

ABSTRACT

Title of Dissertation: CONTRIBUTING FACTORS TO
RESILIENCE IN RELAPSING-REMITTING
MULTIPLE SCLEROSIS

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This study examined the relationship between spirituality, medical access and support, social support and involvement, perceived severity of illness, illness status and resilience (i.e., self-reliance, equanimity and meaningfulness) in multiple sclerosis (MS).

The sample consisted of 152 individuals diagnosed with relapsing-remitting MS who were either attending a neurology clinic, members of the National MS Society or members of a support group in the Northern Virginia, Washington DC area. Participants completed the Contributing Factors Questionnaire (CFQ), the Resilience Scale (RS), and the Spiritual Perspective Scale (SPS).

The results indicated that individuals who had attributed higher rates of importance to medical access and support from doctors and nurses had an increased awareness that their lives had purpose and meaning. Furthermore, perceived severity of illness was significantly negatively related to self-reliance; those individuals who

had a more severe perception of illness had a decreased belief in themselves and their capabilities. There was also a significant interaction effect between perceived severity of illness and spirituality on self-reliance and meaningfulness. That is, individuals with a more severe perception of illness who had higher levels of spirituality reported increased belief in themselves and their capabilities and an increased awareness that their lives had purpose and meaning. In addition, there was a significant interaction effect between illness status and spirituality on self-reliance and meaningfulness. That is, those individuals experiencing a relapse with higher levels of spirituality reported an increased belief in themselves and their capabilities and an increased awareness that their lives had purpose and meaning.

There was neither a statistically significant relationship between spirituality, illness status and self-reliance, equanimity and meaningfulness nor between social support and involvement and self-reliance, equanimity and meaningfulness. There was not a significant relationship between medical access and support and self-reliance and equanimity. There was not a significant relationship between perceived severity of illness and equanimity and meaningfulness. There was not a significant relationship between spirituality and self-reliance, equanimity and meaningfulness after controlling for other contributing factors. There was not a significant interaction effect between perceived severity of illness and spirituality and between illness status and spirituality on equanimity.

CONTRIBUTING FACTORS TO RESILIENCE IN RELAPSING-REMITTING
MULTIPLE SCLEROSIS

by

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Dedication

To God, my Lord and Savior

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TABLE OF CONTENTS

	Page
Dedicationii
Acknowledgments.iii
Table of Contents.iv
List of Tables.vii
List of Figures.ix
Chapter 1 – Introduction.1
Statement of the Problem.2
Need for the Study.7
Purpose of the Study.8
Research Questions8
Hypotheses.9
Definition of Terms10
Perceived Severity of Illness11
Illness Status11
Resilience11
Spirituality.12
Conclusion.13
Chapter 2 – Literature Review.15
Multiple Sclerosis (MS).15
Types of Multiple Sclerosis.16
Relapsing-Remitting.16
Primary Progressive.16
Secondary Progressive.17
Progressive-Relapsing17
Characteristics of Relapsing-Remitting MS.17
Physical Symptoms.19
Psychosocial Responses to MS.20
Resilience as a Response to Adversity.26
Defining Resilience.26
Contributing Factors to Resilience31
Resilience as a Response to Losses40

Spirituality	42
Spirituality and Counseling	44
Spirituality and Health	47
Summary	56
Chapter 3 – Methodology	60
Procedures	60
Instruments	62
Demographic Information	62
Contributing Factors Questionnaire	62
Perceived Severity of Illness	63
Illness Status	63
Resilience Scale (RS)	63
Spiritual Perspective Scale (SPS)	64
Research Questions	65
Hypotheses	66
Definition of Terms	67
Contributing Factors	67
Perceived Severity of Illness.	67
Illness Status	67
Resilience	68
Spirituality	68
Statistical Analysis	69
Principal Components Analysis (PCA)	69
Correlation Analyses	69
Multiple Regression Analyses	70
Chapter 4 – Results.	72
Previous Research Questions	73
Current Research Questions	74
Current Hypotheses	77
Sample Description	80
Factor Analyses on Instruments	83
Spiritual Perspective Scale (SPS)	84
Resilience Scale (RS)	85
Self-Reliance	85
Equanimity	86
Meaningfulness.	86
Contributing Factors Questionnaire	90
Social Support and Involvement	90
Medical Access and Support	90

Descriptive Analyses	92
Correlation Analyses	92
Multiple Regression Analyses	106
Interactions between Spirituality and Perceived Severity of Illness	115
Interactions between Spirituality and Illness Status	121
Conclusions	129
Chapter 5 – Discussion.	130
Summary of Significant Results	130
Relationship to Previous Literature	137
Limitations	139
Implications of the Study	140
Implications for Practice.	140
Implications for Training.	142
Implications for Future Research.. . . .	144
Conclusions.	145
Appendices.	147
Appendix A – Introduction Letter.	147
Appendix B – Informed Consent Form.	149
Appendix C – Questionnaires.	151
References.	158

LIST OF TABLES

Table	Page
1. Demographic Characteristics of Participants	81
2. Principal Components Analyses of Resilience Scale	87
3. Principal Components Analyses of Contributing Factors Questionnaire.	91
4. Correlations and Intercorrelations Among Spirituality, Equanimity, Self-Reliance and Meaningfulness	94
5. Correlations and Intercorrelations Among Social Support and Involvement, Medical Access and Support and Spirituality	98
6. Correlations and Intercorrelations Among Perceived Severity of Illness, Self-Reliance, Equanimity and Meaningfulness	101
7. Means and standard deviations for the different categories of perceived severity of illness on spirituality and self-reliance, equanimity and meaningfulness	102
8. Correlations and Intercorrelations Among illness Status, Self-Reliance, Equanimity and Meaningfulness	104
9. Means and standard deviations for the two categories of illness severity on spirituality and self-reliance, equanimity and meaningfulness	105

10.	Regression Analysis of Predictor Variables on Self-Reliance	109
11.	Regression Analysis of Predictor Variables on Meaningfulness	113
12.	Interaction Effect between Spirituality and Illness Status on Self-Reliance	123
13.	Interaction Effect between Spirituality and Illness Status on Equanimity	125
14.	Interaction Effect between Spirituality and Illness Status on Meaningfulness	127
15.	Correlations and Intercorrelations Among Spirituality, Perceived Severity of Illness, Social Support and Involvement, Medical Access and Support, Illness Status, Self-Reliance, Equanimity, and Meaningfulness.	135

LIST OF FIGURES

Figure	Page
1. The interaction between spirituality and perceived severity of illness on self-reliance	118
2. The interaction between spirituality and perceived severity of illness on meaningfulness	120
3. The interaction between spirituality and illness status on self-reliance	124
4. The interaction between spirituality and illness status on meaningfulness.	128

CHAPTER 1

Introduction

Multiple Sclerosis (MS) is a chronic, progressive and degenerative neurological disease of the Central Nervous System (CNS). It has been estimated that between 250,000 and 350,000 individuals in the United States live with multiple sclerosis. MS is more common in women, affecting women twice as often as men (Smith & Schapiro, 2000). In MS the immune system attacks the myelin sheath around the axons in the CNS, resulting in an autoimmune mediated demyelination. This demyelination produces plaques or lesions that bring about a variety of symptoms—loss of motor function, loss of bowel or bladder control, problems in sexual functioning, debilitating fatigue, visual disturbances, pain, cognitive problems, and emotional changes (Goodkin, 1992; Holland, Murray, & Reingold, 1996). The symptoms usually appear when the individual is between the ages of 16 and 60 (Smith & Schapiro, 2000).

Multiple Sclerosis induces significant lifestyle changes and disruptions as the diagnosed person confronts constant ambiguity of his/her health status, a sense of marginality as well as uncertainties for the future (VanderPlate, 1984). MS follows an unpredictable and uncertain path—marked by periods of exacerbations and periods of remissions. The ambiguous and uncertain nature of MS combined with physical discomfort and psychosocial challenges often leave the person

vulnerable to experience emotional distress (Schubert & Foliart, 1993; Rao, Huber, & Bornstein, 1992).

Statement of the Problem

Multiple Sclerosis affects the person's life and the life of his or her family. Persons living with MS face multiple challenges as they try to make sense of life with MS. Multiple Sclerosis does not follow a predictable, steady course. Instead, the individual may experience periods of relapses or flare ups followed by periods of remission. Regardless of physical disabilities, there are individuals who "do well" while others "do poorly" on psychosocial adjustment (Wineman, 1990). Individuals who "do poorly" present elevated levels of emotional distress (McIvor, Riklan, & Reznikoff, 1984; Dalos, Rabins, Brooks, & O'Donnell, 1982; Mohr, Dick, Russo, Pinn, Boudewyn, Likosky, & Goodkin, 1999), sleep disturbance, lack of interest in activities, lack of energy, feelings of failure, suicidal ideations (Schiffer, Rudick, & Herndon, 1983), helplessness, anxiety and overwhelming feelings of one's life going out of control (Minden, 1992). Researchers, for example, have referred to patients who reported a more severe perception of illness and who had never experienced remission, and indicated that those individuals were more depressed than individuals who had a less severe perception of illness and had experienced remission (McIvor, Riklan, & Reznikoff, 1984).

On the other hand, there are individuals who manage the unexpected changes and losses by embracing the possibilities of the situation (Wagnild & Young, 1990) as they make sense out of their losses. These individuals are resilient in that they preserve hope and construct a meaningful account of their situation (Druss & Douglas, 1988). They reach out to others—family, social, community support, and helping professionals when they need help (Rabkin, Remien, Katoff, & Williams, 1993).

In addition, researchers have referred to contributing factors to resilience (Dyer & McGuinness, 1996; Rabkin et al., 1993). Patients with AIDS, for example, have identified social support, excellent medical care, personal resources (e.g., intelligence, education), and access to supplementary services (e.g., visiting nurses, home health aides) as contributing factors to resilience (Rabkin, Remien, Katoff, & Williams, 1993). Although several studies identify many qualities and contributing factors to resilience, few have been the focus of research efforts. “Instead, indicators of adaptive outcomes are described as evidence of resilience, usually in the realm of social and psychological competence” (Wagnild & Young, 1993, p. 165). The literature on MS has provided studies on coping and adjustment, but not on resilience. The adjusted person is believed to “become used to a new situation” (Compact Oxford English Dictionary, 2002) as determined by “the act of adjusting or the state of being adjusted, a modification, fluctuation, or correction” and coping refers to “contend

with difficulties and act to overcome them.” (American Heritage Dictionary of English Language, 2000). Resilience is “the ability to recover quickly from illness, change, or misfortune” (American Heritage Dictionary of the English Language, 1994), “the ability to resist or recover from adversity” (Jacelon, 1997); the ability to “rebound or spring back” (Oxford English Dictionary, 1971). Resilience “...moderates the negative effects of stress and promotes adaptation...” (Wagnild & Young, 1993, p. 165). The resilient person “...lies in the power of recovery and in the ability to return once again to those patterns of adaptation and competence that characterized the individual prior to the pre-stress period...” (Garmezy as cited by Jacelon, 1997, p. 123). Though in the earliest psychiatric literature, invulnerability, invincible and resilience were used interchangeably (Dyer & McGuinness, 1996), the concept of resilience is different from the concept of coping and adjustment.

In terms of recovering from difficulties, while a number of contributing factors to resilience have been identified, the relationship between spirituality and resilience in MS has not been yet addressed and studied in depth. The literature, however, is clear about the positive influence of spirituality on health (Coyle, 2002; Carbage Martin & Smith Sachse, 2002; Tate & Forchheimer, 2002). Spirituality has been described as an “awareness of one’s inner self and a sense of connection to a higher being, nature, others, or to some dimension or purpose greater than oneself.” (Reed, 1986). Furthermore, researchers have indicated that

spirituality provide meaning out of difficulties (Tam, 1993), and enhances emotional and physical health (Coyle, 2002).

Research on spirituality in MS has been limited to few studies. Kutsunai (2000) examined the relationship of perceived control, spirituality and psychological adjustment. In terms of psychological adjustment, Kutsunai (2000) assessed participants' reported psychological well-being (emotional ties and general positive affect) using the Mental Health Inventory (MHI). Her findings indicated that psychological adjustment was positively related to secondary and primary control, but found no relationship between spirituality and psychological adjustment. Kutsunai (2000) referred and questioned the instrument she used to assess adjustment, and suggested that the use of a different instrument may have provided different outcomes in terms of spirituality and psychological adjustment. Despite her findings, researchers have found a positive relationship between spirituality and well-being (Carbage Martin & Smith Sachse, 2002; Reed, 1987), life satisfaction and quality of life (Tate & Forchheimer, 2002).

The literature on MS lacks empirical research on resilience and spirituality. Nor have any studies examined the relationship of spirituality to other factors that have been reported as contributing to resilience.

This dissertation examines these relationships. It is hypothesized that spiritual perspectives (as measured by the Spirituality Perspective Scale)

contribute to resilience in multiple sclerosis. That is, individuals with MS who have high levels of spirituality would be significantly more resilient than individuals with MS who have low levels of spirituality. It is also hypothesized that spirituality will be a dominant factor among other contributors (i.e., social support, access to health services, involvement in activities) to resilience in multiple sclerosis. This study will also consider the relationship between perceived severity of illness (more severe and less severe) and resilience, and illness status (remission and relapse) and resilience in MS. In addition, it is hypothesized that levels of spirituality influence the relationship between perceived severity of illness (less severe and more severe) and resilience and between illness status (relapse and remission) and resilience.

This study may provide clinicians with a better understanding on the possible relationship between spirituality and contributing factors to resilience in multiple sclerosis as it may identify if spirituality relates to one's ability to rebound from adversity as the person lives with a chronic illness. In addition, this study may provide some insight about the possible interaction between spirituality and illness status, and spirituality and perceived severity of illness on resilience. These findings may then guide health providers when developing therapeutic interventions.

In today's health care practice, it is extremely important to determine why certain individuals bounce back while others falter in their capacity to deal with

distressing experiences related to living with a chronic illness. This study may suggest one answer as to what keeps people rising above adversity.

Need for the Study

Resilience moves the health profession from the illness to the health system; the focus is on one's ability to bounce back. There have been no empirical research on resilience and its contributing factors in MS, but instead researchers have studied coping (Pakenham, 1999) and psychological adaptation (Wineman, 1990). Moreover, there are no studies that explore the possible relationship between spirituality and resilience in MS. Thus, this study is unique in that it attempts to examine spirituality and other contributing factors to resilience as well as the possible interaction effect between spirituality and illness status and spirituality and perceived severity of illness on resilience.

Based on the findings of this study, health professionals may identify methods to strengthen or promote resilience in individuals with MS as well as design interventions on bolstering the individuals' resilience during periods of exacerbations. Health professionals may recognize the need to explore their patients' spirituality as a contributing factor to resilience; they can gain insight into the spiritual differences between those individuals who resist, recover and rise above adversity versus those who feel defeated by the illness. Moreover, they could utilize resources that capitalize on the spiritual beliefs of their patients and determine how to assist those patients who have surrendered to their health

circumstances. For instance, if findings indicate that spirituality may strengthen one's resilience, clinicians may decide to incorporate the spiritual dimension in their work with those patients who desire to pursue this aspect.

Purpose of the Study

The objective of this study is to examine the possible relationship between spirituality, contributing factors, perceived severity of illness, illness status and resilience. In addition, this research studies the role of spirituality as a potential moderator in the relationship between illness status and resilience, and between perceived severity of illness and resilience. The literature has primarily focused on adjustment and coping, but there have been no studies on resilience in MS.

Thus, this study endeavors to answer the following questions:

Research Questions

1. What is the relationship between spirituality and resilience in MS?
2. What is the relationship between contributing factors—social support, access to health services, involvement in social, cultural, and recreational activities to resilience in MS?
3. What is the relationship between perceived severity of illness and resilience in MS?
4. What is the relationship between illness status and resilience in MS?

5. What is the relationship between resilience and spirituality after controlling for contributing factors (e.g., social support, access to health services, involvement in social, cultural and recreational activities) in MS?
6. What is the relationship between perceived severity of illness and resilience in MS, with spirituality as a moderator variable?
7. What is the relationship between illness status (remission and relapse) and resilience in MS, with spirituality as a moderator variable?

Hypotheses

It is hypothesized that spiritual perspectives and a number of factors: social support, access to health services, involvement in social, cultural, and recreational activities, illness status, and perceived severity of the illness will be significantly related to resilience in multiple sclerosis. In addition, it is hypothesized that spirituality moderates the impact of perceived severity of illness and illness status (relapse or remission) on resilience.

1. Spirituality is positively related to resilience.
2. Contributing factors—social support, access to health services, involvement in activities— are related to resilience.
3. Perceived severity of illness is significantly related to resilience.
4. Illness status is significantly related to resilience.
5. Spirituality is positively related to resilience after controlling for contributing factors (e.g., social support, access to health services,

involvement in social, cultural and recreational activities, illness status, and perceived illness severity).

6. The relationship between perceived severity of illness and resilience depends on whether one scores high or low on spirituality as measured by the Spiritual Perspective Scale (SPS).
7. The relationship between illness status (remission and relapse) and resilience depends on whether one scores high or low on spirituality as measured by the Spiritual Perspective Scale (SPS).

Definition of Terms

Multiple Sclerosis. Individuals (ages 20-70) who have been diagnosed by a neurologist with a definite diagnosis of multiple sclerosis. The participants must have received a diagnosis of Relapsing Remitting (RR) MS.

Contributing Factors. Based on the literature review, a number of variables have been identified as contributing factors to resilience: social support, access to health services, involvement in valued activities, illness status and perceived severity of the illness. The researcher developed a 13-item questionnaire for participants to rate the degree of importance of social support (family, friends, doctors, nurses, spiritual leader, support group), access to health services (treatment, insurance coverage, prescription plan, home assistance), and involvement in valued activities (church/religious organization, recreational activities, and work-related activities). Participants

are required to rate each question on a seven-point scale from 1 = ‘disagree’ to 7 = ‘agree’. Participants are also asked to report and rate any other important factor that may contribute to adjustment.

Perceived Severity of Illness. Participants will be asked to rate the severity of their illness or symptoms on a 5-point scale: 1 = Not Severe, 2 = Mild, 3 = Moderate, 4 = Severe and 5 = Very Severe.

