within the MS Community Is the Result of Emotional, Behavioral and Cognitive Adjustment**

Even though each member of this community has a great deal in common because of this disease, the way each copes with the difficulties and trials presented to them as a direct result of having MS is profoundly unique. Coping with disease involves the use of the emotional, behavioral and cognitive adjustment in order to participate in this community and in the society in which they live. Past MS research has found that “passive avoidant emotion-focused coping strategies” (e.g., wishful thinking, self-blame and avoidance) are related to inferior outcomes across a multiple number of adjustment studies (Pakenham 2001, 412). For example, Brooks and Matson (1982) found in their study that better life adjustments or better coping skills were a direct result of accepting, not denying or avoiding the fact that one has a chronic disease. Acceptance of disease led to a higher degree of self worth and a more pro-active stance in one’s lived experiences (2133). Other studies even went further to suggest that taking a pro-active stance is closely connected with dependence on problem-focused coping (O’Brien 1993, 70; Pakenham 1999, 390; Pakenham 2005, 128) which is vital to successfully dealing with the ever changing issues that arise when living with MS.

Coping with disease involves all areas of one's lived experience, bringing into play the emotional, behavioral and cognitive influences of each MSer. For this reason I chose to explore how the members of this community have incorporated these influences into their lived experiences.

The *emotional influences* at times become the guiding force for one's actions as a MSer. During the interview process each in this community pointed out how important it was to incorporate a positive approach to their daily lives. For example: Brenda stated that when someone else attempts to put a "sad" spin on her lot in life, she reminds herself and others that she "got up out of the bed and both legs didn't collapse. Everything's positive if you look at it. Just keep positive."

Another area of exploration was a consideration as to how the MSer deals with the *physical requirements* of this disease. Is it a "*que sera sera*" attitude, or an attitude consistent with the notion of moving ahead and creating new avenues for one's self? It is an outlook that seeks to make improvements in one's physical condition in order to return to the many activities previously enjoyed by the MSer. It is working on their behalf to promote a high standard of health and actively seeking to prevent and to treat if possible the disease. All the participants in this study were actively seeking to find ways to better deal with the difficulties brought about by this disease, whether perceived as a need for better information on the disease itself, securing equipment that would help in mobility or enlisting in a medication regimen that might slow the progression of the disease.

For example, Cathy was looking for equipment that would help her to drive longer distances without getting too fatigued—

*I started have problems with my walking. I still just have a limp and I still do use an AFO sometimes. We do short trips [in the car]. Which is not bad. I think I just need to . . . the driving long distances bothers me a little bit. Well, it's where my right leg—that's my weaker leg—and that where the accelerator is. I've read a little bit about the hand devices and that might help some. So I need to check.*

The next area of exploration deals with the MSer's *cognitive adjustment* to living with this disease. This describes the individual's ability to move past the tumultuous aspect of having a disease and arrive at a place in one's life where the thought of having MS is accepted. It includes the feeling that they need not worry excessively about their difficulties, and allows times free from worry about present or future struggles. An example of this was evident during a discussion with Jane—

*To me, positive attitude. Find what you like, go to your happy place, even if it's in your attitude. Just keep a positive outlook, even when you start to feel down because down attitudes drag you down further. Negative thoughts are extremely energy draining. But I've never seen myself as having any kind of debilitation. I won't say I never think of it. Again, I don't dwell on it.*

One goal of this research was to identify and therefore understand how the members of this community cope and adjust to a life lived with MS. It has become quite evident that each of the individuals in this research have spent a great deal of time, thought and energy creating ways that has equipped them to live with a great deal of success and satisfaction within their homes and communities. These individuals have sought to manage their own chronic illness in ways that allow them to understand issues

and needs required to navigate in the world where illness is to not only be avoided but kept in the shadows.

## CHAPTER 6

### *Findings: Power; Voice and Place; Medical Establishment*

#### *Introduction*

As my interviewees shared their experiences of their struggle in the process of receiving an official diagnosis of MS, common themes around the topics of power, voice, place and the medical establishment emerged. The interview question that led to the following findings was: “What factors have hindered your ability to deal effectively with MS?”

#### *The Issue of Power for MS*

Murphy, Scheer, Murphy and Mack (1988) state that individuals with a chronic illness live in a “marginal state,” one that connotes that they have lost their old status and they have not yet acquired a new one. The view in society is that an illness consists of two phases where “people get worse” or “people get better.” But though MSers might be perceived as entering into the phase of “getting worse,” their MS does not really get better. There is no cure. It is an ongoing process at best, which brings the individual into a period of remission with no guarantee that the disease will stay in this condition. Murphy, et al. stated that individuals living in this situation exist “in a kind of limbo” (235) and “in twilight zones of social indefiniteness” (237). MSers are suspended in a social space without solid identity or role designation. Kagawa-Singer (1993) addressed this notion by suggesting that:

Being neither sick nor well, the chronically ill or disabled are socially in a state of limbo. They must create socially valued positions for themselves by re-establishing the fact that they are still the same individuals even though they are inside bodies which no longer meet society’s requirements of “health” (296).

To many living outside the MS community, MSers are perceived as individuals with impairments who lack wholeness, and they are therefore pushed to the margins of society. This perception leads to the disruption in the power and status of the disabled. Our need for membership in a group becomes very strong when we are faced with health problems and possible disability, because these experiences tend to threaten our personal identity and performance, which even the most individualistic of us needs and looks externally to others for support and validation. However, since the acquisition of a chronic illness and/or disability are seen as countering current values such as “prosperity, speed, independence, self-reliance, and productivity” (Lyons 1999, 1), it is of little astonishment that individuals and their relationships struggle to adapt to this new environment that feels unknown and strange.

The amount or lack of support an individual receives from family members, friends and their medical provider directly affects the perceived degree of wellness and general overall outlook on life (Boise, Heagerty and Eskenazi 1996, 75). Many MSers quickly come to realize that generally people with whom they come in contact have a low tolerance for anyone who has an illness. Many express verbally or through their actions their propensity for wanting to “fix things,” and their lack of this ability to “fix things” only makes them feel helpless when confronted with another person’s health problem. Individuals with chronic conditions are frequently urged to “get on with it” or “snap out of it,”—anything except talk about it.

While interviewing the members in this community about the struggles they have faced, almost all within this group felt it very important to bring to my attention that over time most realized at some point before receiving an “official” diagnosis of MS they

*knew* that was the source of their physical difficulties. This was not a new suggestion to me, having gone through the same experience years earlier. Yet I listened with great interest to the experiences of the various members in this community in an effort to understand their view of physicians and the medical establishment as a whole.

All the participants felt it necessary to discuss what I have called their “journey to diagnosis.” All had very strong feeling on this subject. In fact, no one refrained from dialoging about this topic. Each participant felt that this story and/or topic must be told in an effort to make outsiders aware of the difficulties at the beginning of this lifelong struggle and also to demonstrate that they were correct in their choice to push on to eventually receive the conformation of their suspicions. To tell their story seemed to bring validation to their lived experiences. For example, Nancy states about her validation in the following way—

*I started feeling like a female . . . I felt that’s how I was being perceived until I got that diagnosis [of MS using the MRI scanner] that gave me a stamp of approval.*

### **Journey to Diagnosis**

The entire group of participants in this research expressed a sense of relief once they were finally given the news by their attending physician that they had a definite clinical diagnosis of MS. For these participants, the struggle to obtain a concrete diagnosis of MS was a long drawn-out process of elimination due to a number of factors including the elusive nature of the disease itself and the availability of diagnostic equipment. In this community the MSer had to interact with a number of doctors in order to establish a diagnosis of MS, but along this journey there was nowhere to turn even for temporary relief. Often the MSer was left to his/her own devices to cope alone with the

disturbing symptom that brought them to the doctor in the first place, hoping to find help at their next appointment with a new physician.

Early MS diagnosis is especially important because early treatment can help slow the progression of the disease. In fact, early treatment can help even if you don't have visible symptoms of MS. That's because the disease often progresses silently, causing nerve damage before you're even aware of any problems. One of the few options used to diagnose this problem involves the use of an MRI (Magnetic Resonance Imaging) machine. It creates a magnetic field to create "cross-sectional images or scans" of the brain and spinal cord. These scans reveal damaged myelin and scar tissue associated with this disease and can eliminate the prospect of the patient having a number of other neurological disorders and diseases (MSActiveSource 2008). Yet some of the newly diagnosed MS patients in this research still stated that they had difficulty getting their physicians to have the test performed at their local hospital, citing that their symptoms could possibly be from other causes.

In an effort to find answers to their difficulties, most MSers look for answers from numerous sources because the physician is now perceived as unwilling to help in their struggles. As a result of the MSer's persistence to find the elusive piece of the mysterious puzzle, usually over time and through the process of self-reflection he/she finds the answer to their problem. This diligence often results in the patient's own confirmation of having MS long before the physician makes the diagnosis. Armed with their suspicions, many prospective MS patients try to make a case for an MRI scan, only to have their views and observations dismissed or ignored by the attending medical professional. Most all in this study expressed an overwhelming sense of paternalism and disempowerment

when in the doctor's office. According to this group of individuals, interactions with the physicians and their staff are an oft-cited instance in which the MS community's voice is dismissed.

A study conducted by Ian Robinson (1991) in the United Kingdom surveyed 900 MS patients and found that many patients experienced lengthy periods of time between the first perceived symptom of the disease and the point an "official" diagnosis of MS was made. The mean number of years between first symptoms and diagnosis in Robinson's study (consisting of 242 men and 676 women) was approximately four years (18). The mean between first symptoms and diagnosis in my study that consisted of ten participants (eight women and two men) was 7.31 years.

Many in this study became very animated when dialoguing about their struggle to receive an "official" diagnosis of MS that, when received, seemed to address the issue of worth and vindication to their lived experiences.

Brenda, a local shop owner and civic activist, spent a number of years going to various doctors only to receive any number of reasons for her difficulties. She began telling me about her struggles and frustrations—

*I have been diagnosed with everything. You have this, this, this and not this, this, this. So I then would wait—okay, I found an answer to my question until I would go to the next doctor. So every time they'd tell me I had a disease, I would go into the library and do some research on it. Anyway, that's how I found out [I had MS]. All the diagnoses and everything they gave me and all the different diseases—I became very anxious. Now I still have anxiety attacks.*

Now through her personal research she had a disease that she thought fit her experiences, but the steps to diagnosis meant—

*Finally, I lied to the doctor. I told him I was having violent headaches I didn't know what I was doing. I couldn't see. So that's when she sent me to a neurologist and they did an MRI. And that's when I found out. That's how I did. That's the only way I could get them to do an MRI. So I lied. Well, sometimes when there's a will, there's a way. When you want to know something. Because I had done so much research that an MRI would tell them—they would see it on an MRI. But I had to have a reason for them to order an MRI.*

Similarly, Donna, who directs and leads a community organization that helps to feed and clothe the needy families in a small community, found that her experience to get answers for her vision problems brought a quick and belittling remark and tone—

*I lost the vision in my left eye and it was a total loss for a couple of weeks and just went to one eye doctor and the man was like what do you mean you can't see? I said, I don't know—I was 26 years old. Hold on one second. There was a decrease, just vision, there's something wrong. And, yeah, I remember him and can't see. And I was terrified. But I just felt like—I didn't go back. They said, well, come back in a couple of weeks, you know.*

Nancy's experience with the medical establishment was even more revealing—

*I went to a neurologist, just over the river and he was very dismissive of my symptoms. None of the physicians down here seemed to want to take it seriously. I started feeling like female . . . I'm moving into that age . . . I felt that's how I was*

*being perceived until I got that diagnosis [of MS using the MRI scanner] that gave me a stamp of approval.*

For Doris, all the pieces fit when she finally received the diagnosis of MS. Her intuition, the symptoms and the results of the MRI scan only gave credence to what she had been trying to tell all the physicians in the past, if they had only listened and not shushed the obvious—