Illness Status. Participants will respond to the following question: “My present situation can be best described as: in remission or experiencing a relapse”. The sample will be divided into two groups: relapsing group (those individuals who are experiencing a flare up or exacerbation during their participation in the study), and remission group (those participants whose symptoms have improved or disappeared). Depending on the number of individuals responding to either group, the researcher will separate and study one or both groups.

Resilience. Resilience is a positive trait; it “...moderates the negative effects of stress and promotes adaptation...” (Wagnild & Young, 1993, p. 165). Resilience will be measured by the Resilience Scale (RS) developed by Wagnild & Young (1993) and conceptualized as:

- (a) Equanimity: A balanced perspective of one’s life and experiences; it is the ability to consider a broader range of experience and to ‘sit loose’ and take what comes, thus moderating extreme responses to adversity.

- (b) Perseverance: The act of persistence despite adversity; it is a willingness to continue the struggle to reconstruct one's life and to remain involved and to practice self-discipline.
- (c) Self-reliance: It is a belief in oneself and one's capabilities; it is the ability to depend on oneself and to recognize personal strengths and limitations.
- (d) Meaningfulness: It is the realization that life has a purpose and the validation of one's contribution; it conveys the sense of having something for which to live.
- (e) Existential aloneness: The realization that each individual's life path is unique. Some experiences are shared, however, other experiences must be faced alone; there is a feeling of freedom and sense of uniqueness.

The Resilience Scale (RS) is a 25-item instrument that assesses the individual's degree of resilience. The RS is rated on a seven-point scale from 1 'disagree' to 7 'agree'. Higher scores reflect higher resilience; scores range from 25 to 175 (Wagnild & Young, 1993).

Spirituality. Spirituality is "an awareness of one's inner self and a sense of connection to a higher being, nature, others, or to some dimension or purpose greater than oneself." (Reed, 1986). Spirituality will be assessed by the Spiritual Perspective Scale (SPS), designed by Reed (1986) which

measures the significance of a spiritual perspective in one's life. It refers to the extent of one's perception of holding certain spiritual beliefs and engaging in spirituality-related activities. The SPS is a 10-item scale. Participants will rate each item, from "1 = Not at all/Strongly Disagree to 6 = About once a day/Strongly Agree" (6-point Likert-type scale). The SPS scores will be computed by summing all 10 items and then dividing by 10. A high total score on the SPS will indicate higher spiritual perspective (Reed, 1986).

Conclusion

There are between 250,000 and 350,000 people in the United States living with multiple sclerosis, an unpredictable, debilitating and progressive disease affecting the central nervous system (Smith & Schapiro, 2000). The diagnosed person recognizes the lifestyle changes and disruptions in one's life when he/she is confronted with an uncertain future (VanderPlate, 1984).

Studies have primarily focused on the psychological and social aspects of multiple sclerosis (Mohr, Dick, Russo, Boudewyn, Likosky, & Goodkin, 1999; Rao, Huber, & Bornstein, 1992; Devins & Seland, 1987). Researchers have assessed adjustment, adaptability and coping strategies among individuals with MS, conceptualizing it by the degree of depression, global distress, social adjustment, subjective health status (Pakenham & Stewart, 1997; Pakenham, 1999), and emotional adaptation (Wineman, 1990) to MS. However, resilience,

the ability to bounce back and rise above adversity, has not been empirically studied in MS.

The literature on spirituality and contributing factors to resilience in MS has been neglected. Accordingly, the study of these variables would be a valuable contribution to the existing literature as findings could provide some answers as to why some individuals falter in their capacity to bounce back whereas others rebound in the face of a chronic illness, particularly multiple sclerosis.

The next chapter will elaborate upon what is known about the variables presented in this study.

CHAPTER 2

Literature Review

This chapter provides the reader with information on multiple sclerosis (MS). It defines the course of the illness and identifies the symptomatology in MS. In addition, this section includes information on the psychosocial aspects of multiple sclerosis. Furthermore, it presents a review of the literature on resilience, contributing factors and spirituality in chronic illnesses. Finally, it summarizes what the literature has concluded regarding the variables presented in this study.

Multiple Sclerosis

Multiple sclerosis is a chronic, progressive and debilitating illness that affects between 250,000 and 350,000 people in the United States. It has been estimated that about 10,000 individuals per year receive a diagnosis of MS (Smith & Schapiro, 2000). MS is more prominent among women, affecting women twice as often as men (Smith & Schapiro, 2000; Mohr, Dick, Russo, Pinn, Boudewyn, Likosky, & Goodkin, 1999). The onset of the illness most commonly occurs between the ages of 16 and 60. MS is more prominent in temperate areas farther from the equator, and it is uncommon in the tropics. The illness is seen more frequently in people from England, Scandinavia, Northern Germany, Canada and the northern part of the United States, and it is more frequently seen

in white individuals. It is less frequently seen in Hispanics or African Americans, and rarely seen among Asians and other groups (Smith & Schapiro, 2000).

In MS, the immune system attacks and damages the myelin sheath that protects and nourishes the nerve fibers in the central nervous system (CNS), thus, individuals experience a thickening of the tissue at multiple sites throughout their CNS, resulting in lesions. The damage to the myelin sheath disrupts the transmission of nerve impulse from the brain through the spinal cord to various parts of the body (Holland, Murray, & Reingold, 1996; Mohr et al., 1999; Smith & Schapiro, 2000).

Types of Multiple Sclerosis

The course of the disease is uncertain in that the individual can never anticipate its course. Some individuals experience a rapid progression of the illness, few have a “benign course”, and most experience a relapsing-remitting course (Mohr et al., 1999). Based on the severity and progression of the symptoms, however, MS can be classified as (Smith & Schapiro, 2000):

1. *Relapsing-Remitting*: It is characterized by defined acute attacks, lasting from days to weeks. After a relapse, the person may experience full recovery, partial recovery or residual deficits. The illness does not progress between relapses or during remissions.
2. *Primary Progressive*: It is characterized by the progression of the disease and disability from the beginning with no obvious remission. There may

be only temporary minor improvements.

3. *Secondary Progressive*: The disease begins with a relapsing remitting course, followed by progression that may include occasional relapses and minor remissions.
4. *Progressive-Relapsing*: This type presents a clear progression in the level of disability from the onset of the illness. There are clear acute relapses. The individual may or may not recover from relapse-related symptoms.

Characteristics of Relapsing-Relapsing MS (RRMS)

Multiple sclerosis usually begins as relapsing-remitting, characterized by “inflammatory attacks, reversible neurological deficits or residual deficit upon recovery, and variable periods of remission.” (Trojano, Paolicelli, Bellacosa, & Cataldo, 2003, p. 5268). In relapsing-remitting MS (RRMS), there are repeated occurrences of acute illness, producing a moderate level of disability (Minden, 1992). The individual experiences “periodic attacks or exacerbations that remit partially or fully.” (Mohr et al., 1999, p. 376). The disease goes into remission and symptoms improve or disappear, usually for about four to eight weeks. The person in remission may have subtle attacks that go unnoticed. For example, the person may experience numbness or slight awkwardness in coordination (Multiple Sclerosis, 2001).

During a relapse, there is “a sudden worsening of an MS symptom or symptoms or the appearance of new symptoms.” (MS dialogue, 2004) due to an

inflammatory response by the body's immune system, damaging the myelin (i.e., a protective insulating sheath around the nerves) in the white matter (Relapsing/Remitting Multiple Sclerosis, 2004). Relapses are also described as attacks, exacerbation, or flare-ups. They can be mild or severe and may last days, weeks, or even months. Based on the damage to the myelin, the person experiences a number of symptoms. After a relapse, the person may experience a period of remission and symptoms may partially improve (MS dialogue, 2004). Remissions may be spontaneous or induced by "immunosuppressive" treatment (Multiple Sclerosis, 2001).

Schiffer, Rudick, and Herndon (1983) described the experience of one of their patients living with Relapsing-Remitting MS (RRMS):

A 26-year-old woman had classic relapsing-remitting multiple sclerosis for three years. She experienced frequent attacks involving optic nerves, oculomotor pathways, and pyramidal tracts. Despite frequent attacks, recovery was substantial and she had no obvious persisting physical deficits...she experienced overwhelming fatigue... Without a rest period she remained incapacitated for the rest of the day, unable to prepare dinner and retiring to bed in the early evening. (Schiffer et al., 1983, p. 313).

It is estimated that 50% of patients with relapsing-remitting MS experience a shift in the course of their illness from relapsing-remitting to secondary progressive about 10 years after initial diagnosis, and 90% of patients experience a shift from relapsing-remitting to progressive MS after a 20-year period since diagnosis (Trojano et al., 2003).

In contrast to relapsing-remitting MS, the progressive type involves “the deterioration of lower extremity function and a decline in ambulation.” (Trojano, Paolicelli, Bellacosa, & Cataldo, 2003, p. S268). The disease is progressive and the person does not experience improvement in his/her symptoms, but instead a decline in his/her condition (Dr. Eliaz, 2002).

Physical Symptoms

In MS, the immune system attacks the myelin sheath that covers the nerve fibers, resulting in demyelination and lesions, which affects the proper functioning of the central nervous system. Lesions cause a number of physical symptoms, depending upon which part of the central nervous system is damaged. Initial attacks may involve the optic nerve, the spinal cord, brainstem or cerebellum (Trojano et al., 2003). Symptoms usually become more severe with the passage of time (Pakenham & Stewart, 1997) and with the progression of the illness (Trojano et al., 2003). Early symptoms usually include optic neuritis, fatigue, heaviness or clumsiness in the arms and legs, tingling sensations, poor coordination and “lhermitte’s sign” (electrical sensation on the back going from

the back of the neck into the legs). As the illness develops and changes its course over months or years, symptoms may affect every part of the body. The person may experience spasticity, imbalance and dizziness, tremors, facial pain, speech difficulties, difficulty swallowing, gastrointestinal and urinary problems, and emotional mood swings (Multiple Sclerosis, 2001), blindness, blurred, double vision, fatigue, weakness, disturbances of balance and gait, walking difficulties, sexual problems, bladder and bowel control problems, swallowing problems, cognitive difficulties, vertigo, weight gain, facial numbness, pain, hearing changes, cold feet, swollen ankles, numbness (Holland, Murray, & Reingold, 1996), tingling and pins and needles sensation in hands or legs, stiffness or clumsiness sensation, impotence, neuralgia, or severe pains, and problems with memory, attention, thought speed and perception (Multiple Sclerosis, 1999). Although the individual with MS experiences a number of symptoms, some of these symptoms are considered 'invisible' in that they are felt by the individual with the illness, but they can not be observed by others (Devins & Seland, 1987).

Psychosocial Responses to MS

Multiple Sclerosis is a lifetime of challenges.

It demands that no day be taken for granted,

that every accomplishment is seen significant.

MS can change habits, rearrange priorities,

demand sacrifices. (National Multiple Sclerosis

Society, 1999, p. 1).

The person with MS may have to endure not only the psychological aspects, but the social challenges imposed by the illness, such as, school disruption, unemployment, problems with family functioning (Pakenham & Stewart, 1997), concerns with parenting, pregnancy, sexual problems, independence and financial strain (Minden, 1992). Thus, most of the literature has traditionally focused on the psychosocial aspects or responses to the illness, namely depression, stress and psychological maladjustment.

Individuals with MS had reported higher levels of emotional disturbance (Whitlock & Siskind, 1980; Dalos, Rabins, Brooks, & O'Donnell, 1982; Mullins, Cote, Fuemmeler, Jean, Beatty, & Paul, 2001), a loss of interest in meaningful activities, lack of enjoyment in relationships, hopelessness, despair, suicidal ideations, changes in sleeping and eating patterns as common reactions to the illness. The person receiving the diagnosis usually experiences a profound feeling of sadness as he or she has been forced "to confront the frailty and vulnerability of the human condition in a personal and immediate way." (Holland et al., 1996, p. 52).

Whitlock and Siskind (1980) referred to depression as a major symptom of multiple sclerosis. Their sample consisted of 30 individuals with MS and 30 individuals with other chronic neurological diseases (10 patients with Ataxia, 3 patients with muscular dystrophy, 3 patients with motor neurone disease, four

with dystrophia myotonica, 3 with chronic polyneuritis, and seven with diagnosis varying from myasthenia gravis to cerebral palsy). Researchers interviewed and assessed participants' mood, using the Beck Depressive Mood Inventory. These two groups were matched for age, sex and severity of disability. Whitlock and Siskind (1980) concluded that individuals with MS were significantly more depressed than individuals with other chronic diseases, and indicated that the unpredictability of the illness had stirred up feelings of hopelessness. Along these lines, researchers wondered about the absence of depression reported by some individuals who did not have MS, but instead had other chronic illnesses.

Dalos, Rabins, Brooks, and O'Donnell (1982) compared the prevalence and nature of emotional disturbance in three groups: individuals with multiple sclerosis in remission (n = 61), individuals with active demyelination or exacerbation (n = 12), and individuals with spinal cord injury (n = 23). Participants were followed in a controlled study on a monthly basis for one year. When comparing these groups on reported somatic symptoms, anxiety, social dysfunction and depression from the General Health Questionnaire (GHQ), the prevalence of emotional disturbance of individuals with MS in remission was slightly higher (39%) than the scores reported for individuals with spinal cord injury (12%). Furthermore, the prevalence of emotional disturbance was 90% for individuals in the exacerbation group. Dalos et al. (1982) reported significant severe emotional disturbance with increasing MS activity. They also indicated

that although individuals with spinal cord injury group were more functionally disabled, they reported less emotional disturbance than individuals with MS. As a result, Dalos et al. (1982) concluded that MS activity was a precipitant to emotional disturbances. Based on the small number of participants in each group, these findings must be interpreted with caution.

Baretz and Stephenson (1981) referred to their professional experiences with MS patients, and suggested that an individual's optimistic attitude toward the illness masked an underlying depression. They analyzed the emotional responses of 40 individuals with multiple sclerosis. The sample consisted of 16 hospitalized inpatients, 16 individuals living at home, and 8 individuals living in nursing homes. The length of time since diagnosis ranged from 1 to 31 years. There were 16 ambulated patients, 18 patients who needed a wheelchair and 6 bed-ridden patients. All patients responded to a clinical interview and completed a questionnaire on their affective reaction to the illness. Based on participants' responses, they were assigned to categories: (1) individuals experiencing overt depression, (2) concealed depression, (3) neutral mood, or (4) elevated mood. The researchers found concealed depression as the most prevalent reaction and overt depression as the second most common reaction. In addition, a high rate of elevated mood was not reported. They suggested that depressive symptoms—overt and concealed—were present from early stages of the disability, and that

overt depression increased with the progression of the disease. These findings, however, are limited by the small sample size.

Mohr, Dick, Russo, Pinn, Boudewyn, Likosky, and Goodkin (1999) studied the patient-perceived psychosocial effects of MS. The sample consisted of 94 patients with relapsing-remitting MS: 70 women and 24 men with an average age of 42.6 years. There were 59 married, 15 single, 18 separated or divorce, and two widowed participants. In their study, 52 participants had a job, 21 were on disability, 16 had no employment, perhaps due to disabilities related to MS, and 5 indicated "other". Participants responded to 48 statements on the psychosocial ramifications of MS. Their responses indicated that they experienced distress, helplessness, subjective incompetence, alienation and loss of self-esteem as a result of MS. Furthermore, participants had a perception of significant other's victimizing them as well as a sense of personal inadequacy, resulting from MS. Researchers, however, found that individuals with MS experienced psychosocial benefits; they reported "a deepening of relationships with others, an increased appreciation for life, and an increased focus on spirituality attributed to having MS." (Mohr et al., 1999, p. 380). Despite researchers' confidence on the factor structure of the MS specific instrument, they recognized that perhaps their instrument may have missed some psychosocial effects and warned the reader about its reliability.

Mullins, Cote, Fuemmeler, Jean, Beatty, and Paul (2001) referred to illness intrusiveness and uncertainty as mediating constructs related to psychosocial adjustment in chronic illnesses. Their sample consisted of 78 non-institutionalized individuals diagnosed with MS (55 women, 23 men), ranging in age from 30 to 73 years. Participants completed self-report measures of illness intrusiveness, illness uncertainty, cognitive status and psychological distress. Their findings indicated that illness uncertainty was significantly related to illness intrusiveness and to psychological distress. Illness intrusiveness was also moderately correlated to psychological distress. That is, higher levels of illness intrusiveness and illness uncertainty were significantly related to greater psychological distress. Furthermore, illness intrusiveness was not found to be a moderator variable. The researchers cautioned the reader regarding the generalization of these findings because the sample selected only represented a self-selected group from a limited geographic area.

In summary, studies on reactions to MS had mainly focused on participants' negative psychosocial responses to the illness, and particularly on the psychosocial aspects, namely depression in MS. Despite these findings, though, there is the resilient individual who regardless of his/her medical condition endures and rises above adversity (Fine, 1991).

Resilience as a Response to Adversity

Most of the research on multiple sclerosis has referred to the presence or absence of depression, emotional distress, helplessness, and anxiety as indicators of coping, adjustment and maladjustment in MS. Researchers have studied the person's ability to adjust—"become used to a new situation" (Oxford English Dictionary, 2002) or cope—"contend with difficulties and act to overcome them." (American Heritage Dictionary of the English Language, 2000), but no research has studied the concept of resilience in multiple sclerosis.

Defining Resilience

Resilience has been defined as "the ability to recover quickly from illness, change, or misfortune" (American Heritage Dictionary of the English Language, 1994, p. 1534), the ability to 'rebound' (Oxford English Dictionary, 1971), 'spring back' (Jacelon, 1997), and "the ability to bounce back from adversity" (Dyer & McGuinness, 1996, p. 276). In Jacelon (1997)'s article, he referred to Garmezy's description of resiliency:

...lies in the power of recovery and in the ability to return once again to those patterns of adaptation and competence that characterized the individual prior to the pre-stress period.... 'to spring back' does not suggest that one is incapable of being wounded or injured... under adversity, a [resilient] individual can bend...yet

subsequently recover...(as cited by Jacelon, 1997, p. 123).

In the earliest psychiatric literature, invulnerability, invincible and resilience were used interchangeably (Dyer & McGuinness, 1996). Resilience “refers to the process of, capacity for, or outcome of successful adaptation despite challenging or threatening circumstances.” (Masten, Best, & Garmezy, 1990, p. 426); it means “emotional stamina”; it refers to people who have “courage and adaptability in the wake of life’s misfortunes” (Wagnild & Young, 1990, p. 254). It suggests “...the promise of something good resulting from misfortune, hope embedded in adversity.” (Dyer & McGuinness, 1996, p. 276).

Dyer and McGuinness (1996) reviewed the literature on resilience, and described its different definitions. Resilience used to be defined as “a pliant or elastic quality of a substance or organ” (Harriman, 1958; Chapman, 1992 as cited by Dyer & McGuinness, 1996, p. 276). Resilience has been also defined as ‘the act of rebounding or springing back...’ (Oxford English Dictionary, 1933, as cited by Dyer & McGuinness, 1996). According to Dyer and McGuinness (1996), resilience has a “toughening effect”, claiming that those individuals who prevail when confronted with difficulties would have the ability to overcome other difficult situations. Resilience, thus, may result from having previously encountered difficult situations (Rutter, 1993). Dyer and McGuinness (1996) referred to resilience as “a process whereby people bounce back from adversity and go on with their lives...a dynamic process highly influenced by protective

factors.” (p. 276). In their analysis of the concept, they explored “why one person reacts with symptoms to an objectively minor event when someone else may not experience distress even in the face of apparent major disruption.” (p. 276). They indicated that resilience gave the individual an assurance of something positive resulting from difficulties, and that there was hope ingrained in misfortune. In their writing, they also illustrated the specific critical attributes of the resilient person: rebounding and carrying on, a sense of self, determination, and pro-social attitude. In their views, resilient individuals bounced back and went on with their lives after having experienced difficulties. The resilient person has “a balanced perspective” of life and experiences. The individual appreciates and accepts life events with a sense of “determination”, perseverance and an expectation that there are difficulties that one has to deal with in life. Resilient individuals have a “prosocial attitude”; they easily connect to others and draw them into their lives when experiencing difficulties. Along these lines, researchers referred to “adversity itself”, and “the presence of at least one caring, emotionally available person at some point (even briefly) in the person’s life” (Dyer & McGuinness, 1996, p. 277) as experiences contributing to resilience.

Similarly, Rutter (1993) studied the concept of resilience. In his review of the literature, he reported that resilience was not an avoidance of negative or positive experiences. Instead, resilient individuals dealt with life challenges and

difficulties which provided them with feelings of control and with the ability to cope with future adversities.

Druss and Douglas (1988) studied the nature and source of resilience in three individuals facing a serious illness and disability. In their study, resilience was described as the specific cognitive style of hardiness and ego strength reported by participants. The researchers also examined the relationship between “healthy denial” and adaptive responses to illness. The first case, Ms. A, was a 51-year old single woman who had metastatic breast cancer and received biweekly chemotherapy. She knew that she only had at most 1 or 2 years to live. In spite of cancer and severe osteoporosis causing constant pain, she was in good spirits and never overly depressed. Her self-deception about the seriousness of her condition was evident when she attributed her somnolence and liver function abnormalities to hepatitis instead of metastases. She approached death with courage and determination. The second case was “Cousins”, a 65-year old man who suffered a massive heart attack. Although, he had experienced bouts of breathlessness in the weeks prior to the attack, he continued traveling and lecturing. During the heart attack, he was short of breath, coughing up blood and with severe pain; he joked with paramedics and refused morphine, insisting that his ‘own endorphins could do the job.’ (p. 164). He referred to his first experience in dealing with a medical diagnosis at the age of 10 when he was sent to a tuberculosis sanitarium for 6 months. According to Cousins, patients divided

themselves into two groups: patients who were confident that they would beat back the illness and be able to resume normal lives, and those who resigned themselves to a prolonged and fatal illness. Cousins and those who experienced an optimistic view had a higher percentage of discharge as cured. In his latter experience with the heart attack, he again felt confident that he could beat the odds as he experienced a sense of ‘curiosity or challenge’ rather than threat. The third case was the story of a 40-year old woman born with both legs, but no arms. She played the organ and washed the dishes with her feet. This woman lectured about her experiences to groups of individuals with disabilities, and published an autobiography in which she stated: ‘All of our lives we strive to be different in what we do...And here it was just handed to me on a silver platter: I’m different.’ (p. 165). These three live accounts described how these individuals remained optimistic in the face of adversity as they had continued to engage in productive activities. They denied the most threatening implications and emotional impact of their condition. They referred to their illness not as a “narcissistic injury but as an opportunity for personal growth.” (p. 165). Moreover, these three individuals felt no self-pity, anger, or envy towards those who were healthy.

The literature has identified a number of characteristics in the resilient individual: “absence of health problems”, “positive temperament”, “positive self-esteem”, “autonomy”, “higher than average intelligence”, “good peer relationships” (Hechtman, as cited by Jacelon, 1997), “equanimity”,

“perseverance”, “self-reliance”, “meaningfulness”, and “existential aloneness” (Wagnild & Young, 1990). Although there have been an agreement on the positive characteristics of the resilient individual, resilience as such, has not been measured. Instead “indicators of adaptive outcomes”, generally in terms of social and psychological adaptability or adjustment have been described as evidence of resilience (Wagnild & Young, 1993).

Contributing Factors to Resilience

Contributing factors have been described as “specific competencies that are necessary for the process of resilience to occur.” (Dyer & McGuinness, 1996, p. 280). They do not only increase the resistance to adversities, but also have “catalytic or reverse-catalytic effects by which a feature modifies the influence of some risk factor.” (Rutter, 1993, p. 630). Despite their suggested significance, only few studies have investigated a number of factors contributing to resilience, and no studies had explored contributing factors to resilience in multiple sclerosis. Furthermore, most of the information on contributing or influential factors has been inferred from the literature on adjustment.

Researchers have identified social support (Rabkin, Remien, Katoff, & Williams, 1993; Resnick & Hutton, 1987; Wineman, 1990; Willoughby, Kee, & Demi, 2000; Kyngas, Mikkonen, Nousiainen, Ryttilahti, Seppanen, Vaattovaara, & Jamsa, 2001; Long & Miller, 1991; Byrne, Love, Browne, Brown, Roberts, & Streiner, 1986, Devins, Styra, O’Connor, Gray, Seland, Klein, & Shapiro, 1996);

personal resources (Rabkin et al., 1993; Willoughby et al., 2000); access to health services (Rabkin et al., 1993); participation or involvement in activities (Resnick & Hutton, 1987; Byrne, Love, Browne, Brown, Roberts, & Streiner, 1986; Devins et al., 1996), severity of the illness (Resnick & Hutton, 1987; Wineman, 1990; Chwastiak, Ehde, Gibbons, Sullivan, Bowen, & Kraft, 2002), illness status (McIvor, Riklan, & Reznick, 1984), and spirituality (Kyngas et al., 2001; Long & Miller, 1991; Devins et al., 1996) as possible contributing factors to adjustment.

Social Support, Access to Health Services, and Medical Support

Rabkin, Remien, Katoff, and William (1993) studied resilience among long-term survivors of AIDS. They evaluated 53 men with AIDS who had lived at least three years after receiving the diagnosis. Participants were assessed in terms of their mental status, medical care, mood status, quality of life, future outlook, as well as their physical impairment, outlook, and mood. Their findings indicated that despite physical and psychological distress, the majority reported that “good times lay ahead and that their lives were worthwhile.” (p. 166), and that “nearly all” participants reported an extraordinary psychological resiliency. Rabkin et al. (1993) also identified the following contributing factors to resiliency: social support, excellent medical care, access to supplementary services (e.g., visiting nurses, home health aides), personal resources (e.g., intelligence, education, wide-ranging interests, ability to adapt), and participation

in psychotherapy. It is important to mention though that resilience per se was not measured. Instead, researchers used indicators of adaptive outcomes as evidence of resilience.

Social Support and Personal Resources

Willoughby, Kee, and Demi (2000) investigated the psychosocial adjustment to diabetes among 115 women whose ages ranged from 22 to 70 years (mean age = 48 years). Participants completed a demographic data form, an instrument that assessed level of social support, scales that measured personal resource and coping, and the psychosocial adjustment to illness scale which included: health care orientation, vocational and domestic environment, sexual relationship, extended family relationship, social environment and psychological distress. Researchers used descriptive correlation to interpret participants' responses. Their findings indicated a positive relationship between social support and effective coping. Higher levels of social support and personal resources were related to fewer problems in psychosocial adjustment and better adjustment to the illness. Social support and personal resources explained 47% of the variance in adjustment (personal resources accounted for 43%, and social support accounted for 4% of the variance).

Social Support, Severity of Illness and Involvement in Activities

Resnick and Hutton (1987) studied resilience in terms of participants' perception and rating of their self-image. The sample consisted of 60 adolescents

living with cerebral palsy. Researchers reported that adolescents who perceived themselves as “disabled” had lower self-image than those who perceived themselves as less disabled. In addition, those who reported having good friends had higher self-image. Also, participants who interacted with individuals with disabilities as well as with individuals with no disabilities had a better self-image than those who had only friends with disabilities. Researchers found no relationship between self-image and having a best friend as well as no relationship between self-image and participation in a group or organized group. In addition, adolescents who were involved in household chores had higher self-image than those adolescents who were not involved in household tasks or chores. Furthermore, individuals who had overprotective parents had poor self-image. Resnick and Hutton (1987) referred to self-image as an evidence of resilience; they incorporated measures of self-esteem, happiness, anxiety, self-consciousness, body image, and self-perceived popularity. Thus, indicators of adaptive outcomes were described as evidence of resilience, but resilience per se was not measured in this study.

Social Support and Severity of Illness

Wineman (1990) examined the influence of social support, functional disability, and perceived uncertainty on the psychosocial adaptation of 118 individuals with MS. The sample consisted of 38 males and 80 females. Fifty-one participants had relapsing-remitting MS and 67 had progressive MS.

Researcher assessed participants' degree of satisfaction with social interactions, illness related functioning and uncertainty, and participants' level of adaptation as measured by depression and purpose-in-life. Their findings indicated that social support was directly related to purpose-in-life. In addition, the researcher found that perceived lack of support, illness uncertainty and disability were related to higher levels of depression and a lower sense of purpose in life. Thus, these findings corroborated the positive contribution of social support to adaptation and the negative influence of disability on psychological adjustment.

Severity of the Illness, Social Support, and Illness Status

McIvor, Riklan, and Reznikoff (1984) investigated adjustment to MS as a function of severity and length of the illness, perceived social support, age, and course of the illness. Researchers hypothesized that depression was related to: (1) the length of the illness—the shorter the length of the illness, the more depressed the patient would be, (2) the degree of disability—the more disabled patient would be more depressed, (3) the age of the patient—younger patients would be less depressed than older patients, (4) the perceived presence or absence of social support—depression would be less severe for those with social support, and (5) the presence or absence of remissions—depression would be less severe for individuals that had experienced remissions. Their sample consisted of 120 non-hospitalized individuals diagnosed with MS. Their findings indicated that length of the illness was not related to the degree of depression. However, they did find

a significant positive correlation between depression and degree of disability—the more disabled tended to be more depressed. They also found a significant positive correlation between depression and age—older subjects were more depressed than younger subjects. In addition, there was a significant correlation between severity of depression and perceived social support from family and friends. That is, individuals who reported little or no social support were more depressed than those individuals who reported greater support. Finally, their findings revealed a significant positive relationship between depression and absence of remissions—individuals who never experienced a remission were more depressed than those individuals who had experienced remissions.

Social Support, Medical Support, and Spirituality

Kyngas, Mikkonen, Nousiainen, Ryttilahti, Seppanen, Vaattovaara, and Jamsa (2001) studied a group of individuals with cancer. Their sample consisted of eight females and six males; they were between the ages of 15 and 22. Participants had received the diagnosis at least 2 months prior to participation in the study. All participants were interviewed and their responses were analyzed using content analysis. Participants identified social support—conversations with family, friends, health care providers, beliefs in one’s resources, belief in God, and quick return to “normal life” as significant factors related to successful coping. In specific, individuals valued the support received from family, friends, and health professionals. They considered the consistency, permanency and

safety of the relationship with their physician and nurse as a very significant source of support.

In addition, Long and Miller (1991) studied the relationship among perceived social support, hopelessness, religiosity and suicidal ideations among individuals with MS. The sample consisted of 147 individuals with MS. There were 34 males and 113 females; the mean age was 43. Participants responded to items that measured suicidal tendency, social support, physiological and psychological factors. Those individuals who were at a highest risk for contemplating suicide were significantly more hopeless, had a decreased self-perception of religiosity and experienced less family support. Thus, these findings may suggest and confirm the positive contribution that social support and spirituality may have on resilience.

Social Support, Involvement in Activities, and Duration of Illness

According to Byrne, Love, Browne, Brown, Roberts, and Streiner (1986), most studies on the psychosocial adjustment of children following burn injury have focused on those who had done “poorly”, often ignoring those individuals who have done surprisingly well. Byrne et al. (1986) conducted a study on children’s resiliency. They assessed the social competence of 145 children who had either major (47 boys and 20 girls) or minor (50 boys and 28 girls) burns. Participants received scores on social competence as defined by the amount and quality of the child’s participation in sports, hobbies, games, activities,

organizations, jobs, chores, friendships, and school functioning. Researchers also assessed family reaction to their children's burn injury, and investigated the social and environmental characteristics of the family. Byrne et al. (1986) reported that the degree of disability, disfigurement, age at the time of participation in the study, and age at the time of burn did not differentiate between low social competence and high social competence. However, they found that the severity of the burn was related to social competence, that is, the more severely burned child was more socially competent. In addition, they identified the following contributing factors to resilience or social competence: greater interest and involvement in intellectual, political, social, recreational and cultural activities, higher socioeconomic status, longer time since burn, positive appraisal by caregiver, and having a larger number of family members. These factors made a distinction between the less and the more socially competent resilient child. Although this study referred to children's resiliency, researchers assessed social competence instead as an indicator of resilience.

Illness Intrusiveness and Emotional Distress

Devins, Styra, O'Connor, Gray, Seland, Klein, and Shapiro (1996) examined the psychosocial impact of illness intrusiveness—the degree to which illness-induced impairments interfered with valued activities, causing emotional distress. Thus, researcher explored the relationship between psychological well-being and the following factors indicative of illness intrusiveness: health, diet,

work, finances, recreational activities (e.g., sports, reading, listening to music), relationship with significant other, intimacy, family, social relationships, expression of self, religiosity, community and civic involvement. They collected data from two groups of MS outpatients (n = 174) and tested the hypothesis that illness intrusiveness influenced psychological well-being and emotional distress in patients. Participants completed questionnaires on illness intrusiveness, emotional distress and psychological well-being. Their findings indicated that individuals who reported greater levels of illness intrusiveness or greater illness interference with their valued activities experienced decreased psychological well-being and higher levels of distress. Devins et al. (1996) concluded that life changes and disruptions in valued activities led to emotional distress.

Severity of Illness and Illness Status

Chwastiak, Ehde, Gibbons, Sullivan, Bowen, and Kraft (2002) examined the prevalence of clinically significant depressive symptoms across categories of MS: severity of the illness, duration of the illness, and course of illness.

Chwastiak et al. (2002) also investigated the relationship of depressive symptoms with decreasing cognitive functioning, vision and mobility. Their findings were based on a large sample of individuals with multiple sclerosis (n = 739).

Participants completed a survey that included questions on demographic information. Participants also completed the CES-D Scale--measuring depression, the Expanded Disability Status Scale--measuring disease progression,

and a short version of the Modified Social Support Survey--measuring perceived social support. Their findings indicated that 41.8% of the subjects reported clinically significant depressive symptoms (CES-D Scale score ≥ 16) and 29.1% of the subjects had moderate to severe depression (score ≥ 21). Participants with advanced multiple sclerosis reported clinically significant depressive symptoms than participants with less advanced MS. Furthermore, shorter duration of the illness was related to significantly higher levels of depression. On the other hand, the pattern of illness progression was not related to depression. These findings, however, may not be representative. This survey was mailed to 1,374 individuals, but only 739 returned it, a response rate of 53.8%. Thus, individuals with depressive symptoms could be either over represented or under represented in the sample.

Resilience as a Responses to Losses

Wagnild and Young (1990) reported that "Despite adversity, however, many...adjust successfully, continuing to embrace life with enthusiasm and facing new challenges with strength and determination." (p. 252). They investigated how individuals responded to changes in health, social contact, finances and loss of independence. The sample consisted of 24 women who had experienced a major loss. Twelve women reported the loss of their spouse, six reported the loss of their child, two referred to the loss related to relocation, one reported the loss of employment and three identified the loss of health as recent major events.

According to researchers, these women had a positive morale and were “successfully adjusted” because they had remained socially involved through participation in a senior center. Their responses to “what gets them through difficult times in general” indicated that they had internal source of strengths (e.g., “a positive comparison with others, belief in self, determination, sense of humor and faith in God”) as well as external source (e.g., “family and friends, meaningful work and activities). According to Wagnild and Young (1990), most participants had a positive perception of their lives and experienced satisfaction. Their responses were grouped into five themes that related to resilience:

1. *Equanimity*: The “balanced perspective of one’s life was illustrated by a 70-year old participant who reported “...seems as if you have to take things in stride... You have to be able to laugh at things that just seem terrible tragic—kind of see it in a different perspective.” (p. 253).
2. *Perseverance*: The willingness to continue the struggle and keep on going despite adversity or discouragement” was illustrated by a 78-year old woman. She experienced difficulties with her balance, memory and emotions after a stroke. Her words “Just my determination to keep on going... You don’t give in to troubles... You can’t just sit and vegetate.” (p. 254) illustrated her perseverance.
3. *Self-reliance*: People who are self-reliant believe in themselves and in their capabilities. One of the participants, a 78-year old widow woman,

exemplified self-reliance. Although she “did not have a lot of physical strength” (p. 254), she joined the Peace Corps and found resources within herself to manage her daily struggles.