*But all of these years I have suspected it. I'd go to the doctor and the symptoms were like, use the trunk of the elephant. Here's the tail of a camel and when he said you know what I've got to tell you, it was a relief. [The doctor] said he had never heard anybody cheer for an MS diagnosis. I said but I have a diagnosis. I now know what is wrong. And it's a relief to know what's wrong. Because then you can deal with it. I had been telling doctors how bad I had MS and they would tell me it was all in my head. Well, in my case, it's all in my spine—I just, all I could think of was here I go again with another year trying to get somebody else [to listen to me].*

Dick went to his physician over the period of a month and received this response when he told the physician his difficulties—

*I kept going to my doctor because I knew something was wrong with me. And about this time I was in a triathlon. After a couple weeks of him doing tests and not finding anything wrong with me, I said, Heck with this. I went and did this triathlon and after the thing was over, well, I knew during the event, while I was running something wasn't right. But I kept getting dizzy. So after the event was over, some guy that passed me during the run came up to me and goes, Is*

*something wrong with your leg? and I said, There's nothing wrong with my leg. I was just real dizzy. And he said, No, there's something wrong with your leg. So I went back to my doctor so I said, somebody passed me during the run and said there's something wrong with my leg and he said, Hmm, walk down the hall. So I walked down the hall and I walked back and he said, Walk down the hall again. So I walked down the hall again and back and he said, I'm going to give you some more blood tests. And if that doesn't show anything I'm going to give you an MRI.*

Danny had few symptoms of MS, but when he was in a car wreck and had an MRI he was told that he did in fact have MS—

*I first had the symptoms that I noticed back in 1978–79, primarily it was numbness in my hands, arms, forearms, and then a little bit down under my legs. And then I got into the car crash and that was like '83 or '84 and that's when they took the MRI and found the lesions. I was diagnosed with relapsing, remitting initially.*

## **Gender and Diagnosis**

It also became evident after analyzing the data that not only were there powerful forces working against the well being of the individuals in this group, but that credence to the patient's complaints seemed to be brought into a higher degree of question when the patient was a woman. I am aware that there were more women participating in this study than men (8 to 2), which will call into question my assumption that physicians are more readily open to acknowledge and accept the man's view of his thoughts on illness than the women's view of her possible MS diagnosis. Yet the dialogue of my participants spoke volumes.

I exclude Danny from this discussion since he found out he had MS through extenuating circumstances (a car wreck). From my conversations with Dick it was clear that his prospective thoughts and comments to his physician about something “not quite right” were taken seriously and explored. Four blood tests were given and an MRI was performed after approximately two weeks of investigation. When he received his diagnosis, Dick felt that his relationship with his physician took a turn for the worse—

*I'll never forget the next thing [he said after my diagnosis]. He says, You go out and talk to my nurse and I just felt like he was kicking me out of his office.*

At no time during our discussion did Dick mention that he thought that the doctor ignored, played down or criticized his thoughts about his possibly of having MS.

In this study the women had a more difficult time acquiring an “official” diagnosis of MS, even though they read and collected data in support of their claim. One example comes from Brenda—

*So every time they'd [doctors] tell me I had a specific disease, I would go into the library and do some research on it. That's how I found out [I had MS].*

The women in this study used words and phrases like the following to describe their experience: “dismissive”; “I'd go to the doctor and the symptoms were like, use the trunk of the elephant. Here's the tail of a camel [in the room]”; “They would tell me it was all in my head”; “They thought I was a hypochondriac.”

Coming face-to-face with what I could only describe as an injustice by members in the medical profession toward women, I sought out other studies that would either confirm or bring into question my assumptions brought about by my research. To my knowledge no studies have investigated the differences in the care of men and women

who have MS. The one study I did locate that had information that could be somewhat relevant was Ian Robinson's research (1991) that discussed under "what circumstances the communication of the diagnosis of multiple sclerosis should take place" (17). This research explored issues relating to when, how and in what situations the diagnosis should be disclosed to the patient.

Embedded in this study were some interesting statistics pertinent to my research. First, it must be stated that this research study was performed for the Department of Human Sciences at the University of West London in the United Kingdom and was part of a larger research program. This study's conclusions were based on completed questionnaires asking questions about the circumstances when their diagnosis of multiple sclerosis was disclosed. These surveys were returned by 918 patients. Some information was quite interesting in light of my findings that the male patient's opinions and ideas concerning his possible diagnosis of MS was legitimized and given a greater degree of credence than the women in my research.

In Robinson's work, the mean number of years between the perceived first symptom and the discovery of the diagnosis was 4.2 years. Second, the women in Robinson's study were diagnosed 1.2 years later than men, even though the women's first symptoms were distinguishable 11 months earlier than the men. One reason given in this research for the delay in telling the MS patient that he truly has MS was the physician's opinion that the patient would react negatively to the news, since the physician had no satisfactory therapy for the disease nor an idea of the course outcome of the disease.

## **Conclusion Five: Hegemonic Forces in Play**

It was evident in my research that the MSer had little, if any, control over their health physically or emotionally. All the women had to repeatedly return to their initial physician or seek out a new physician in an effort to receive what they believed to be the right direction for diagnosis. I also conclude that hegemonic forces were in play when the women had to spend a great deal of energy to be heard and taken seriously by the physician, especially when the man in this study met with no type of emotional attack and his ideas were given credence.

It would seem to me that my research, though small, is consistent with the findings put forth in Robinson's research that examined the context in which individuals received their MS diagnosis. In my study, the participants dialogued a great deal about how and when they received their MS diagnosis. In both studies the men received their MS diagnosis earlier than women; 1.2 years earlier in Robinson's study and 1.3 years earlier in my research. In the Robinson study women exhibited symptoms eleven months before the men. Even though I cannot say how long the women in my study had symptoms relative to the men, I can state that the women had experienced numerous symptoms before they were given the opportunity to have an MRI scan in order to receive an "official" diagnosis. The man in my study only complained of a slight limp before he was allowed to have an MRI scan to receive his diagnosis.

The woman participants in my study stated that they were given little respect when they spoke about their struggles, and their suggestion that they may have MS was ignored. They believe this is why it took longer for an "official" MS diagnosis. No exact reason was given to account for the "official" diagnosis difference in the Robinson study

except that the “patient’s reaction” to troubling news hindered the physician from giving a quick and timely disclosure of the patient’s MS diagnosis. I believe it is this perception that led to the disruption in the power and status of the women participants in my research study.