4. *Meaningfulness*: Individuals who experienced difficulties found meaning in their experiences and had a renewed meaning in life. Their negative experiences became transformed into personal development and contentment.
5. *Existential aloneness*: Although there are circumstances that are shared and experienced by everyone, some situations must be confronted alone. This realization provides the person with a sense of freedom, uniqueness and self-acceptance.

Wagnild and Young (1990) concluded that resilience reflected the individual’s ability to incorporate stressful trials into one’s life as the person re-establishes a sense of stability. The resilient person considers difficulties or adversities as an opportunity for personal growth and development. These women found meaning in the myth of their losses and remained actively involved in valued activities.

Spirituality

Spirituality has been defined “as an awareness of one’s inner self and a sense of connection to a higher being, nature, others, or to some purpose greater

than oneself” (Reed, 1987). Spirituality derives from the Latin word “spiritus, which means ‘breath’—referring to the breath of life.” (Elkins, 1999, p. 47).

It involves opening our hearts and cultivating our capacities to experience awe, reverence and gratitude. It is the ability to see the sacred in the ordinary, to feel the poignancy of life, to know the passion of existence and to give ourselves over to that which is greater than ourselves. (Elkins, 1999, p. 47).

Others have used words, such as, “harmonious, interconnectedness, inner strength, being, knowing, doing, spiritual well-being, spiritual needs” as some of the definitions most favored within the social sciences (Hall, 1998).

Peterson and Nelson as cited by Turner, Lukoff, Barnhouse, and Lu (1995) defined spirituality as ‘the transcendent relationship between the person and a Higher Being, a quality that goes beyond a specific religious affiliation’ (p. 437). Although spirituality and religiosity have been used “interchangeably”, these terms are not the same (Turner et al., as cited by Powell Stanard, Singh Sandhu & Painter, 2000). Spirituality, for example, may or may not include religious rituals or involvement in a religious organization (Reed, 1987). Religion, on the other hand, does refer to an ‘adherence to the beliefs and practices of an organized church or religious institution’ (Shafranske & Maloney as cited by Powell Stanard et al., 2000).

Spirituality and Counseling

Although “good health” consists of social, physical, intellectual, emotional and spiritual dimensions, spirituality has been the one dimension that is often overlooked (Craig Hospital, 2000) in secular settings (Havranek, 1999). Elkins (1999)’s article “Spirituality: It’s what’s missing in mental health” referred to spirituality as vital to happiness and health. He reflected on his own experiences when told ‘You are spiritually hungry.’ In his writing, he indicated that “contemplation, mediation, prayer, rituals and other spiritual practices have the power to release the ‘life force’ in the deepest levels of the human psyche” and that “...spiritual interventions can help when everything else has failed.” (p. 45).

The healing component of spirituality has been documented in the literature in regards to the importance of integrating intellectual, moral and spiritual perspectives when individuals attempt to cope with their daily predicaments (Powell Stanard et al., 2000).

Maimes (2002), a freelance writer and researcher, described spirituality as “that inner quest for contact with the divine within oneself.” He referred to the importance of spirituality in the presence of a serious or chronic illness, and mentioned the comfort felt by the person engaged in prayer. He urges health care professionals to recognize “the healing effects of spirituality” in that spirituality has a positive influence in the “health of the body”.

Kuhn (1988) also wrote about spirituality and the medically ill person. He described the spiritual person as having the capacity “to rise above or transcend” any situation. According to Kuhn (1988), the spiritual person seeks meaning and purpose, has faith, loves, forgives, prays, meditates, worships and sees beyond present conditions. The literature has also referred to spirituality as enhancing health and reducing stress by providing the person with a sense of meaning and purpose (Oxman, 1985), hope, comfort and internal harmony (American Family Physician, 2001).

The field of rehabilitation has recognized the positive role of spirituality in the lives of individuals who have illnesses and disabilities, indicating that those with higher spirituality “bounced back more quickly” than those who had low spirituality” (p. 4). These findings provided evidence that “the health of the spirit can indeed make a difference in the health of the body.” (Health & Nutrition Letter, 2001, p.3) and that spirituality has a positive influence on health (Oxman, 1995).

Havranek (1999) examined the role of spirituality in rehabilitation counseling and cited Wright’s definition, rehabilitation counseling “...is designed to attend to the physical, mental, emotional, spiritual, social, and vocational aspects of life.” (p. 32). According to Havranek (1999), counselors incorporate the spiritual component in their practice, depending on the significance of their client’s spirituality, and the degree to which spirituality is therapeutically related

to the client's rehabilitation process. Counselors who incorporate the spiritual component in their practice help their clients by increasing their awareness of God's love for them, encouraging them to openly ask for what they need, increasing their sense of integration, self-image, respect, and participation in recreational and social activities (Lane, 1992 as cited by Havranek, 1999). In the delivery of services, counselors must not make generalizations about client's spirituality, but instead must recognize and be aware of his/her client's culture, ethnicity and race in regards to the expression of spirituality (Havranek, 1999).

Despite health professionals' acknowledged belief in the importance of spirituality, they are frequently hesitant to provide spiritual interventions. It has been suggested that many individuals in the health profession have not received training in spirituality (as cited by Tuck, Pullen, & Wallace, 2001), thus, limiting the use of spiritual interventions.

Meyer (2003) investigated contributing factors to perceived effectiveness in providing spiritual care, and found that participants acknowledged a relationship between spiritual well-being and health, however, they felt inadequately prepared to conduct spiritual assessment and care. She also reported that student's spirituality provided the strongest contribution to preparedness in providing patients with spiritual care, followed by their commitment to religion. In regards to environmental factors, the emphasis in spirituality in the nursing

program was the most significant predictor of students' perceived ability to provide spiritual care.

Likewise, Young, Cashwell, Wiggins-Frame, and Belaire (2002) studied spirituality in counseling education, and indicated that it was likely that counselor educators did not have graduate training in spirituality. Cashwell et al. (2002) conducted a national survey of 94 Counsel for Accreditation of Counseling and Related Educational programs (CACREP), accredited counselor education programs. Their findings indicated that 73 individuals reported that their counseling education program did not offer a specific course in spiritual and religious issues in counseling, but instead the instruction of spirituality was "provided at some place in the curriculum" (n = 66). Participants reported a moderate strong agreement that spirituality was an important training issue for the effective preparation of counselors-in-training, however, only 46% considered themselves prepared or very prepared to introduce spirituality into their teaching and supervision of counselors, thereby, raising questions about the likelihood that students will be trained in spiritual issues.

Spirituality and Health

Coyle (2002) conducted an extensive review of the literature on spirituality and explored the relationship between spirituality and health. She identified meaning and purpose in life as the dimension of spirituality that contributed to health by providing the individual with a greater sense of peace and

self-confidence. In addition, she referred to connectedness with God or a higher power (i.e., transcendence) as providing the individual with “a shared sense of responsibility” (p. 594), encouragement and hope. In other words, individuals acknowledge the illness is beyond their control, thereby, their sense of responsibility for their illness “weigh less” as they share their responsibility with God or a higher power. She concluded that spirituality enhanced health, helping individuals cope with a chronic illness in that the spiritual dimension may allow the person to transcend pain and suffering.

Researchers have studied spirituality in women who had received a kidney transplant (Carbage Martin & Smith Sachse, 2002), spinal cord injury, amputations, polio or cancer (Tate & Forchheimer, 2002), brain injury (McColl, Bickenbach, Johnston, Nishihama, Schumaker, Smith, Smith & Yealland, 2000), terminally ill adults (Reed, 1987) chronically ill patients (Narayanasamy, 2002), and patients with disabilities (Boswell, Knight, & Hamer, 2001).

Although research on spirituality and disabilities has been conducted, more systematic research is necessary. In regards to MS, for example, two researchers had examined the influence of spirituality in multiple sclerosis (Kutsunai, 2000; McNulty, Livneh, & Wilson, 2004).

Kutsunai (2000) examined the relationship of perceived control and spirituality to psychological adjustment in MS. The sample included 70 individuals (54 women and 16 men; the mean age was 50.5 years) with multiple

sclerosis. She reported that individuals were more likely to rely on secondary control. In addition, she reported that psychological adjustment was positively related to secondary and primary control. In regards to spirituality and psychological adjustment in MS, she did not find a relationship. She explained though, that the lack of the relationship between spirituality and adjustment related to the instrument she used to measure well-being—the Mental Health Inventory. Thus, the use of a different instrument to measure adjustment may have provided different results.

Although Kutsunai (2000) found no correlation between spirituality and adjustment, others had reported different outcomes. Carbage Martin and Smith Sachse (2002) examined the spiritual perspectives and spiritual well-being of 28 women (mean age = 44.36) who had received a kidney transplant. Findings indicated that participants who reported high levels of spiritual perspective also reported high spiritual well-being—there was a moderate correlation between spiritual perspective and spiritual well-being. Researchers also indicated that age was related to spirituality; older women had higher levels of spiritual perspectives. Although findings suggested a positive relationship between spirituality and well-being, it is important to consider the limitations of the study. Researchers used a small sample size and only included women; thus, one must be cautious when generalizing these findings.

McNulty, Livneh, and Wilson (2004) examined the relationship between perceived uncertainty and psychosocial adaptation to multiple sclerosis, with spirituality as a mediator and moderator variable. The sample consisted of 50 (40 women, and 10 men) individuals with MS, ranging in age from 22 to 76 years. Individuals completed self report measures on illness uncertainty, spiritual well-being, and adjustment. Their findings indicated that uncertainty was significantly related to psychosocial adjustment, and that spiritual well-being was also related to psychosocial adjustment. That is, individuals who had higher levels of uncertainty and decreased spirituality had lower levels of psychosocial adjustment. Researchers also found that the relationship between perceived uncertainty and psychosocial adaptation was mediated by spiritual well-being. In addition, they found that the interaction effect between perceived uncertainty and spiritual well-being did not influence psychosocial adjustment, that is, spirituality did not moderate the relationship between perceived uncertainty and adaptation. When interpreting these findings however, it is important to consider the small sample size of this study, restricting the generalizability of the findings.

Reed (1987) studied the significance of spirituality among terminally ill adults. Her sample consisted of 300 adults. Participants were divided into three groups: Group 1 consisted of 100 terminally ill and hospitalized cancer patients (mean age = 61.1 years); Group 2 consisted of 100 non-terminally ill patients (mean age = 60.23) and Group 3 consisted of 100 healthy non-hospitalized

individuals (mean age = 60.54). Eighty one percent of participants in each group were white, 3 to 4% black; 12 to 13% Hispanics; and 2 to 3% American Indian or Asian American. Participants' spiritual perspective and satisfaction with life were assessed. Reed (1987)'s findings supported that the terminally ill hospitalized adult reported greater spiritual perspective than either the non-terminally ill hospitalized adult or the healthy non-hospitalized adult. In addition, she found a low but significant positive relationship between spiritual perspective and well-being in the terminally ill group. In regards to the non-terminally ill hospitalized or the healthy non-hospitalized group, the relationship between spirituality and well-being was not significant.

Tate and Forchheimer (2002) reviewed the literature on spirituality and reported that spirituality was not the same as religion, but related in that both concepts indicated "transcendence", and provided the person with the ability to "rise above" difficulties. They conducted research to determine differences in quality of life, satisfaction, and spirituality across different patient groups, comparing outcomes between rehabilitation patients with spinal cord injury, amputations, and polio (n = 136) and cancer (n = 72) patients. Their findings indicated that cancer patients reported higher scores on quality of life, life satisfaction and spirituality. Spirituality showed a strong relationship with life satisfaction and quality of life. In addition, spirituality was a significant predictor of life satisfaction among rehabilitation patients. Researchers also reported that

spirituality seemed to be related to demographic factors. Cancer patients reported higher levels of spiritual well being; furthermore, they were the oldest, most likely to be married, and the least physically limited group.

McColl, Bickenbach, Johnston, Nishihama, Schumaker, Smith, Smith, and Yealland (2000) studied the effect of sudden-onset disability on spirituality. Their sample consisted of 16 individuals (8 had spinal cord injury, 7 had brain injury and 1 had both). There were 12 men and 4 women; their average age was 37. All participants met with a trained interviewer who had experience in pastoral and rehabilitation care. The data collected indicated significant changes in spirituality. Participants reported a higher awareness of the self in the context of the disability; a change in the outlook of their own self-sufficiency; a sense of purpose in life that was absent prior to the onset of the disability; increased awareness of their own vulnerability; a new understanding of trust—learning to trust others to assist with basic functions; and greater appreciation and closeness to others and the world. It is important when interpreting the results to consider the small sample size in this study and the lack of empirical data collection.

Narayanasamy (2002) described the experiences of 15 chronically ill hospitalized patients (10 men and 5 women; their ages ranged from 23 to 80 years). Participants had received a medical diagnosis and had lived with the illness for 6 months or longer. The diagnosis included leukemia, melia fibrosis, bowel cancer, chronic liver disease, Crohn's disease, lung cancer, ulcerative

colitis and melanoma. According to Narayanasamy (2002), participants reported “Reaching out to God in the belief and faith that help will be forthcoming to rescue them from the illness.” (p. 1465). Faith provided them with the strength to cope with the demands of living with a chronic illness. Some participants also reported that they felt “connected to God through prayer”, and used prayer to cope with the illness. They also indicated the need to connect with those who provided them with spiritual support: family, friends, and/or religious fellowships. Thus, faith, prayer and related sources of support assisted individuals in their daily battle against the illness.

Kim, Heinemann, Bode, Sliwa, and King (2000) conducted a longitudinal assessment of 155 adults who were admitted to a rehabilitation hospital. Participants had a primary diagnosis of spinal cord injury, amputation, stroke, traumatic brain injury, generalized weakness, organ transplantation, burns, cancer, chronic obstructive pulmonary disease, or multiple sclerosis. Participants were grouped by the onset patterns of the condition: “Acute onsets” (n = 114); “Chronic with acute exacerbation” (n = 38); and “Chronic impairments” (n = 3). Kim et al. (2000) assessed how spiritual well-being, emotional well-being, life satisfaction, and functional status changed during and after rehabilitation. Their findings indicated that emotional well-being increased during rehabilitation, but spiritual well-being and life satisfaction did not change during rehabilitation. However, there was a change in spiritual well-being and life satisfaction over

time. African Americans as a group reported greater spiritual well-being than other racial ethnic groups on admission. However, this group emotional well-being was the least likely to increase over time. Participants with less than a high school education experienced significant declines in life satisfaction while those with more than a high school education were least likely to experience gains in spiritual well-being over time. Thus, researchers identified those who were more highly educated, African Americans, and those who had small functional gains during rehabilitation as a group of individuals at risk for declines in spiritual well-being or emotional well-being. These findings, although informative, lack specificity in that they did not provide information based on the specific medical condition, but instead divided the sample into groups based on the onset patterns of the condition.

Boswell, Knight, and Hamer (2001) explored the relationship between disability and spirituality. Their sample consisted of 6 women (5 Caucasian and 1 African American) with disabilities (spastic cerebral palsy, quadriplegia, post polio syndrome and congenital glaucoma), ranging in age from 35 to 55 years. Their findings indicated that spirituality and disability were “intricately” related. Participants referred to spirituality and disability as “core dimensions of their lives that were emergent, interactive, and interdependent” (p. 22). That is, their spiritual beliefs shaped their perception of their disability, and their experience of the disability shaped the expression and development of their spirituality. These

women viewed their disability as an integral part of themselves, often bringing about a search for personal development and spiritual meaning; resulting in a stronger sense of spirituality. These women found meaning, and accepted their disability through their spiritual beliefs. One participant stated: 'I think that it (spirituality) has an awful lot to do with my acceptance, with my ability to deal with this (disability)'. Another participant expressed her acceptance of disability through her own spirituality: 'Why are there some people with disabilities who accept...and some who fight the whole time and are angry and negative? What's the difference? Spirituality was the spark that set us apart.' (p. 23). These women recognized the positive influences of spirituality "as a springboard for meaning and acceptance" of their health condition. Although these findings illustrated the significance of spirituality on the lives of six women, the researchers also cautioned the reader not to generalize the results of the study to the majority of women with disabilities.

Kaye and Kumar Raghavan (2002) conducted a comprehensive literature review on spirituality and illness, and acknowledged the significance of spirituality in terms of coping with a disability. They concluded that spirituality was a primary resource among individuals dealing with hypertension, chronic obstructive pulmonary disease, diabetes, HIV/AIDS, chronic renal failure, rheumatoid arthritis, multiple sclerosis and Polio and addictive illnesses.

Summary

Multiple Sclerosis (MS) is a chronic, progressive and debilitating illness affecting between 250,000 and 350,000 individuals in the United States (Smith & Schapiro, 2000). During the course of MS, individuals experience physical symptoms (e.g., vision loss, fatigue, spasticity, weakness, memory problems (Holland et al., 1996) interfering with daily living. Along with physical symptoms, there are psychosocial aspects related to MS, for example, high prevalence of depression, lack of interest in activities and relationships (Rao et al., 1992), helplessness, subjective incompetence, alienation, loss of self-esteem, perception of being victimized by significant others, and a sense of inadequacy (Mohr et al., 1999). Most studies investigating multiple sclerosis have focused on maladjustment and emotional problems rather than on resilience.

Despite physical symptoms and distressing emotions, there are individuals who do well regardless of their medical condition. The literature in the rehabilitation field has called them resilient in that they have the capacity to bounce back and recover (Garmezy, 1993 as cited by Jacelon, 1997) by embracing the possibilities of their circumstances (Wagnild & Young, 1990).

In terms of serious illnesses and disability, the literature has provided evidence on resilience in the face of adversity. Druss and Douglas (1988) found that individuals not only remained optimistic in the midst of difficulties, but also considered their illness an opportunity for growth. Other studies have

corroborated these findings, for example, individuals who suffered from a terminal illness or disability (e.g., AIDS, cerebral palsy, burn injury, major losses) have also shown resilience. That is, participants' responses indicated a balanced perspective of life, perseverance, self-reliance, meaningfulness in their experiences, and realization of aloneness. Participants bounced back following adversity (Wagnild & Young, 1990); they reported social competence despite severe burned injury (Byrne et al., 1986); and good times ahead in the presence of AIDS (Rabkin et al., 1993).