## ***The Importance of Voice and Place***

### ***Voice***

My goal in this research has been to make the experiences of these ten individuals within the MS community come to life, with the hope that their stories of struggles, their successes and their dreams would allow their voices to be heard and their realities seen. The participants’ stories brought forth new knowledge, proving insight into the lived experiences of the members of the MS community may assist a variety of groups in their knowledge, understanding and care for individuals living with MS. It was exciting to see our conversations move from skepticism to enthusiasm and excitement as the members of this community realized it was their voice that I was interested in, not mine, and not that of an organization.

All wanted and needed to tell their story. Some could not openly declare their position to the world for fear of oppression and marginalization. With these MSers my heart cries. To have an illness that so dictates what you will do and achieve each day and not be able to openly shout your frustrations and successes saddens me. But I know your pain. To tell or not to tell—it is a line if crossed there is no return to the former state in any relationship, whether close or extended.

A study by Bury (1991) that explored the lasting and long-term effects of rheumatoid arthritis stated that the phenomenon of chronic illness makes a “significant impact upon the physical, social, psychological and even the political events in a patient’s life” (452). Attempting to adjust to living with a chronic illness introduces new problems of gigantic inconsistencies and irregularity, which is strongly linked to and influenced by the patient’s social and environmental settings (Bury 1982, 176). Another study by Hayden (1993) that looked at the relationship between having a chronic illness and communication in which he drew this conclusion: “[T]hose who live with chronic illness face a multitude of issues that challenge the communication process, yet we know very little about how those living with chronic illness face these challenges” (266).

To have MS and make it known in any number of settings can often mean that the MSer is displaced and relegated in a number of ways to the outer boundaries or the margin of society and could lead to a lifelong “feeling of otherness” (Viitanen, E. and Piirainen 2001, 132). The term “other” or “otherness” has been used by Africanist, Latino, gay/lesbian and feminist scholars to indicate their marginalized status within society (Sheared and Sissel 2001, 13). It is a term most often used to emphasize and draw attention to society’s silencing of a particular group of people. Even though the term *other* is not readily associated with a person with the chronic disease of MS, many individuals in this community can describe their lived experience among various groups and institutions as limiting because they are given the impression through comments, actions and reactions that they are not worthy enough to participate in the decisions and intricacies of society. They are forced to use creative means in order to just exist in our society. Our goal is to listen to others discuss their struggles and take their discourse into

consideration; then we can act more favorably to everyone involved in whatever the situation. Who better understands the effects of marginalization and oppression than the group who are the target of this type of injustice? One way that Hayden suggests is to listen to *their* stories. Listen to them discuss their experiences and situations.

### ***Place***

Members of the MS community are very much afraid that society will view them as individuals who are not able to make decisions and care for themselves. In fact there are occasions when the very institutions that are supposed to help MSers in their struggle to be fully recognized members of society at times affect their lives in a negative way. Some individuals in this community must keep their illness a secret for fear of losing a job or being perceived as an individual who can no longer carry out their tasks in the workplace. Kate, who just recently became a tenured instructor, still feels vulnerable—

*I think if more people outside [school department heads] knew. . . I don't know, I think I'm afraid of discrimination, job discrimination. I really am. I'm afraid of that.*

Others are troubled about the way they are viewed and treated by society in general.

Danny made that very clear in his interview—

*I've noticed, like in the airports and stuff like that when I've had MaryAnn [wife] or my nephew or somebody like that pushing me around people will avert, they won't look at you. They tend to look away. And then the second thing is, like when we go through security, they would talk to MaryAnn. They wouldn't talk to me. I'm like, Hey guys, I'm down here. You can talk to me.*

Examples like the ones above abound in my research material. It is time that we as a society open our arms and welcome members of the MS community to take part in all activities granted to members in the mainstream of society. This inclusion will only come through the struggles of members of the MS community itself, pushing to get the recognition they deserve. It is getting involved in the political process, as well as dialoguing with everyone who will listen about the virtues and justice that only comes through equality. Those outside this MS community must also take it upon themselves to see that the rights and privileges of those on the margins of society are given a voice and a place to pursue their dreams and aspirations. Again, this is done through political means and enlightening those who have yet to be persuaded to rethink and question their learned beliefs. We all, MSer or not, must make it a high priority to uplift the marginalized groups in this society.

### ***The Medical Establishment***

The majority of people who speak about MS and those who get the most press coverage or air time come from the medical and scientific community. In my estimation, this unfortunately works against the members within the MS community who are trying to live a well-rounded life with this chronic illness. For these participants, the struggle to obtain a concrete diagnosis of MS was a long drawn-out process of elimination. They often had to interact with a number of doctors in order to establish a diagnosis.

Individuals in this community spoke on numerous occasions about their inability to get their physician to take seriously their complaints and suggestions as to what they felt caused their distress. Beisecker (1990) argued that the “medicalization of society has allowed the medical establishment to increase the scope of its power and control” (105).

The “medicalization” to which Beisecker refers is the infringement of the physician’s authority into the day-to-day living, well beyond diagnosis and treatment (ibid.). The infringement includes silencing their patients, especially the women patients. This silencing recalls numerous references to what is called the “medical gaze.” This term, attributed to Foucault (1963), details the medical establishment’s view of the patient. The patient in the hospital is the subject of his disease; in the clinic he is a case, the accident of his disease, the temporary object of that disease (59). In other words, the patient is only the carrier of the disease and therefore loses some of his status as an individual.

Rood (1996) explored issues of chronic disease from the perspectives of the illness itself (diabetes), the individuals who suffer from the illness, the physicians who are in charge of their care, and the physician’s training process that prepares them to take care of diabetic patients. He states one of the first things is that physicians must realize that “chronic disease is chronic” (730). The patient may have good and bad days, but the disease will never go away. The research goes to great lengths to relay to the reader the struggles that both the physician and patient have when perceptions of the type of care needed and goals in the patient’s disease management have not been obtained. This leads to a discussion of what the ideal physician should do to foster understanding and camaraderie in the patient’s care, only for the researcher to then make the following statement that is key to many of the difficulties faced by the MSer: “Despite recognizing intellectually that no one is omnipotent and no one can control another, most physicians still want to control patients. They believe emotionally that they have the power to direct outcomes” (737).