These studies all referred to resilience, but instead assessed adaptive outcomes. For example, Druss and Douglas (1988) studied resilience in terms of cognitive style of hardiness and ego strength among individuals with an illness or disability. Resnick and Hutton (1987) assessed positive self-image among adolescents with a physical disability as an evidence of resilience. Wagnild and Young (1990) measured social involvement, morale, and subjective well-being as an indicator of resilience among older women who had experienced a major loss. Rabkin et al. (1993) described resilience in terms of psychiatric assessment, future outlook, quality of life and physical functioning among AIDS survivors. Research on the psychological adjustment of burned children also referred to the "more resilient" child, but in terms of social competence. Studies assessing resilience per se have not been empirically conducted, but instead other

measurements have been used to assess individuals' social and psychological competence as evidence of resilience.

In most studies, the literature have referred to adjustment and coping as resilience. It is important though, to establish the difference between these terms. While adjustment and coping have traditionally focused on the presence or absence of emotional disturbances or psychiatric problems (e.g., depression, anxiety, life satisfaction, hopelessness), resilience relates to equanimity, perseverance, self-reliance, meaningfulness, and existential aloneness (Wagnild & Young, 1993).

Among contributing factors to resilience, spirituality may be an important variable to explore. The literature has suggested that spirituality—the awareness of one's inner self, others, a sense of connection to a higher being, an awareness of purpose greater than oneself (Reed, 1987) help individuals deal with their ailments, providing human happiness and health (Elkins, 1999). The literature has identified spirituality, social support, access to services, involvement in valued activities, severity of the illness and illness status as contributing factors to adjustment, however, there have been no research exploring these variables in regards to resilience in MS.

The literature on chronic illness and disability support the positive nature of the relationship between spiritual perspective and well-being in the terminally ill (Reed, 1987; Tate & Forchheimer, 2002) and chronically ill (Carbage Martin &

Smith Sachse, 2002; Narayanasamy, 2002). Research on other medical conditions, such as, amputation, stroke, spinal cord injury, traumatic brain injury had also referred to the positive relationship between spiritual well-being and life satisfaction (Kim et al., 2000). Similarly, studies on cerebral palsy, polio, congenital glaucoma had also stated the positive influence of spirituality; participants reported not only finding meaning, but also accepting their health condition through their spiritual beliefs (Boswell et al., 2001).

These findings have reflected the significance of spirituality in terms of well-being and adjustment in chronic illnesses. There is a difference, though with respect to this dissertation and previous research. The present study does not focus on adjustment or maladjustment, but instead on resilience. The literature on multiple sclerosis, for example, cited only one study on spirituality and psychological adjustment. Kutsunai, (2000) examined the relationship between perceived control, spirituality and psychological adjustment among individuals with MS. Her findings though indicated no relationship between adjustment and spirituality, and she explained her results in terms of the instrument she used for assessing adjustment. Thus, this dissertation is unique in that no other study has investigated spirituality and factors that may contribute to resiliency in MS.

The next section will be chapter 3. This chapter describes the methodology. It includes a description of procedures, instruments, research questions, hypotheses, and statistical analysis.

CHAPTER 3

Methodology

Procedures

Three hundred forty four questionnaires were distributed. The criteria for participation was that subjects needed to be between the ages of 20 and 70 and who had received a diagnosis of Relapsing-Remitting Multiple Sclerosis (RRMS) by a neurologist.

The researcher provided the nurse at an outpatient neurology clinic with two hundred and sixty six packets. The nurses distributed the packets to patients who came for their follow up visit. The nurse asked participants if they were interested in participating in a research study about adjustment to MS, and those who expressed an interest received a packet with the questionnaires. Participants either completed the packets at the clinic while waiting for their neurologist or took the packet home and after completion sent them back to researcher.

In addition, fifty packets were distributed at an event sponsored by the National MS Society, National Capital Chapter. Prior to packet distribution, the researcher contacted the MS Society and informed the person coordinating the event of the purpose of the study. The coordinator read the questionnaires and approved distribution of the packets. During the event, researcher addressed the individuals in the room and told them that the researcher was conducting a study about adjustment in MS and asked for volunteers to complete the questionnaires.

Individuals who were interested in participating in the study approached the researcher and received a packet. All participants who volunteered to participate took the packet home. They were provided with stamped envelopes for the return of the questionnaires.

Few days after the event, the researcher received an e-mail from the National MS Society, Capital Chapter asking the researcher for more packets. Fourteen packets were mailed to the National MS Society; these packets were to be distributed by the National MS Society, Capital Chapter to individuals with MS in the Northern Virginia, Washington DC area.

In addition, the researcher contacted an MS support group leader in the Northern Virginia area by phone and told the leader about the purpose of the research. The leader approved of having the researcher come to the group meeting. The researcher came to the meeting and told participants that the study was about adjustment in MS. Anyone interested received a packet. Volunteers took the packet home for completion and agreed on sending the packet back to researcher.

In order to promote participation and completion of the questionnaires, the researcher provided each participant with a sharpened pencil, thus making it more convenient. As a way to compensate participants for their time, participants' names were entered to win 1 of 10 gift certificates for Starbucks of \$10 dollars. Thus, participants who were interested completed a Prize Entry Card and returned

it in an envelope separate from the questionnaires. The cards and questionnaires were kept separately so that respondent anonymity was maintained.

All participants received a return postage-paid envelope so that they could send the packet back to researcher free of charge.

In regards to confidentiality, participants were instructed not to write their names or addresses on the questionnaires. Immediately after receiving the packet, the researcher separated the consent form from the completed questionnaires.

The packet contained the following:

1. Instructions
2. Informed Consent
3. Demographic Information
4. Contributing Factors Questionnaire (CFQ)
5. Resilience Scale (RS)
6. Spiritual Perspective Scale (SPS)

Instruments

Demographic Information. The researcher developed an 10-item questionnaire asking participants: age, gender, ethnicity, marital status, month and year that the person was diagnosed with MS, course or type of MS, illness status, employment status, educational level, and perceived severity of illness.

Contributing Factors Questionnaire. The researcher developed a 13-item questionnaire in which participants had to rate the factors identified in the

literature as contributing or influential to resilience. The contributing factors identified were social support (Rabkin, Remien, Katoff & Williams, 1993; Resnick & Hutton, 1987; Byrne et al., 1986; Wineman, 1990; Willoughby, Kee, & Demi, 2000), access to health services (Rabkin, et al., 1993), and involvement in activities (Byrne, et al., 1986). Participants were asked to rate each factor on a seven-point scale from 1 = 'disagree' to 7 = 'agree'.

Perceived Severity of Illness. Participants were asked to rate the severity of their illness or symptoms on a 5-point scale: 1 = Not Severe, 2 = Mild, 3 = Moderate, 4 = Severe and 5 = Very Severe.

Illness Status. Illness status was determined from the participants' response to the following question: "My present situation can be best described as: in remission or experiencing a relapse". The sample was divided into two groups: relapsing group (those individuals who are experiencing a flare up during their participation in the study), and remission group (those participants whose symptoms have not worsened since their last flare up).

Resilience Scale (RS). The RS is a 25-item instrument designed by Wagnild and Young (1993); this instrument assesses participants' level of resilience. Responses to each item are rated on a seven-point scale from 1 = 'disagree' to 7 = 'agree'. Scores on the RS range from 25 to 175. Higher scores reflect higher levels of resilience. Study samples using the RS have included caregivers of spouses with Alzheimer's disease, graduate students, first-time

mothers returning to work, and residents in public housing. Results from these studies had indicated that the RS had high internal consistency, test-retest reliabilities, construct and concurrent validity (as cited by Wagnild & Young, 1993). In addition, Wagnild and Young (1993) conducted a study using a large sample that consisted of 810 community-dwelling adults. Their findings corroborated previous results indicating that the RS had internal consistency reliability ($r = .91, p \leq .001$) as well as concurrent validity. In addition, factor analysis will be conducted to determine whether there are one or more dimensions underlying the items. Reliability coefficients for the identified factors will be calculated using the Cronbach's alpha.

Spiritual Perspective Scale (SPS). The SPS is a 10-item instrument designed by Reed (1986). The SPS measures the importance of a spiritual perspectives in one's life. It refers to the extent of one's perception of holding particular spirituals beliefs and engaging in spirituality-related activities. The SPS is a 10-item scale. Responses to each item are selected using a 6-point Likert-type scale. Responses range from "1 = Not at all/Strongly Disagree to 6 = About once a day/Strongly Agree". A total score ranging from 1.0 to 6.0 is determined by calculating the arithmetic mean across all items. Higher total score will indicate higher spiritual perspective. In addition, factor analysis will be conducted to determine whether there are one or more dimensions underlying the

items. Reliability coefficients for the identified factors will be calculated using the Cronbach's alpha.

The SPS has "very good" psychometric properties (Reed, 1986). It has been tested on over 400 individuals of all ages—consisting of healthy, hospitalized, and seriously ill participants. Its reliability value has been consistently rated as above .90 using Cronbach's alpha, with "little redundancy" among items. The average inter-item correlation ranged from .54 to .60 across the adult groups, and all item-scale correlations have been above .60. In addition, the SPS has criterion-related validity and discriminant validity (Reed, 1987).

Research Questions

1. What is the relationship between spirituality and resilience in MS?
2. What is the relationship between contributing factors—social support, access to health services, involvement in social, cultural, and recreational activities to resilience in MS?
3. What is the relationship between perceived severity of illness and resilience in MS?
4. What is the relationship between illness status and resilience in MS?
5. What is the relationship between resilience and spirituality after controlling for contributing factors (e.g., social support, access to health services, involvement in social, cultural, and recreational activities, illness status, and perceived severity of illness) in MS?

6. What is the relationship between perceived severity of illness and resilience in MS, with spirituality as a moderator variable?
7. What is the relationship between illness status (remission and relapse) and resilience in MS, with spirituality as a moderator variable?

Hypotheses

It was hypothesized that spiritual perspectives and a number of factors: social support, access to health services, involvement in social, cultural, and recreational activities, perceived severity of illness and illness status would be significantly related to resilience in multiple sclerosis. In addition, it was hypothesized that spirituality moderated the impact of perceived severity of illness, and illness status (relapse or remission) on resilience.

1. Spirituality is positively related to resilience.
2. Contributing factors—social support, health services, involvement in activities are related to resilience.
3. Perceived severity of the illness is significantly related to resilience.
4. Illness status is significantly related to resilience.
5. Spirituality is positively related to resilience after controlling for contributing factors (e.g., social support, access to health services, involvement in social, cultural, and recreational activities, illness status, and perceived illness severity).
6. The relationship between perceived severity of illness and resilience depends

on whether one scores high or low on spiritual perspectives as measured by the Spirituality Perspective Scale.

7. The relationship between illness status and resilience depends on whether one scores high or low on spiritual perspectives as measured by the Spirituality Perspective Scale.

Definition of Terms

Contributing Factors. Based on the literature review, a number of variables have been identified as contributing factors to resilience: social support, access to health services, involvement in valued activities, illness status and perceived severity of the illness. The researcher developed a 13-item questionnaire for participants to rate the degree of importance of social support (family, friends, doctors, nurses, spiritual leader, support group), access to health services (treatment, insurance coverage, prescription plan, home assistance), and involvement in valued activities (church/religious organization, recreational activities, and work-related activities). Participants are required to rate each question on a seven-point scale from 1 = 'disagree' to 7 = 'agree'.

Perceived Severity of Illness. Participants will be asked to rate the severity of their illness or symptoms on a 5-point scale: 1 = Not Severe, 2 = Mild, 3 = Moderate, 4 = Severe and 5 = Very Severe.

Illness Status. Participants will respond to the following question: “My present situation can be best described as: in remission or experiencing a relapse”. The sample will be divided into two groups: relapsing group (those individuals who are experiencing a flare up or exacerbation during their participation in the study), and remission group (those participants whose symptoms have improved or disappeared). Depending on the number of individuals responding to either group, the researcher will separate and study one or both groups.

Resilience. Resilience is a positive trait; it “...moderates the negative effects of stress and promotes adaptation...” (Wagnild & Young, 1993, p. 165). Wagnild and Young (1993) conceptualized resilience as:

- (a) Equanimity: A balanced perspective of one’s life and experiences; it is the ability to consider a broader range of experience and to ‘sit loose’ and take what comes, thus moderating extreme responses to adversity.
- (b) Perseverance: The act of persistence despite adversity; it is a willingness to continue the struggle to reconstruct one’s life and to remain involved and to practice self-discipline.
- (c) Self-reliance: It is a belief in oneself and one’s capabilities; it is the ability to depend on oneself and to recognize personal strengths and limitations.

- (d) **Meaningfulness:** It is the realization that life has a purpose and the validation of one's contribution; it conveys the sense of having something for which to live.
- (e) **Existential aloneness:** The realization that each individual's life path is unique. Some experiences are shared, however, other experiences must be faced alone; there is a feeling of freedom and sense of uniqueness.

Spirituality. Spirituality is “an awareness of one's inner self and a sense of connection to a higher being, nature, others, or to some dimension or purpose greater than oneself.” (Reed, 1986). It refers to the extent of one's perception of holding certain spiritual beliefs and engaging in spirituality-related activities.

Statistical Analysis

Principal Components Analysis (PCA). Principal Components Analysis (PCA) was applied to the Spirituality Perspective Scale (SPS), the Resilience Scale (RS) and the Contributing Factors Questionnaire (CFQ). The PCA detects the structure of the relationship between the items or variables so it classifies the variables in the study. It also reduced the number of variables, so that multiple variables can be expressed by a factor (Hair, Anderson, Tatham, & Black, 1998).

Correlation Analyses. Hypotheses related to assessing the relationship between each predictor variable and the dependent variable (i.e., Hypotheses 1

and 2) were tested using Pearson's Product correlation analysis. The Pearson r values, level of significance (.05, .01, or .001), degrees of freedom, and means and standard deviations for each variable were reported. Spearman's Rho correlation was used to examine Hypotheses 3 and 4.

Multiple Regression. Hierarchical multiple regression was used to test hypothesis 5, 6 and 7. Multiple regression was used to examine if a set of predictor variables were related to the dependent variable (resilience), that is, determining the relationship between resilience (emerging resilience variables after factor analyses of RS) and spirituality, after controlling for the contributing factors that emerged from factor analysis of the Contributing Factor Questionnaire (CFQ), and illness status and perceived severity of illness. Thus, the researcher examined whether the relationship between perceived severity of illness and resilience and illness status and resilience depended on whether one scored high or low on spiritual perspectives. This was analyzed by examining the magnitude of the interaction between perceived severity of illness and spirituality and illness status and spirituality, following those of the main effects in hierarchical multiple regression analysis.

Spirituality was entered at the first block of the model, contributing factors emerging after applying PCA to the Contributing Factors Questionnaire were entered at the second block, perceived severity of the illness was entered at the third block, illness status was entered at the fourth block and the interaction effect

between spirituality and illness status and spirituality and perceived severity of illness were entered at the fifth block. The R^2 and regression coefficients were assessed at each block to determine the unique contribution of the variables in each block to explaining the variance in the dependent variable.

According to Hair, Anderson, Tatham, and Black (1998), the desired sample size is between 15 to 20 observations per independent variable. This allows the results of the multiple regression to be readily generalizable. With six independent variables, at a .05 level of significance, and a power of .80, a sample size of 90 will allow the detection of R^2 values of 15 percent or above (see Hair, Anderson, Tatham, and Black, 1998). That is, the study will have enough power to detect a R^2 of 12 or above 80 percent of the time. Therefore, this study needed 150 participants to ensure its generalizability and statistical power.

CHAPTER 4

Results

This chapter provides a description of the sample and results of the statistical analyses. To be noted, the researcher was advised to conduct Principal Components Analyses (PCA) of the Spiritual Perspective Scale (SPS), the Resilience Scale (RS) and the Contributing Factors Questionnaire (CFQ). PCA were used to determine the structure of the constructs (i.e., SPS, RS, and CFQ), giving a more precise understanding of the nature of spirituality, resilience and contributing factors. Since resilience is a multidimensional construct (Wagnild & Young, 1993), factor analyses were conducted to determine the number of dimensions or factors underlying the construct. PCA indicated that resilience consisted of three factors. These components were labeled: self-reliance, equanimity, and meaningfulness as conceptualized by Wagnild and Young (1993). In terms of the Contributing Factors Questionnaire, factor analysis was conducted to find the common themes or dimensions among the 13-items that were included in the questionnaire. The 13-items were analyzed through factor analyses and a reduced number of variables (i.e., social support and involvement, medical access and support from doctors and nurses) emerged.

As a result of the Principal Components Analyses (PCA), the research questions and hypotheses expanded. Formerly, resilience was referred as a global variable, consisting of 25 items before examination through factor analyses. After

factor analyses were conducted, three dimensions of resilience were found, resulting in three dependent variables: self-reliance, equanimity and meaningfulness. Similarly, after factor analysis was conducted for the Contributing Factors Questionnaire, two dimensions of contributing factors were identified (i.e., social support and involvement, medical access and support). The SPS was also analyzed using factor analysis, and only one factor solution was determined. Therefore, the research questions and hypotheses listed in chapter 3 were expanded, and new hypotheses emerged.

Research Questions

Previous Research Questions

1. What is the relationship between spirituality and resilience in MS?
2. What is the relationship between contributing factors—social support, access to health services, involvement in activities to resilience in MS?
3. What is the relationship between perceived severity of illness (less severe and more severe) and resilience in MS?
4. What is the relationship between illness status (remission and relapse) and resilience in MS?
5. What is the relationship between resilience and spirituality after controlling for contributing factors in MS?
6. What is the relationship between perceived severity of illness (less severe and more severe) and resilience, with spirituality as a moderator variable?

7. What is the interaction between illness status (remission and relapse) and resilience, with spirituality as a moderator variable?

Current Research Questions

1. What is the relationship between spirituality and resilience?
 - 1a. What is the relationship between spirituality and self-reliance?
 - 1b. What is the relationship between spirituality and equanimity?
 - 1c. What is the relationship between spirituality and meaningfulness?
- 2a. What is the relationship between contributing factors (i.e., social support and involvement) to resilience in MS?
 - 2aI. What is the relationship between social support and involvement to self-reliance?
 - 2aII. What is the relationship between social support and involvement to equanimity?
 - 2aIII. What is the relationship between social support and involvement to meaningfulness?
- 2b. What is the relationship between contributing factors (i.e., medical access and support from doctors and nurses) to resilience in MS?
 - 2bI. What is the relationship between medical access and support from doctors and nurses to self-reliance?
 - 2bII. What is the relationship between medical access and support from doctors and nurses to equanimity?

- 2bIII. What is the relationship between medical access and support from doctors and nurses meaningfulness?
3. What is the relationship between perceived severity of illness (less severe and more severe) and resilience in MS?
- 3a. What is the relationship between perceived severity of illness (less severe and more severe) and self-reliance in MS?
- 3b. What is the relationship between perceived severity of illness (less severe and more severe) and equanimity in MS?
- 3c. What is the relationship between perceived severity of illness (less severe and more severe) and meaningfulness in MS?
4. What is the relationship between illness status (remission and relapse) and resilience in MS?
- 4a. What is the relationship between illness status (remission and relapse) and self-reliance in MS?
- 4b. What is the relationship between illness status (remission and relapse) and equanimity in MS?
- 4c. What is the relationship between illness status (remission and relapse) and meaningfulness in MS?
5. What is the relationship between resilience and spirituality after controlling for contributing factors in MS?

6. What is the relationship between resilience and spirituality after controlling for social support and involvement, medical access and support, illness status and perceived severity of the illness?
 - 6a. What is the relationship between self-reliance and spirituality after controlling for social support and involvement, medical access and support, illness status and perceived severity of the illness?
 - 6b. What is the relationship between equanimity and spirituality after controlling for social support and involvement, medical access and support, illness status and perceived severity of the illness?
 - 6c. What is the relationship between meaningfulness and spirituality after controlling for social support and involvement, medical access and support, illness status and perceived severity of the illness?
7. What is the relationship between illness status (remission and relapse) and resilience, with spirituality as a moderator variable?
 - 7a. What is the relationship between illness status (remission and relapse) and self-reliance, with spirituality as a moderator variable?
 - 7b. What is the relationship between illness status (remission and relapse) and equanimity, with spirituality as a moderator variable?
 - 7c. What is the relationship between illness status (remission and relapse) and meaningfulness, with spirituality as a moderator variable?

Current Hypotheses

1. Spirituality is positively related to resilience.
 - 1a. Spirituality is positively related to self-reliance.
 - 1b. Spirituality is positively related to equanimity.
 - 1c. Spirituality is positively related to meaningfulness.
- 2a. Social support and involvement are positively related to resilience.
 - 2a.I. Social support and involvement are positively related to self-reliance.
 - 2a.II. Social support and involvement are positively related to equanimity.
 - 2a.III. Social support and involvement are positively related to
meaningfulness.
- 2b. Medical access and support are positively related to resilience.
 - 2b.I. Medical access and support are positively related to self reliance.
 - 2b.II. Medical access and support are positively related to equanimity.
 - 2b.III. Medical access and support are positively related to
meaningfulness.
3. There is a significant relationship between perceived severity of the illness
and resilience.
 - 3a. There is a significant relationship between perceived severity of the illness
and self-reliance.
 - 3b. There is a significant relationship between perceived severity of the illness
and equanimity.

- 3c. There is a significant relationship between perceived severity of the illness and meaningfulness.
- 4. There is a significant relationship between illness status (remission or relapse) and resilience.
 - 4a. There is a significant relationship between illness status (remission or relapse) and self-reliance.
 - 4b. There is a significant relationship between illness status (remission or relapse) and equanimity.
 - 4c. There is a significant relationship between illness status (remission or relapse) and meaningfulness.
- 5. Spirituality is positively related to resilience after controlling (i.e., taking into account other variables that may contribute to the explanation of the dependent variable) for social support and involvement, medical access and support, illness status and perceived severity of illness.
 - 5a. Spirituality is positively related to self-reliance after controlling for social support, involvement in activities, medical access and support, illness status and perceived severity of illness.
 - 5b. Spirituality is positively related to equanimity after controlling for social support, involvement in activities, medical access and support, illness status and perceived severity of illness.
 - 5c. Spirituality is positively related to meaningfulness after controlling for

social support, involvement in activities, medical access and support, illness status and perceived severity of illness.

6. The relationship between perceived severity of the illness and resilience is moderated (i.e., a moderated variable is a variable that changes or influences the relationship between two other variables; in this case spirituality was hypothesized to influence the relationship between perceived severity of illness and resilience) by spirituality.
 - 6a. The relationship between perceived severity of the illness and self-reliance is moderated by spirituality.
 - 6b. The relationship between perceived severity of the illness and equanimity is moderated by spirituality.
 - 6c. The relationship between perceived severity of the illness and meaningfulness is moderated by spirituality.
7. The relationship between perceived severity of the illness status and resilience is moderated by spirituality.
 - 7a. The relationship between illness status and self-reliance is moderated by spirituality.
 - 7b. The relationship between illness status and equanimity is moderated by spirituality.
 - 7c. The relationship between illness status and meaningfulness is moderated by spirituality.

Sample Description

Three hundred forty four questionnaires were distributed. The criteria used for participation in the study was that subjects needed to be between the ages of 20 and 70, and that participants had received a diagnosis of Relapsing-Remitting Multiple Sclerosis (RRMS). There was a response rate of 44%. Thus, the sample consisted of 152 individuals diagnosed with RRMS who volunteered to participate in this study. There were 112 participants (73.7%) in remission and 40 participants (26.3%) were experiencing a relapse at the time of the study. The following demographic data was derived from the sample: White (90.8%), Black (3.9%), Hispanic (3.9%), and other ethnic groups (1.3%); females (86.2%) and males (13.8%). In regards to marital status, 61.2% of participants were married, 16.4% were single, 18.4% were divorced, and 3.3% were widowed.

Participants' educational level, employment status and age are presented in Table 1. Almost half of the sample (42.8%) had completed a bachelor's degree. Half of the participants (51.3%) indicated full time employment and most of the participants' age ranged from 36 to 45 (28.3%). See Table 1 for further demographic characteristics of participants.

Table 1

Demographic Characteristics of Participants (N = 152)

Characteristics	N	%
Educational level completed		
High school	16	10.5
Some college	28	18.4
BA or BS degree	65	42.8
Graduate school	36	23.7
Other	7	4.6
Employment status		
Full time	78	73.7
Part-time	22	14.5
Disability benefits	22	14.5
Unemployment	10	6.6
Homemaker	13	8.6
Retired	7	4.6

(Table 1 continued)

Demographic Characteristics of Participants (N = 152)

Characteristics	N	%
Age in years		
20-25	4	2.6
26-35	29	19.1
36-45	43	28.3
46-55	47	30.9
56-64	26	17.1
65-70	3	2.0

Factor Analyses on Instruments

Principal components analyses (PCA) were conducted for the Spiritual Perspective Scale (SPS), Resilience Scale (RS) and the Contributing Factors Questionnaire. This technique is used to detect the structure of the relationship between the items or variables as to classify variables, and to reduce the number of variables, so that multiple variables can be expressed by a single factor (Hair, Anderson, Tatham, & Black, 1998). Three criteria were used to decide on the factors to be retained: (1) the magnitude of the eigenvalue (i.e., the variance in a set of items explained by a factor or component) of factors (eigenvalue-greater than-one criterion), (2) the scree plot (i.e., a graphical plot of the eigenvalues), and (3) the a priori theoretical definitions and beliefs about the constructs.

In order to determine and construct the final factors, items with strong factor loadings (above .40) were selected as recommended by Hair, Anderson, Tatham and Black (1998). Greater loadings indicate more accurate and precise measure of the factor by the items. In deciding on the number of factors to extract, after the initial factor solution had been computed, the researcher examined a number of different trial factor solutions to arrive at the most interpretable factors (Hair, Anderson, Tatham, & Black). Internal consistency estimates of reliability were computed using Cronbach's alpha to understand how well the items comprising each factor fit together. Higher values indicate greater reliability among the items ($\alpha \geq .60$ indicates acceptable internal consistency).

Spiritual Perspective Scale

The Spiritual Perspective Scale was analyzed using Principal Components analysis (PCA) with oblimin rotation (i.e., a method of deriving factors or ‘clusters’, so that the resulting factors are correlated with one another) and Kaiser normalization (i.e., the variance in a set of items explained by a factor). The factor solution indicated only one factor (i.e., spirituality); the scree plot criterion and the eigenvalue-over-one criterion also indicated one global factor (i.e., spirituality). The percentage of variance explained by the factor, spirituality, was 69.3%. That is, the factor captured 69.3% of the total variance in the 10 items on the spirituality scale. Factor loadings ranged from .65 to .90. All items had strong factor loadings (above .40), thus, they were selected in interpreting and constructing the spirituality factor. The reliability coefficient alpha was .95, indicating a strong relationship among all the items in the spirituality scale.

Spirituality was used as a continuous variable in the correlations and multiple regression analyses, and it was used as a categorical variable after significant interaction effects were found. Spirituality was categorized into three levels using the 33rd and the 66th percentile (scores for low spirituality fell below -.28 (33rd percentile), scores for moderate spirituality ranged from -.28 to .62 (between the 33rd and the 66th percentile), and scores for high spirituality fell above .62 (66th percentile). In order to better interpret a significant interaction effect in multiple regression it is useful to examine plots of the relationship

between the independent variables (i.e., perceived severity of illness, illness status) and the dependent variable (self-reliance, equanimity, meaningfulness) at different levels of the moderator variable (i.e., spirituality) (Hair, Anderson, Tatham, & Black, 1998; Tabachnick & Fidell, 2001).

Resilience Scale: Self-Reliance, Equanimity and Meaningfulness

The Resilience Scale (RS) was examined using PCA with oblimin rotation and Kaiser normalization. Although the eigenvalue-over-one criterion suggested six factors, the scree test indicated two possible factors. The factor solutions for two and three factors were examined. The three factor solution had the strongest interpretability based on prior research and theoretical definitions of resilience (Wagnild & Young, 1993). These factors were labeled: self-reliance, equanimity and meaningfulness and corroborated the definition of resilience as conceptualized by Wagnild and Young (1993). Factor 1 (self-reliance) included nine items, Factors 2 (equanimity) included eight items, and factor 3 (meaningfulness) included eight items. Items with strong factor loadings (above .40) were selected in interpreting and constructing the factor. All factor loadings were above .45. The three-factor solution explained 49% of the total variance in the items on the resilience scale. See Table 2 for the three factors with item loadings.

Self-Reliance. Factor 1 consisted of nine items that reflected self-reliance, namely, a belief in oneself and one's capabilities; it is the ability to depend on

oneself and to recognize personal strengths and limitations (Wagnild & Young, 1993). Factor 1 accounted for 8.5 % of the total variance in the 25 items (variability in the responses) with factor loadings ranging from .59 to .80, and a reliability coefficient alpha of .83, indicating that the scale has high internal consistency.

Equanimity: Factor 2 consisted of eight items that reflected equanimity, namely, a balanced perspective of one's life and experiences, the ability to consider a broader range of experiences and to 'sit loose' and take what comes (Wagnild & Young, 1993). It accounted for 34.1% of the total variance in the 25 items with factor loadings ranging from .48 to .78. The reliability coefficient alpha for Factor 2 was .78, indicating a fairly relationship among the items that make up the factor.

Meaningfulness. Factor 3 consisted of eight items that reflected meaningfulness, that is, the realization that life has a purpose and the validation of one's contribution. It conveys the sense of having something for which to live (Wagnild & Young, 1993). It accounted for 6.0% of the total variance in the 25 items with factor loadings ranging from -.48 to -.84. The reliability coefficient alpha was .95, indicating a high relationship among the items.

Table 2

Principal Components Analyses of Resilience Scale

Items	Factors		
	I	II	III
Factor I: Self reliance			
I am able to depend on myself more than anyone else	.80	.16	-.30
I feel that I can handle many things at a time	.75	.48	-.28
When I make plans I follow through with them	.72	.26	-.23
I usually manage one way or another	.72	.49	-.21
I can be on my own if I have to	.67	.68	-.29
I feel proud that I have accomplished things in my life	.59	.31	-.50
In an emergency, I am someone people generally can rely	.59	-.02	-.47
I have enough energy to do what I have to do	.57	.40	-.20
I can get through difficult times because I have experienced difficulty before	.56	.30	-.39

Note. I = Self-reliance, II = Equanimity, III = Meaningfulness.

(Table 2 continued)

Principal Components Analyses of Resilience Scale

Items	Factors		
	I	II	III
Factor II: Equanimity			
I do not dwell on things that I can't do anything about	.24	.78	-.29
I usually take things in stride	.37	.74	-.51
I take things one day at a time	.15	.71	-.21
When I'm in a difficult situation, I usually find my way out of it	.35	.69	-.39
I am friends with myself	.49	.55	-.45
It's OK if there are people who don't like me	.21	.50	-.17
Sometimes I make myself do things whether I want to or not	.18	.50	-.45
I seldom wonder what the point of it all is	.24	.48	-.21

Note. I = Self-reliance, II = Equanimity, III = Meaningfulness.

(Table 2 continued)

Principal Components Analyses of Resilience Scale

Items	Factors		
	I	II	III
Factor III: Meaningfulness			
I keep interested in things	.38	.32	-.84
Keeping interested in things is important to me	.21	.21	-.74
I can usually look at a situation in a number of ways	.29	.33	-.69
I can usually find something to laugh about	.38	.47	-.62
I am determined	.58	.55	-.60
My life has meaning	.47	.57	-.58
I have self-discipline	.34	.44	-.50
My beliefs in myself gets me through hard times	.46	.47	-.48

Note. I = Self-reliance, II = Equanimity, III = Meaningfulness.

Contributing Factors

The contributing factor questionnaire was also analyzed using the PCA with oblimin rotation and Keiser normalization. The scree test criterion indicated a two factor solution while the eigenvalue-over one-criterion suggested a five factor solution. In order to better determine the number of factors to retain, two, three and four factor solutions were explored. The two-factor solution proved to be the most interpretable.

Factor 1 was labeled social support and involvement and included eight items, and Factor 2 was labeled medical access and support and included five items. See Table 3 for the two-factors with item loadings.

Social Support and Involvement. Factor 1 included: support from family, friends, spiritual leader, support group, involvement in church, community organization, recreational activities, and access to home services. It accounted for 30.5% of the total variance in the 13 items with factor loadings ranging from .44 to .79, indicating a high relationship among the items. The reliability coefficient alpha was .79.

Medical access and support. Factor 2 included: access to prescriptions, health services, health insurance coverage, and support from doctors and nurses. It accounted for 14.0% of the total variance in the 13 items with factor loadings ranging from .58 to .66, indicating a high relationship among items. The reliability coefficient alpha was .64.

Table 3

Principal Component Analyses of Contributing Factors Questionnaire

Items	Factors	
	I	II
Factor I: Social Support and Involvement		
Involvement in a church/religious organization	.79	.39
Support from spiritual leader	.77	.08
Involvement in a community organization	.68	.13
Involvement in a support group	.67	-.05
Support from family	.62	.15
Support from friends	.57	.22
Involvement in Recreational Activities	.53	.23
Access to Home Assistance	.44	.39
Factor II: Medical Access and Support		
Access to prescription plan coverage	-.10	.66
Access to health services	.32	.63
Access to health insurance coverage	-.06	.58
Support from doctors	.46	.65
Support from nurses	.40	.63

Note. I = Social Support and Involvement, II = Medical Access and Support.

Descriptive Analyses

As a number of factors were determined, scores were generated for each identified factor. These scores were used as the variables in the subsequent correlation and regression analyses. Pearson Product Correlation and Spearman's Rho Correlation were used to examine the relationship between the independent variables: spirituality, social support and involvement, medical access and support, perceived severity of the illness, and illness status and the dependent variable: resilience (i.e., self-reliance, equanimity and meaningfulness). Each of these variables had a mean of zero and a standard deviation of one ($M = 0$, $SD = 1$) since factor scores are standardized.

Correlation Analyses

Hypothesis 1. Spirituality is positively related to resilience.

Hypothesis 1a. Spirituality is positively related to self-reliance. The relationships between spirituality and self-reliance was examined using Pearson Product Correlation. The hypothesis was not supported, indicating that there was not a significant relationship between spirituality and self-reliance. In other words, there was not a significant relationship between one's perception of holding certain spiritual beliefs and engaging in spirituality-related activities and a belief in oneself and one's capabilities (see table 4).

Hypothesis 1b. Spirituality is positively related to equanimity. The relationship between spirituality and equanimity was examined using Pearson

Product Correlation. The hypothesis was not supported, indicating that there was not a significant relationship between spirituality and equanimity. In other words, there was not a significant relationship between one's perception of holding certain spiritual beliefs and engaging in spirituality-related activities and having a balanced perspective of one's life and experiences (see Table 4).

Hypothesis 1c. Spirituality is positively related to meaningfulness. The relationship between spirituality and meaningfulness was examined using Pearson Product Correlation. The hypothesis was not supported, indicating that there was not a significant relationship between spirituality and meaningfulness. In other words, there was not a significant relationship between one's perception of holding certain spiritual beliefs and engaging in spirituality-related activities and the realization that life has a purpose and the validation of one's contribution (see Table 4).

Table 4

Correlations and Intercorrelations Among Spirituality, Equanimity, Self Reliance and Meaningfulness

Variables	S	E	SR	M
1. Spirituality (S)	—	—	—	—
2. Equanimity(E)	.06	—	—	—
3. Self-Reliance (SR)	-.08	.55**	—	—
4. Meaningfulness (M)	.11	.68**	.62**	—

** $p < .01$, two-tailed.

Hypothesis 2a. The contributing factor, social support and involvement, is positively related to resilience.

Hypothesis 2a.I. Social support and involvement is positively related to self-reliance. The relationship between social support and involvement and self-reliance was examined using Pearson Product Correlation. The hypothesis was not supported, indicating that there was not a significant relationship between social support and involvement and self-reliance. In other words, there was not a significant relationship between social support and involvement (i.e., involvement in church, support from spiritual leaders, involvement in community organizations, support from family and friends, involvement in recreational activities, and access to home assistance) and a belief in oneself and one's capabilities (see Table 5).