It is time for physicians to realize that they cannot cure or control all the ramifications that come with having MS and to seek the insight and wisdom of the individual who knows firsthand the difficulties and trials associated with this illness. Perhaps the need is not for the individual to come to terms with the adjustments they must make in order to live with MS. Instead, the need is for society to adjust to the changed requirements of an individual. Perhaps health professionals need “rehabilitation” more than MSers do.

### ***Emotional Support***

It has been demonstrated by this study that the emotional well being of the individual with MS is closely connected to their ability to cope successfully in our society. I am amazed when I hear that after the official diagnosis in the physician’s office, the patient is dismissed to find whatever they can to cope with this disease. The most help that I have ever received from a physician on the day of diagnosis is: “I’m sorry to have to tell you this but . . .” All I have ever heard from other MSers is similar: “Sorry . . . see the nurse,” who tells the patient to contact the Multiple Sclerosis Society. The society is a wonderful place to go for suggestions and answers to questions, but the physician holds some level of responsibility to start the MSer on a successful journey. After all, the physician has been the person in power, “calling the shots” in the physician/patient relationship.

The study by Rood (1996), mentioned in detail earlier in this chapter, carried an interesting statement that speaks volumes on the subject of emotional support. Rood, while discussing how the physician views him/herself stated, “Physicians are taught they can conquer disease. Most believe in themselves and their power.” Yet when they are

unable to cure the disease the physician sees this *failure* as “personal. To some physicians failure is intolerable” and they “cease to being involved with their patients; they become angry, hostile, and combative” (737).

I implore the MS community to make their wishes known to the physicians; let them know that just giving a diagnosis of MS to the patient is inadequate. To the physician, given the fact that MS is the most common neurological disease, would you strive to have material in your office about the disease and spend a little time, even though time is in short supply, talking about the gamut of emotions that will be experienced by the MSer? Direct them to information, phone numbers, addresses and so forth. I believe this will at least reassure the newly diagnosed MSer that you really care about their plight. A little goes a long way when one is given such shocking news.

## CHAPTER 7

### *Recommendations*

#### **Transformative Learning: Rational and Emotional**

The first recommendation comes directly from the implications in the previous chapter. More research should be conducted to determine how and to what extent rationality and emotions play in the transformative learning process.

Mezirow (1991, 1995, 2000), Cranton (1994) and others suggest that adult learning is a never-ending process of “re-constructing the meaning of our experience and reflecting a capacity for individual growth, change, and transformation” (Dirkx 1998, 1). Using this paradigm, the emphasis is on rationality that can lead to transformation. Empirical studies support Mezirow’s argument that critical reflection is vital to transformative learning; others have “concluded that critical reflection is granted too much importance in a perspective transformation, a process too rationally driven” (Taylor 1998, 33–34). Critics have pointed out that Mezirow places too high an emphasis on rationality with little regard given to the significance of feelings, insight and the nonrational in the transformative learning process.

A number of studies now exist that explore the connection between human thinking and decision making. One such study by Muramatsu and Hanoch (2003) suggests that emotions themselves can be viewed as “an information-processing system,” a way to make decisions (9). Another study by Damasio (1994) explored the interconnections between emotion and cognition and found that emotions played a vital role in processing activities involved with higher forms of cognition like decision making

(xvii). Emotions should be recognized as inherently cognitive, because research shows that “emotions anticipate future needs, prepare for actions, and even prepare for thinking certain types of thoughts” (Parrott & Schulkin 1993, 56). The purpose of emotions is recognized more and more as bridging the “gaps left by pure reason in the determination of action and belief” (de Sousa 1991, 195).

A second recommendation for further research involves investigating learning transformations that may not reach the traditionally expected levels of discrimination, integration and permeability as described by Mezirow, and those who had not progressed through the three stages of discernment (receptivity, recognition and grieving) as described by Boyd and Myers. Please note that this research study actively enlisted participants who demonstrated by their answers to an initial survey that they had to some degree acquired the acceptable levels of discrimination, integration and permeability.

A third recommendation for future research would be to explore whether the presence of both Mezirow’s and Boyd and Myers’s learning processes makes a difference in the outcomes consistent with transformation. For example, is the acquisition of a new paradigm a smoother or more difficult transition for the learner; is the length of the learning process shortened or lengthened?

A fourth recommendation would be to conduct research that incorporates mandates in the curriculum for the inclusion of practices that would promote not only the “rational” aspects of transformation but also the emotional aspects of transformation. We should make room in classroom discussions for self-awareness or self-knowledge that leads to a deeper “more imaginative and profound relationship with one’s self and the

world starting with fundamental questions with regard to who we are as persons, what our world is about, and our role in the world” (Dirkx 2000a, 82).

### **Support in the MS Community**

A fifth recommendation for future investigation would be to discover what the transformative learning process would look like for an MSer who has no relational support (immediate family). In this study all the members in this community of MSers had the overwhelming support of family and friends during their diagnosis and adjustment to a life living with MS. This is not the case for a great number of MS patients. The divorce rate for marriages in the United States in which one partner has MS is between 75 to 80 percent (Hitch 2007, 1). Many MSers will be forced to face the diagnosis and effects of MS without the help of a strong family support system.

The amount or lack of support an individual with a chronic disease receives from family members, friends and their medical provider directly affects the perceived degree of wellness and general overall outlook on life (Boise, Heagerty and Eskenazi 1996, 75). Grytten and Maseide (2006) concluded that emotional support from family members enhanced the MSer’s sense of well being and attributed to greater social adjustment (202).

The impact of a chronic illness such as MS brings a number of changes that encompasses many relationships: family, friendships, co-workers and community members. Illness can change relationships substantively, and the impacts on network structure, function and quality are surprisingly similar across a broad range of health problems (e.g., cancer, multiple sclerosis, spinal injury) (Lyons 1999, 2). MS brings many changes in one’s social network, including a diminished size of one’s social group,

decreased frequency of interaction and the loss of friendships (1991, 245). Illness not only affects the amount of time one may devote to participation in a social group, but also brings about discomfort in communication and support processes (253). For this reason, it is imperative that researchers continue to identify and provide suggestions that will help individuals to acquire the support needed to battle against this disease.

A sixth recommendation for future investigation would be to create a family support model for MSers. As more and more individuals are being diagnosed daily—approximately 200 individuals per week worldwide (Multiple Sclerosis Society, 2008b)—it becomes more critical that a model to help individuals and families sustain their optimum health and well being is necessary. There is a need for programs and/or guidelines that will enable the MSer to take responsibility for their own selves by enhancing their knowledge of how to stay well.

### **Medical Support for the MS Community**

A seventh recommendation is that the health community creates a curriculum that would prepare physicians to counsel and care for their patients with chronic illnesses. Although medical advancements have made it possible for individuals to live longer and healthier lives, the health care system has made only incremental adjustments to meet the needs brought about by these advancements (HarrisInteractive 2003, 1).

The MS participants in this research study felt that their physicians were neither anxious to find the physical cause of their difficulties nor were they available to discuss the intricacies of MS when they did receive their “official” diagnosis. A comprehensive survey that explored how individuals successfully managed their chronic health conditions and how the patient-physician relation could be optimized found that patients

who viewed their care as including “a productive and efficient exchange of information” viewed themselves as “living well,” compared to patients who felt a disconnect between themselves and their physician (46% vs. 30%) (HarrisInteractive 2003, 18). The disconnected patients, who viewed themselves as “not living well,” were given pamphlets, brochures or other ways to learn about the condition. Neither the physician nor the patient should underestimate the power of relationships when it comes to health issues.

An eighth recommendation would be to examine the perceived needs of individuals with MS or chronic diseases and/or the perceived needs the physicians who play a major role in their health care in order to create programs that would attend to the needs of both groups. This could provide the MSer with satisfactory care and also improve the patient-physician relationship.

### **Medical Community Policies**

A ninth recommendation would be for the health community to reevaluate their stance on the availability of the MRI screening to possible MS patients. Early MS diagnosis is especially important because early treatment can help slow the progression of the disease. In fact, early treatment can help even if you don’t have visible symptoms of MS. One of the few options used to diagnose this problem involves the use of a MRI machine. It creates a magnetic field to create “cross-sectional images or scans” of the brain and spinal cord. These scans reveal damaged myelin and scar tissue associated with this disease and can eliminate the prospect of the patient having a number of other neurological disorders and diseases (MSActiveSource 2008). Yet some of the newly

diagnosed MS patients in this research still stated that they had difficulty getting their physicians to have the test performed at their local hospital.

The participants of this research struggled for an average of 7.3 years to obtain a concrete diagnosis of MS. During this time they read, studied and spoke with a number of doctors about their suspicions of having MS, only to have their physicians dismiss their idea. Through the persistent efforts of the members of this community, they were eventually able to obtain the necessary papers to get an MRI to either confirm or deny the possibility of having MS. If the goal is to help the MSer, access to medication as quickly as possible seems reasonable.

Lastly, the tenth recommendation would be an exploration into why the men in this study were “officially” diagnosed 1.3 years earlier than the women, even though the women had numerous symptoms compared to the man’s single symptom when explaining their condition to the physician. The study conducted by Robinson (1991) that was mentioned also presented disturbing statistics about gender differences in diagnosis (17). Further investigation into diagnosis on the bases of gender seems appropriate.

### ***Final Thought***

To the best of my ability, I have honored my commitment to the ten individuals in this MS community who worked with me in creating this work. These are their experiences within these pages, a glimpse into a community of strong, courageous and caring individuals who desire to live a life that will bring understanding and hope to all within and without this unique community.

## **AFTERWORD**

### ***The Adult Learner and MS***

As a teacher for a number of years, I would be remiss if I did not make those who educate adults aware of some possible strategies that an educator can incorporate into the classroom dynamics that may prove beneficial and vital to the learner's success in the classroom. Approximately 400,000 people live with MS in the United States; more than 200 individuals are diagnosed with MS every week (National Multiple Sclerosis Society 2008b). Because MS is the most widely diagnosed neurological disorder that often makes itself known to the adult when they are in their twenties, it is quite possible that educators will have students who are struggling to understand and adapt to their physical, emotional and cognitive issues brought about by this disease of MS.

The daily life of an individual with MS requires a great deal of spontaneity, for each day brings a different set of difficulties with which to cope. One day it could be walking; the next day, your legs could be stronger and your hands are shaky. The MSer must be a quick study when it comes to adapting, which will make it hard in most cases for the fellow classmates and instructor to get a true picture of the struggles the student is facing throughout the course of the school term. This being said, there are a number of things that both the student and instructor can do to make learning a more enjoyable experience for all involved in this process.

### ***Possible Cognitive Difficulties for the Student***

Most of the attention focused on the disease of MS points to the physical difficulties associated with this disease. In the last ten years researchers have found that MS affects the mind's ability to perform a wide variety of tasks, including the ability to

“store, organize, and recall information. Memory deficits, a slower response to problem solving, or a shorter attention span” are consequences of having this disease (National Multiple Sclerosis Society 2008a). Research suggests that 40 to 60 percent of individuals with MS have to some degree or another some cognitive issues. According to Dr. Rao, who has been exploring the topic of cognitive issues of MSers since 1981, most of the time these issues are just mild problems affecting the area of memory and attention.

Below is a brief outline of the most common symptoms:

- Recent memories are difficult to recall. MSers can still learn and retain new information, but recall will take a little longer.
- Fluency with words may decrease. The MSer tries to recall a word. It is on the tip of the tongue, but they just can't move it from their thoughts to their speech.
- If a great deal of information comes at the MSer at once, or if material is coming from multiple sources at once, processing the material may take longer.
- Problem solving may be slower due to MS, which tends to frustrate the MSer who will need more time to get over the feelings of frustration and refocus on the problem.

(Adapted from *MS and the Mind* brochure Summer 2000, 14.)

### ***Suggestions for the Instructors of MS Students***

Each MSer enters comes into the classroom with an ample dose of experiences, knowledge, knowledge, talents and abilities that are uniquely their own. All these will help provide the necessary ingredients to help create a wonderful, learning experience for adults wanting to take part in the educational process. By being conscious of the specific needs of the various individuals in the classroom, a greater degree of success will be found within and without the classroom.