Hypothesis 2a.II. Social support and involvement is positively related to equanimity. The relationship between social support and involvement and equanimity was examined using Pearson product Correlation. The hypothesis was not supported, indicating that there was not a significant relationship between social support and involvement and equanimity. In other words, there was not a significant relationship between social support and involvement (i.e., involvement in church, support from spiritual leaders, involvement in community organizations, support from family and friends, involvement in recreational

activities, and access to home assistance) and having a balanced perspective of one's life and experiences (see Table 5).

Hypothesis 2a.III. Social support and involvement is positively related to meaningfulness. The relationship between social support and involvement and meaningfulness was examined using Pearson Product Correlation. The hypothesis was not supported, indicating that there was not a significant relationship between social support and involvement and meaningfulness. In other words, there was not a significant relationship between social support and involvement (i.e., involvement in church, support from spiritual leaders, involvement in community organizations, support from family and friends, involvement in recreational activities, and access to home assistance) and the realization that life has a purpose and the validation of one's contribution (see Table 5).

Hypothesis 2b. Medical access and support are positively related to resilience.

Hypothesis 2b.I. Medical access and support is positively related to self-reliance. The relationship between medical access and support and self-reliance was examined using Pearson Product Correlation. The hypothesis was not supported, indicating that medical access and support was not significantly related to self-reliance. In other words, there was not a significant relationship between medical access and support (i.e., access to prescription plan coverage, access to health services, access to health insurance, support from doctors and nurses) and a belief in oneself and one's capabilities (see Table 5).

Hypothesis 2b.II. Medical access and support is positively related to equanimity. The relationship between medical access and support and equanimity was examined using Pearson Product Correlation. The hypothesis was not supported, indicating that medical access and support was not significantly related to equanimity. In other words, there was not a significant relationship between medical access and support (i.e., access to prescription plan coverage, access to health services, access to health insurance, support from doctors and nurses) and a balanced perspective of one's life and experiences (see Table 5).

Hypothesis 2b.III. Medical access and support is positively related to meaningfulness. The relationship between medical access and support and meaningfulness was examined using Pearson Product Correlation. The hypothesis was supported, indicating that there was a significant relationship between medical access and support and meaningfulness, $r(146) = .24, p < .01$. Individuals who rated medical access and support (i.e., access to prescription plan coverage, access to health services, access to health insurance, support from doctors and nurses) as important had a higher sense that their lives had a purpose and an increased sense of having something for which to live (see Table 5).

Table 5

*Correlations and Intercorrelations Among Social Support and Involvement,
Medical Access and Support and Spirituality*

Variable	SSI	MAS	SR	E	M
Social Support/Involvement (SSI)	—	—	—	—	—
Medical Access/Support (MAS)	.33**	—	—	—	—
Self reliance (SR)	-.10	.17*	—	—	—
Equanimity (E)	.13	.15	.55**	—	—
Meaningfulness (M)	.07	.24**	.62**	.68**	—

** $p < .01$, two tailed; * $p < .05$, two-tailed.

Hypothesis 3. There is a significant relationship between perceived severity of the illness and resilience. Although perceived severity is treated as a continuous variable in subsequent analyses, it was divided into two categories (i.e., less severe and more severe) for the purpose of examining the means.

Hypothesis 3a. There is a significant relationship between perceived severity of the illness and self-reliance. This hypothesis was supported. A Spearman's Rho Correlation indicated a low negative, but significant relationship between perceived severity of the illness and self-reliance, $r(149) = -.29, p < .01$ (see Table 6). That is, individuals with a more severe perception of illness had decreased belief in themselves and their capabilities compared to individuals with a less severe perception of illness. Means and standard deviations for the different categories of perceived severity of illness on spirituality and self-reliance are presented in Table 7

Hypothesis 3b. There is a significant relationship between perceived severity of the illness and equanimity. A Spearman's Rho Correlation indicated that was not a significant relationship between perception of illness severity and equanimity (See Table 6). Means and standard deviations for the different categories of perceived severity of illness on spirituality and equanimity are presented in Table 7.

Hypothesis 3c. There is a significant relationship between perceived severity of the illness and meaningfulness. A Spearman's Rho Correlation

indicated that there was not a significant relationship between perception of illness severity and meaningfulness (see Table 6). Means and standard deviations for the different categories of perceived severity of illness on spirituality and meaningfulness presented in Table 7.

Table 6

Correlations and Intercorrelations Among Perceived Severity of Illness, Self Reliance, Equanimity and Meaningfulness

Variables	PS	SR	E	M
Perceived Severity (PS)	—	—	—	—
Self Reliance (SR)	-.29**	—	—	—
Equanimity (E)	.001	.55**	—	—
Meaningfulness (M)	-.03	.62**	.68**	—

** $p < .01$, two tailed; * $p < .05$, two-tailed.

Table 7

Means and standard deviations for the different categories of perceived severity of illness on spirituality and self-reliance, equanimity and meaningfulness

	Perceived Severity of Illness					
	Less Severe			More Severe		
	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>
Spirituality	86	-.09	.99	61	.13	1.01
Self-Reliance	86	.20	.89	63	-.25	1.07
Equanimity	83	-.09	1.11	62	.15	.79
Meaningfulness	85	-.06	1.06	63	.11	.90

Note. No significant differences.

Hypothesis 4. There is a significant relationship between illness status (remission or relapse) and resilience.

Hypothesis 4a. There is a significant relationship between illness status (remission or relapse) and self-reliance. A Spearman's Rho Correlation indicated that there was not a significant relationship between illness status and self-reliance (see Table 8). Means and standard deviations for the two categories of illness severity on spirituality and self-reliance are presented in Table 9.

Hypothesis 4b. There is a significant relationship between illness status (remission or relapse) and equanimity. A Spearman's Rho Correlation indicated that there was not a significant relationship between illness status (relapse or remission) and equanimity (see Table 8). Means and standard deviations for the two categories of illness status on spirituality and equanimity are presented in Table 9.

Hypothesis 4c. There is a significant relationship between illness status (remission or relapse) and meaningfulness. A Spearman's Rho Correlation indicated that there was not a significant relationship between illness status and meaningfulness (see Table 8). Means and standard deviations for the two categories of illness on spirituality and meaningfulness are presented in Table 9.

Table 8

Correlations and Intercorrelations Among Illness Status, Self Reliance, Equanimity and Meaningfulness

Variables	IS	SR	E	M
Illness Status (IS)	—	—	—	—
Self Reliance (SR)	-.10	—	—	—
Equanimity (E)	-.04	.56**	—	—
Meaningfulness (M)	.05	.62**	.68**	—

** $p < .01$, two-tailed.

Table 9

Means and standard deviations for the two categories of illness severity on spirituality and self-reliance, equanimity and meaningfulness

	Illness Status					
	Remission			Relapse		
	<i>N</i>	<i>M</i>	<i>SD</i>	<i>N</i>	<i>M</i>	<i>SD</i>
Spirituality	112	-.04	1.03	40	.09	.91
Self-Reliance	110	.08	.93	39	-.21	1.16
Equanimity	107	.03	.98	38	-.07	1.07
Meaningfulness	110	-.01	.96	38	.03	1.14

Note. No significant differences.

Multiple Regression Analyses

Hierarchical multiple regression was conducted in order to determine the independent contributions of the independent variables in the prediction of the dependent variable, that is, to determine if the variables were related, and the degree to which they were related. The first step in multiple regression analyses was to identify the variable that best predicted the dependent variable. The researcher identified spirituality as the variable that best predicted resilience (i.e., self-reliance, equanimity and meaningfulness), so it was entered at the first block to determine its relationship to self-reliance, equanimity and meaningfulness. The next step was to identify the variables that were most likely to improve the prediction which was based on the first variable only. Thus, contributing factors (i.e., social support and involvement, medical access and support) were entered at the second block, illness status at the third block and perceived severity of the illness at the fourth block to determine by how much the prediction would be improved when these variables were included. At each step, it was determined which variable added the most to the prediction of the dependent variable and how much it added.

Illness status is a categorical variable with two categories (remission, relapse), therefore, it was dummy coded and the relapse group was entered into the model as the reference group. Furthermore, if the regression coefficient related to the reference group (i.e., relapse) was significant, it would mean that

there were significant mean differences in resilience (i.e., self-reliance, equanimity and meaningfulness) between those in relapse and remission.

Violations of the assumptions of multiple regression were assessed by examining the residual plots and the normal probability plots for each regression analysis. These indicated the satisfactory presence of linearity, normality, and homoscedasticity (i.e., the variability in scores in one independent variable was about the same in all the other independent variables in the analyses). An examination of the correlations among the independent variables indicated that there was no threat of multicollinearity (i.e., independent variables were not related with each other) in the models since correlations between the variables were less than .60. Multicollinearity becomes problematic when $r > .80$ (Tabachnick & Fidell, 2001).

Hypothesis 5. Spirituality is positively related to resilience after controlling for social support and involvement, medical access and support, illness status and perceived severity of illness.

Hypothesis 5a. Spirituality is positively related to self-reliance after controlling for social support and involvement, medical access and support, illness status and perceived severity of illness. The hypothesis was not supported. Spirituality was not significantly related to self-reliance at any block of the regression model. When illness status was entered at the third block, it was significantly related to self-reliance, $\beta = -.17$, $t = -2.01$, $p < .05$. However, when

perceived severity of the illness was entered at the fourth block, the relationship between illness status and self-reliance was no longer significant. Instead, perceived severity of the illness was the sole predictor of self-reliance, $\beta = -.25$, $t = -2.91$, $p < .01$. Perceived severity of the illness accounted for a significant proportion of the variability in self-reliance, $\Delta R^2 = .06$, $F(1, 131) = 8.45$, $p < .01$. This indicated that those individuals with a more severe perception of illness had decreased self-reliance compared to individuals who perceived their illness as less severe (see Table 10). These results were consistent with the Spearman's Rho correlation used to test hypothesis 3a (see Table 6).

Table 10

Regression Analysis of Predictor Variables on Self-Reliance

Predictors	<i>B</i>	<i>SEB</i>	β	ΔR^2	<i>F</i>
Step 1				.00	.04
Spirituality	.02	.08	.02		
Step 2				.03	2.16
Spirituality	.10	.10	.10		
Family & Social Support	.21	.10	-.20		
Medical Access & Support	.12	.09	.12		
Step 3				.03	4.03*
Spirituality	.10	.09	-.10		
Family & Social Support	-.20	.10	-.19		
Medical Access & Support	.16	.09	.15		
Relapse	-.41	.21	-.17*		

(Table 10 continued)

Regression Analysis of Predictor Variables on Self-reliance

Predictors	<i>B</i>	<i>SEB</i>	β	ΔR^2	<i>F</i>
Step 4				.06	8.45**
Spirituality	.10	.09	.10		
Family & Social Support	-.12	.11	-.12		
Medical Access & Support	.12	.09	.12		
Relapse	-.27	.21	-.11		
Perceived Severity	.32	.11	-.26**		
Step 5				.05	7.66**
Spirituality	-.54	.25	-.54*		
Family & Social Support	-.15	.10	-.14		
Medical Access & Support	.10	.08	.10		
Relapse	-.19	.20	-.08		
Perceived Severity	-.31	.11	-.25**		
Spirituality X	.29	.10	.69**		
Perceived Severity					

Note. The excluded group is individuals in remission.

** $p < .01$. * $p < .05$.

Hypothesis 5b. Spirituality is positively related to equanimity after controlling for social support, involvement in activities, medical access and support, illness status and perceived severity of illness. The regression analyses revealed that spirituality was not significantly related to equanimity at any block of the analyses. The full model did not significantly explain any of the variance in equanimity.

Hypothesis 5c. Spirituality is positively related to meaningfulness after controlling for social support and involvement, medical access and support, illness status and perceived severity of illness. The regression analyses indicated that spirituality was not significantly related to meaningfulness at any block of the model.

Medical access and support was significantly related to meaningfulness at the second, third and fourth blocks of the model. The regression model was significant at the second block when medical access and support was first added, $\Delta R^2 = .06$, $F(2, 133) = 4.3$, $p < .05$. Medical access and support was significantly positively related to meaningfulness, $\beta = .26$, $t = 2.84$, $p < .01$. In other words, individuals who rated medical access and support as important had a higher sense that life had a purpose and an increased sense of having something for which to live for compared to individuals who attributed lower importance to medical access and support. These results were consistent with the Spearman's Rho correlation used to test hypothesis 2b.III.

In addition, social support, involvement in activities, illness status and perceived severity of the illness did not contribute to the explanation of variability in meaningfulness as indicated by the insignificant changes in R^2 (see Table 11).

Table 11

Regression Analysis of Predictor Variables on Meaningfulness

Predictors	<i>B</i>	<i>SEB</i>	β	ΔR^2	<i>F</i>
Step 1	.			.02	2.33
Spirituality	.13	.08	.13		.
Step 2				.06	4.30*
Spirituality	.10	.09	.10		
Family & Social Support	-.02	.10	-.02		
Medical Access & Support	.26	.09	.25**		
Step 3				.01	1.33
Spirituality	.10	.09	.10		
Family & Social Support	-.02	.10	-.02		
Medical Access & Support	.28	.09	.28**		
Relapse	-.24	.21	-.09		
Step 4				.00	.16
Spirituality	.10	.09	.10		
Family & Social Support	-.01	.11	-.01		
Medical Access & Support	.28	.09	.27**		
Relapse	-.21	.21	-.09		
Perceived Severity	-.04	.11	-.04		

(Table 11 Continued)

Regression Analysis of Predictor Variables on Meaningfulness

Predictors	<i>B</i>	<i>SEB</i>	β	ΔR^2	<i>F</i>
Step 5				.03	4.22*
Spirituality	-.39	.26	-.39		
Family & Social Support	-.03	.11	-.03		
Medical Access & Support	.26	.10	.26**		
Relapse	-.16	.21	-.07		
Perceived Severity	-.04	.11	-.03		
Spirituality X Perceived Severity	.22	.11	.53*		

Note. The excluded group is individuals in remission.

** $p < .01$. * $p < .05$.

Interactions between Spirituality and Perceived Severity of Illness

The magnitude of the interaction term (Perceived Severity of Illness x Spirituality) will be analyzed, after analyzing the main effects in hierarchical multiple regression analyses. Spirituality (SPS as a moderator) will be explored by examining whether an interactive effect between perceived severity of illness and spirituality influences resilience to MS. In other words, whether the relationship between perceived severity of illness and resilience depends on whether one scores high or low on spirituality.

Hypothesis 6. The relationship between perceived severity of the illness and resilience is moderated by spirituality. A fifth block was added to the three previous regression analyses to test the hypothesis that spirituality moderated the relationship between perceived severity of the illness and resilience (i.e., self-reliance, equanimity and meaningfulness). Spirituality was categorized into three levels using the 33rd and the 66th percentile (scores for low spirituality fell below -.28 (33rd percentile), scores for moderate spirituality ranged from -.28 to .62 (between the 33rd and the 66th percentile), and scores for high spirituality fell above .62 (66th percentile).

In order to determine the interaction effect a new variable was computed to represent the interaction term. This variable was a product of the two predictors (i.e., perceived severity of the illness and spirituality scores).

Hypothesis 6a. The relationship between perceived severity of the illness and self-reliance is moderated by spirituality. There was a significant interaction effect between perceived severity of illness and spirituality on self-reliance, $\beta = .69, t = 2.77, p < .01$. The interactive effect between perceived severity of illness and spirituality (i.e., SPS as a moderator) influenced self-reliance. That is, the relationship between perceived severity of illness and self-reliance changed depending on spirituality level. At block 5, when the interaction term (perceived severity of illness x spirituality) was entered, the variable spirituality became significantly related to self-reliance for the first time (see Table 10). However, since the interaction effect was significant, the main effect of spirituality was not interpreted. The interaction effect was examined by plotting the levels of spirituality (i.e., low, moderate and high) against perceived severity of the illness (Figure 1). Perceived severity of the illness, which was treated as a continuous variable in their regression, was split into two groups (i.e., less severe and more severe) in order to better examine the interaction effect. The less severe group consisted of 86 individuals who rated their severity as one (not severe) or two (mild), and the more severe consisted of 63 individuals who rated their severity as three (moderate) or four (severe). Individuals who perceived the illness as less severe and had low levels of spirituality had higher self-reliance ($M = .35, SD = .90$) than individuals who rated the illness as less severe with moderate levels of

spirituality ($M = .15$, $SD = .89$) or with high levels of spirituality ($M = .10$, $SD = .91$).

However, individuals who perceived the illness as more severe and had high levels of spirituality had higher levels of self-reliance, that is, an increased belief in themselves and in their capabilities ($M = -.04$, $SD = .73$) than individuals in the same group (i.e., more severe group) with moderate spirituality ($M = -.25$, $SD = 1.09$) or low spirituality ($M = -.52$, $SD = 1.37$) (see Table 10).

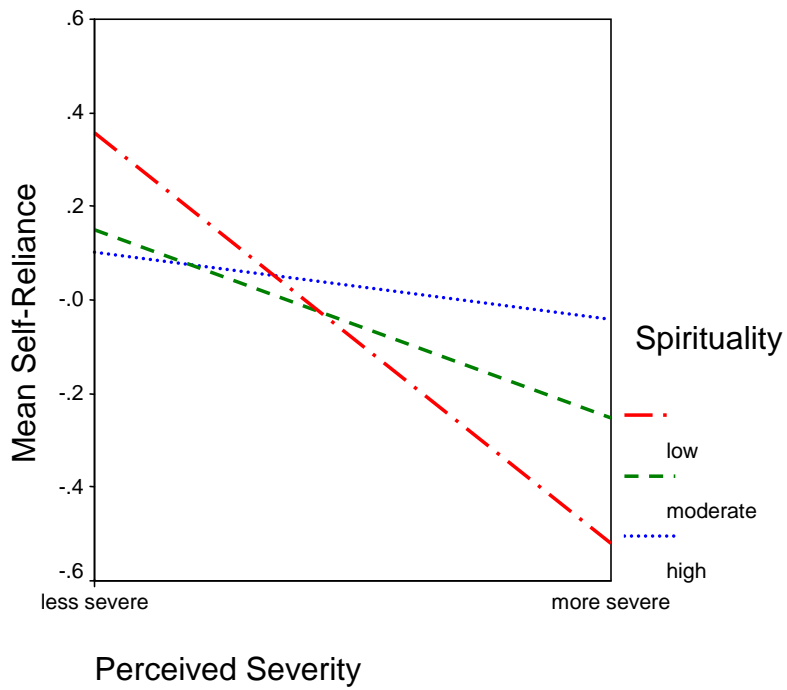


Figure 1. The interaction between spirituality and perceived severity of illness on self-reliance.