Because MS can place the student at times in a difficult place in the classroom, I will provide a few helpful suggestions that the instructor may want to consider when pondering the classroom dynamics with regard to the MSer's possible cognitive issues.

By adapting instruction or modifying the environment the instructor may bring about greater opportunities for success in the classroom and community. Strategies for instructors to help with memory and organizational skills include:

- Frequently repeating information and summarizing it.
- Give the student the freedom to use memory aids or tools. Play up the importance of such tools so that if someone chooses to use them they don't feel like they must apologize for doing so. This can be done by talking about what aids you, as the teacher, may use to remember things and activities.
- Present information in categories or chunks to aid in retention.
- Demonstrate techniques such as mental rehearsal and use of special words or examples as reminders.
- Link new information to the student's relevant prior knowledge when possible.
- Provide experiential presentation of instructional materials.
- Try to eliminate distractions, such as several people talking at once or one person talking too rapidly. Remember, a barrage of information can be too overwhelming for the person with MS to sort out.
- If possible, provide students with additional time for review.
- Change in routines or environments are not always good.
- MSers may be less responsive to immediate feedback from other people and find it harder to adapt.

Incorporating some of the above ideas into the classroom may mean the difference between success and failure for MSers. The suggestions of possible ways to help and support the MS community in their learning environments is, of course, far from complete, but I hope to begin the brainstorming that is necessary when an instructor

endeavors to take on the challenge on participating in another adult educational experience. It was my also my intention to raise awareness of the possible learning difficulties the MSer faces, not only in the formal classroom but also in their everyday life. One thing that is not an intended outcome of this discussion is to promote feelings of pity for the MS community. Rather, by knowing about our struggles, hopefully understanding, patience and acceptance will grow.

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# Appendix 1

## *Definition of Terms*

AFO-Ankle Foot Orthosis—An orthosis is an appliance for any part of the body that serves to support, align, prevent or correct deformities of a body part, or to improve the function of moveable parts of the body. An AFO supports the entire foot and ankle complex, affecting the motion of the entire body.

Constructivism is derived from the idea that each learner actively develops his/her own cognitive structure (i.e. mental models, schema) based on his or her existing knowledge.

Critical Ethnography seeks to shed light on the “unfairness, or injustice within a particular lived domain (Madison 2005, 6). Critical ethnography seeks to examine the status quo and the taken-for-granted assumptions which entrench a particular group of individuals and bring to light the hidden operations of power and control that adversely affect or influence the group’s well-being physically, emotionally, socially and/or economically resulting in a diminished degree of personal and collective freedom and equality (Denzin 2001; Thomas 1993).

Critical reflection means “challenging the validity of presuppositions in prior learning” (Mezirow 1990a). It is a process by which adults identify the assumptions governing their actions, locate the historical and cultural origins of the assumptions, question the meaning of the assumptions, and develop alternative ways of acting (Stein 2000, 1). Brookfield (1995) adds that part of the critical reflective process is to challenge the prevailing social, political, cultural, or professional ways of acting.

Demyelinating disease is any condition that results in damage to the protective covering (myelin sheath) that surrounds nerves in your brain and spinal cord. When the myelin is damaged, nerve impulses slow or even stop, causing neurological problems.

Emic is an approach that considers material from the insiders’ point of view (Wolcott 2008, p. 172 n. 2).

Ethnography is the “art and science of describing a group or culture (Fetterman 1998, 1). This type of study focuses on human society and culture; culture being defined as: “the beliefs, values, and attitudes that shape the behavior of a particular group of people” (Merriam & Associates, 2002, 8).

Exacerbation—The appearance of new symptoms or the aggravation of old ones, lasting at least twenty-four hours (synonymous with attack, relapse, flare-up, or worsening); usually associated with inflammation and demyelination in the brain or spinal cord.

Individuation is a process by which individual beings are being formed and differentiated having as its goal the development of the individual personality (Dirkx 2000b, 2). It involves the discovery of new talents, a sense of empowerment and confidence, a deeper understanding of one's inner self and greater sense of self-responsibility (Boyd 1991, 142).

MS is an acronym for multiple sclerosis.

MSer is an acronym for a person who has been diagnosed with multiple sclerosis.

Ontological progression—Path to greater self-awareness.

Otherness is a term that has come to indicate a person or a group of people marginalized status within society (Sheared and Sissel 2001, 13).

Transformative learning theory/transformative learning is understood as the process of using a prior interpretation to construe a new or revised interpretation of the meaning of one's experience in order to guide future action (Mezirow 1996, 162).

Transformative learning theory/transformative learning is defined as a fundamental change in one's personality involving co-jointly the resolution of a personal dilemma and the expansion of consciousness resulting in greater personality integration [incorporation of emotions into the learning process] (Boyd 1991).

## APPENDIX 2

### Invitation to Participate

#### Local Woman Seeking Others with Multiple Sclerosis

One of the areas most overlooked, as one strives to deal with struggles due to the uncertainty of MS, is the mental and emotional toll upon the individual. As most of the research today is focused upon finding a cure, too often the patient is left to their own devices to cope mentally and emotionally with this disease. As a person who has had their own ups and downs over the last 25 or so years dealing with MS, I have found that my emotional and mental well being plays a vital role as I deal with the issues that this disease presents.

I am presently pursuing my Doctorate in Adult Education with an emphasis on Transformative Learning ( a paradigm shift in one's thinking because of disruptive moments in one's life) and I would like for my doctoral dissertation to address issues that I and others have faced with the diagnosis and ensuing challenges that occur because of MS. My goal would be to interview people who have firsthand knowledge of this disease and at the same time wish to effectively help others who are now facing this challenge and those who are still to be diagnosed. The study would begin in the spring of 2007, the interviews will be recorded but strictly confidential and they will take approximately 1 ½ to 2 hours. I will then compile the information looking for patterns, processes and experiences that are common across MS patients with the hope of sharing these practices with the participants who took part in the study and others who have been touched by this disease.

If you would be interested in taking part in this study, please contact Mary Lewis at [mlewis\\_2@charter.net](mailto:mlewis_2@charter.net) or 144 Leslie Drive, Scott Depot, WV 25560. I will complete the participation list by February 2007 and schedule interviews in March and April of 2007. Please join me in learning from each other with the desire to help many with our combined experiences.

## APPENDIX 3

### Partial Multiple Sclerosis Participant Survey

**Directions:** Please fill in each blank or circle the answer that most accurately describes your situation throughout this entire survey. This first part of the survey will help to identify who is participating in this study. All information will be held in strict confidence.

What is your age? \_\_\_\_\_

Gender:

- 1) Female
- 2) Male

What is your marital status? Is it:

- 1) married
- 2) living common-law
- 3) living with a partner
- 4) widowed
- 5) separated
- 6) divorced
- 7) single, never married

What is the HIGHEST level of school you have completed or the highest degree you have received?

- 1) less than High School
- 2) high school degree or equivalent (GED)
- 3) trade's certificate or diploma from a vocational school or apprenticeship training
- 4) university or college certificate below bachelor's level, i.e. associates degree
- 5) bachelor's degree
- 6) master's degree and/or doctoral degree

What race or races do you consider yourself to be?

- 1) American Indian or Alaska Native
- 2) Asian
- 3) Black/African American
- 4) Native Hawaiian or Pacific Islander
- 5) White
- 6) Other-specify

How long have you been diagnosed with Multiple Sclerosis?

\_\_\_\_\_years, \_\_\_\_\_months, \_\_\_\_\_weeks

### **Personal Reflection**

Directions: The purpose of this last section is to identify in what ways living with Multiple Sclerosis has impacted or made a difference in your dail life. Please try to use the space provided but if more writing space is needed feel free to continue at the bottom or other side of this survey.

- 1) What changes, if any, have you made in your daily routine as a result of having Multiple Sclerosis?
  - A. Physically:
  
  
  
  
  
  
  
  
  
  
  - B. Socially:
  
  
  
  
  
  
  
  
  
  
  - C. Emotionally
  
  
  
  
  
  
  
  
  
  
  - D. Spiritually
  
2. What key factors have been influential in bringing about these (physical, social, emotional and spiritual) changes?
  
  
  
  
  
  
  
  
  
  
3. What have been the outcomes or results to making these changes in your daily routine?
  
  
  
  
  
  
  
  
  
  
4. What is your most difficult challenge as you deal with this disease?

## **APPENDIX 4**

### **Questions for Interviews**

#### **Introduction:**

1. What were your first thoughts when you were diagnosed with MS?
2. How have those initial thoughts changed over time?
3. Have you told your friends and family that you have MS? If so, what were their reactions? If not, why did you choose not to tell them?

#### **How do participants make meaning out of the diagnosis of MS?**

1. Tell me about what being diagnosed (and living) with MS means to you:
  - a. Physically
  - b. Emotionally
  - c. Socially
  - d. Spiritually
2. How does the person you are now compare to the person you were before being diagnosed and living with MS?

#### **What factors were influential in the participants' understanding and coping with this disease?**

3. What individuals or situations helped you better understand your MS experience?
  - a. Why do you think those individuals or situations helped you better understand your MS experience?
4. Speaking for yourself, what actions did you take personally to better understand your experience of living with MS?
5. How do you as a person with MS relieve the stress that is brought about by this disease?

#### **In what ways do subsequent life experiences alter the perspective transformation that resulted from the participants' past diagnosis of MS?**

6. As you move beyond being diagnosed with MS, in what ways has this disease affected your decision-making and outlook on life?
  - a. What are the positive aspects of these changes? And why.
  - b. What are the negative aspects of these changes? And why.

**What factors have hindered participant's ability to deal effectively with MS?**

7. As you journey with this disease, what things have been major sources of frustration to you? And why?

**What role did relationships play in their transformation?**

**Closing Question**

8. As you look to the future, what one thing would you like to see change that could help you better cope with this disease?

## APPENDIX 5

### INFORMED CONSENT—PARTICIPANT

Thank you for agreeing to participate in this study that will take place from September 2007 to June 2009. This form outlines the purposes of the study and provides a description of your involvement and rights as a participant.

I consent to participate in a research project conducted by Mary Lewis, a doctoral student at National-Louis University located in Chicago, Illinois.

I understand that this study is entitled Transformative Learning in the Multiple Sclerosis (MS) Community. The purpose of this study is to examine transformative learning through the lens of living with MS. This study explores how individuals make meaning out of their diagnosis of MS; 2) to identify what factors were influential in one's understanding and coping with this disease; 3) in what ways do subsequent life experiences alter one's perspective due to having a diagnosis of MS; 4) what factors have hindered the participant's ability to deal effectively with MS; and 5) what role did relationships play in your transformation.

I understand that my participation may consist of at least one interview lasting approximately 1 hour and 30 minutes in length. A second interview may be requested for further clarification and discussion of information obtained in the first interview process. I understand that I will receive a copy of my interview(s) at which time I may confirm, clarify or amend the interview transcript.

I understand that my participation is voluntary and can be discontinued at any time without prejudice until the completion of the dissertation.

I understand that only the researcher, Mary Lewis, will have access to a secured file cabinet in which will be kept all transcripts, taped recordings, and field notes gathered during the interview process in which I participated.

I understand that the results of this study may be published or otherwise reported to scientific bodies, but my identity will in no way be revealed.

I understand that in the event I have questions or require additional information I may contact the researcher: Mary Lewis, 144 Leslie Drive, Scott Depot, West Virginia 25560 USA (304)610-8770, Email address: [Mlewis\\_2@suddenlink.net](mailto:Mlewis_2@suddenlink.net).

If you have any concerns or questions before or during participation that you feel have not been addressed by me, you may contact my Primary Advisor and Dissertation Chair: Dr. Thomas Heaney, National Louis University, 122 South Michigan Avenue, Chicago, Illinois, 60603, (312 )261-3274; Email address: [theaney@nl.edu](mailto:theaney@nl.edu).

Participant's Signature \_\_\_\_\_ Date\_\_\_\_\_

Researcher's Signature \_\_\_\_\_  
Date\_\_\_\_\_