Hypothesis 6b. The relationship between perceived severity of the illness and equanimity depends on spirituality. There was not a significant interaction effect between perceived severity of the illness and spirituality on equanimity.

Hypothesis 6c. The relationship between perceived severity of the illness and meaningfulness depends on spirituality. There was a significant interaction effect between perceived severity of illness and spirituality on meaningfulness, $\beta = .53$, $t = 2.01$, $p < .05$ (see Table 11). This interaction effect was further examined by plotting the levels of spirituality (i.e., low, moderate and high) against perceived severity of the illness (i.e., less and more severe) and the level of meaningfulness. The graph indicated that individuals who perceived their illness as more severe and had higher levels of spirituality had higher levels of meaningfulness or an increased realization that their lives had purpose and meaning ($M = .30$, $SD = .91$) than individuals who perceived their illness as more severe and had low levels of spirituality ($M = -.23$, $SD = 1.04$) or moderate levels of spirituality ($M = .25$, $SD = .48$). Similarly, individuals who perceived their illness as less severe and had high levels of spirituality had higher levels of meaningfulness ($M = .76$, $SD = .70$) than individuals with perceived their illness as less severe and had moderate levels of spirituality ($M = -.14$, $SD = 1.14$) or low levels of spirituality ($M = -.08$, $SD = 1.21$). Meaningfulness was equally low for those individuals with moderate and lower levels of spirituality who perceived illness as less severe (see Figure 2).

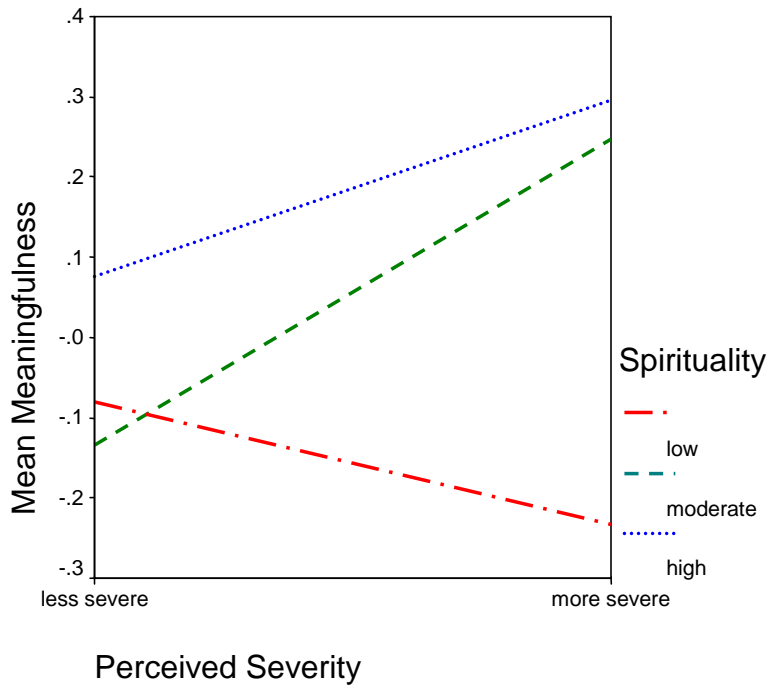


Figure 2. The interaction between spirituality and perceived severity of illness on meaningfulness.

Interaction between Spirituality and Illness Status

The magnitude of the interaction term (Illness Status x Spirituality) will be analyzed, after analyzing the main effects in hierarchical multiple regression analyses. Spirituality (SPS as a moderator) will be explored by examining whether an interactive effect between illness status and spirituality influences resilience to MS. In other words, whether the relationship between illness status and resilience depends on whether one scores high or low on spirituality.

Hypothesis 7. The relationship between illness status (i.e., relapse, in remission) and resilience (i.e., self-reliance, equanimity and meaningfulness) is moderated by spirituality. A fifth block was added to the three previous regression analyses to test the hypothesis that spiritual perspective moderated the relationship between illness status and resilience (i.e., self-reliance, equanimity and meaningfulness). In order to determine the interaction effect a new variable was computed to represent the interaction term. This variable was a product of the illness status and spirituality scores.

Hypothesis 7a. The relationship between illness status and self-reliance is moderated by spirituality. The interaction effect was examined by categorizing levels of spirituality into three groups (i.e., low, moderate and high). Scores for low spirituality fell below $-.28$ (33rd percentile), scores for moderate spirituality ranged from $-.28$ to $.62$ between the 33rd and 66th percentile), and scores for high spirituality fell above $.62$ (66th percentile). Hierarchical multiple regression

analysis, indicated a significant spirituality and illness status interaction effect on self-reliance, $\beta = .26$, $t = 2.83$, $p < .01$ (see Table 12). To further examine the interaction, a graph was used (see Figure 3). The graph indicated that for those individuals in remission, levels of self-reliance fell about the mean ranging from -.03 (below the mean) to .23 (above the mean), regardless of level of spirituality.

However, for those individuals experiencing a relapse, self-reliance varied substantially based on levels of spirituality. Individuals experiencing a relapse who had low levels of spirituality had decreased self-reliance or belief in themselves and decreased belief in their own capabilities ($M = -.77$, $SD = 1.51$).

On the other hand, individuals experiencing a relapse with moderate and high levels of spirituality had increased levels of self-reliance similar to individuals in remission. Interestingly, individuals experiencing a relapse who had moderate levels of spirituality had slightly higher levels of self-reliance ($M = .15$, $SD = 1.04$) than those with high levels of spirituality ($M = -.04$, $SD = .80$).

Table 12

Interaction Effect between Spirituality and Illness Status on Self-Reliance

Predictors	<i>B</i>	<i>SEB</i>	β	ΔR^2	<i>F</i>
Step 5				.05	8.03
Spirituality	-.02	.10	-.02		
Family & Social Support	-.12	.10	-.12		
Medical Access & Support	.11	.09	.11		
Relapse	-.32	.20	-.13		
Perceived Severity	-.28	.11	-.23		
Spirituality X Illness Status	.57	.20	.26**		

**p < .01.

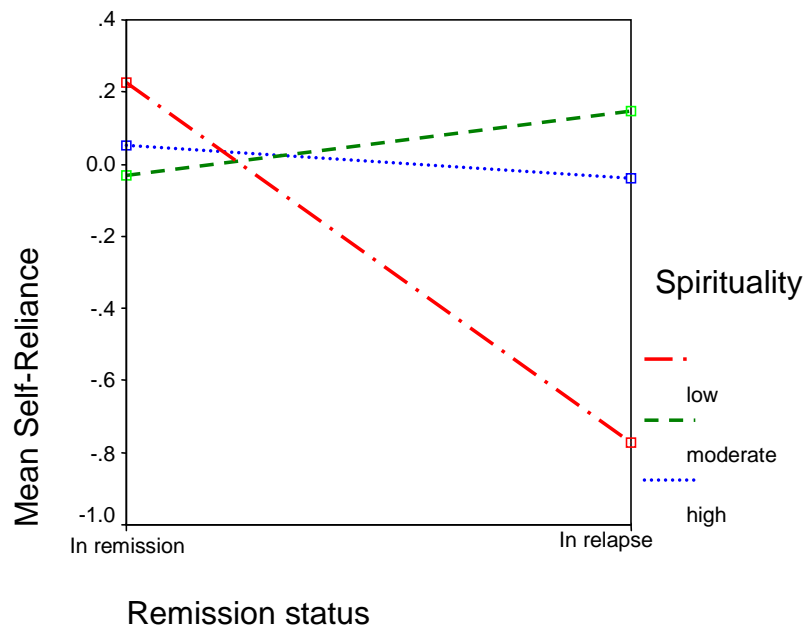


Figure 3. The interaction between spirituality and illness status on self reliance.

Hypothesis 7b. The relationship between illness status and equanimity is moderated by spirituality. There was not a significant interaction between illness status and spirituality on equanimity (see Table 13).

Table 13

Interaction Effect between Spirituality and Illness Status on Equanimity

Predictors	<i>B</i>	<i>SEB</i>	β	ΔR^2	<i>F</i>
Step 5				.01	1.5
Spirituality	-.06	.11	-.06		
Family & Social Support	.11	.11	.11		
Medical Access & Support	.14	.09	.14		
Health Status	-.21	.21	-.09		
Perceived Severity	-.02	.11	-.02		
Spirituality X	.26	.21	.12		
Illness Status					

Hypothesis 7c. The relationship between illness status and meaningfulness is moderated by spirituality. There was a significant interaction effect between illness status and spirituality on meaningfulness $\beta = .19, t = 2.02, p < .05$ (see Table 14). Levels of meaningfulness for individuals in remission fell about the mean with means ranging from $-.02$ to $.22$. In contrast, individuals experiencing a relapse who had low levels of spirituality had decreased meaningfulness or a decreased sense that their lives had meaning or purpose ($M = -.54, SD = 1.5$). Interestingly, individuals experiencing a relapse with moderate spirituality had comparative higher levels of meaningfulness ($M = .48, SD = .60$) than those with high spirituality ($M = .13, SD = .99$).

Table 14

Interaction Effect between Spirituality and Illness Status on Meaningfulness

Predictors	<i>B</i>	<i>SEB</i>	β	ΔR^2	<i>F</i>
Step 5				.03	4.10
Spirituality	.01	.10	.01		
Family & Social Support	-.01	.11	-.01		
Medical Access & Support	.27	.10	.26*		
Health Status	-.24	.21	-.10		
Perceived Severity	-.02	.11	-.02		
Spirituality X Illness Status	.43	.21	.19*		

*p < .05.

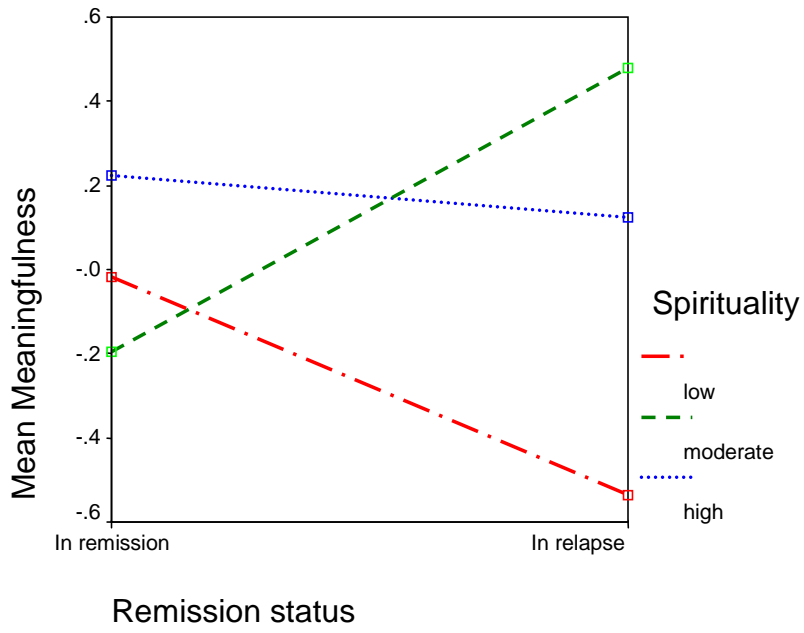


Figure 4. The interaction between spirituality and illness status on meaningfulness.

Conclusions

Prior to examining the seven major hypotheses of this study, Principal Components Analysis (PCA) was applied to the Spirituality Perspective Scale (SPS), the Resilience Scale (RS) and the Contributing Factors Questionnaire. The factor analysis technique was used to detect the structure of the relationship between the items or variables so as to classify the variables in the study. It also reduced the number of variables, in that multiple variables were expressed by a factor (Hair, Anderson, Tatham, & Black, 1998).

The factor analyses revealed that spirituality consisted of one global factor, labeled spirituality. Resilience consisted of three factors which were labeled self-reliance, equanimity and meaningfulness as conceptualized by Wagnild and Young (1993), and contributing factors consisted of two factors which were labeled social support and involvement and medical access and support.

The researcher conducted Pearson Product Correlation, Spearman's Rho Correlation and Hierarchical Multiple Regression analyses to examine the relationship between the independent variables: spirituality, social support and involvement, medical access and support, perceived severity of the illness, and illness status and the dependent variable: resilience (i.e., self-reliance, equanimity and meaningfulness).

CHAPTER 5

Discussion

This chapter presents the major findings of the study, limitations of the study, and the implications for practicing counselors, counselor training and future research recommendations.

Summary of Significant Results

The statistical analysis resulted in a number of major findings.

1. Medical access and support were significantly positively related to meaningfulness.
2. Perceived severity of illness was significantly negatively related to self-reliance.
3. There was a significant interaction effect between perceived severity of illness and spirituality on self-reliance.
4. There was a significant interaction effect between perceived severity of illness and spirituality on meaningfulness.
5. There was a significant interaction effect between illness status and spirituality on self-reliance.
6. There was a significant interaction effect between illness status and spirituality on meaningfulness.

These findings indicated that those individuals with multiple sclerosis who attributed higher rates of importance to medical access and support had an

increased awareness that their lives had purpose and meaning, suggesting that they may be more interested in activities, may look at a situation in a number of ways, find something to laugh about, have determination, self-discipline, and believe they could get through difficult times. Hypothesis 2bIII using Pearson Product Correlation and hypothesis 5c using Multiple Regression Analysis corroborated these findings (see Table 15).

Perceived severity of illness was significantly negatively related to self-reliance. In other words, individuals who had a more severe perception of illness had decreased belief in themselves and their capabilities. These findings suggested that individuals whose illness was more severe may find themselves having difficulties with following through with plans, unable to depend on themselves, and unable to handle many things at a time, doubtful of their accomplishments, and of managing difficult times. Hypothesis 3a using Spearman's Rho Correlation and hypothesis 5a using Multiple Regression Analysis corroborated these findings (see Table 15).

There was a significant interaction effect between perceived severity of illness and spirituality on self-reliance. The relationship between perceived severity of illness and self-reliance depended on spiritual level (i.e., low, moderate, high). Those who perceived the illness as more severe and had low levels of spirituality (i.e., less perception of holding certain spiritual beliefs, less engaged in spiritual activities, and feeling less connected to a higher power) had

decreased belief in themselves and their capabilities. However, those who perceived the illness as more severe, but had high levels of spirituality (i.e., high perception of holding certain spiritual beliefs, more engaged in spiritual activities and feeling a higher sense of connection to a higher power) had increased levels of self-reliance (i.e., belief in themselves and their capabilities) compared to those with low spirituality. On the other hand, those who perceived their illness as less severe had similar levels of self-reliance regardless of their level of spirituality. Thus, these results provided support for viewing spirituality as an important variable influencing the relationship between perceived severity of illness and self-reliance among those with a more severe perception of illness (see Table 15).

Another meaningful result of this study was the significant interaction effect between perceived severity of illness and spirituality on meaningfulness (i.e. having a higher sense of something for which to live for). In other words, individuals who perceived their illness as more severe and had low levels of spirituality reported a decreased sense of purpose and meaning in life while individuals who perceived their illness as more severe and had moderate and high levels of spirituality reported an increased sense of meaningfulness or purpose in life. In addition, individuals who perceived their illness as less severe and had high level of spirituality reported a slightly higher sense of purpose in life compared to individuals who perceived their illness as less severe and had low or moderate levels of spirituality.

These findings indicated that the interactive effect between perceived severity of illness and spirituality (SPS as a moderator) influenced resilience, namely, self-reliance and meaningfulness in MS. Furthermore, levels of spirituality seemed to be more significant for those with a more severe perception of illness. In other words, higher levels of spirituality appeared to be more significant in terms of increased levels of meaningfulness and self-reliance for individuals who rated the illness as more severe.

Likewise, there was also a significant interaction effect between illness status and spirituality on self-reliance. Individuals who were experiencing a relapse and had low levels of spirituality reported decreased levels of self-reliance whereas those who were experiencing a relapse and had high and moderate levels of spirituality reported increased levels of self-reliance. It is notable that those experiencing a relapse with moderate levels of spirituality had the highest levels of self-reliance. However, there were very small differences in self-reliance for those in remission with varying levels of spirituality.

Similar relationships held for the interaction between spirituality and illness status on meaningfulness. In other words, individuals who were experiencing a relapse and had low levels of spirituality reported a decreased sense of meaning or purpose in life whereas those who were experiencing a relapse and had high and moderate levels of spirituality reported an increased

sense of meaning or purpose in life. Interestingly, those experiencing a relapse with moderate levels of spirituality had the highest levels of meaningfulness.

It is important to note that the interaction effects of perceived severity of illness and spirituality on self-reliance and meaningfulness mirrored the interaction effects of illness status and spirituality on self-reliance and meaningfulness. That is, there were similar changes in the levels of self-reliance and meaningfulness as the levels of spirituality changed for the group in remission and for those who rated the illness as more severe. This may be because perceived severity of the illness is a proxy for illness status.

It appears from a review of the results that the dependent variable meaningfulness has an essential role in resilience. Those participants who were experiencing a relapse and had higher levels of spirituality reported an increased awareness that their lives had purpose and meaning. Similarly, those participants who had a severe perception of the illness and had high levels of spirituality reported an increased awareness that their lives had purpose and meaning.

Table 15

Correlations and Intercorrelations Among Spirituality, Perceived Severity of illness, Social Support and Involvement, Medical Access and Support, Illness Status, Self-Reliance, Equanimity, Meaningfulness

Variables	PS	SSI	MAS	IS	SR	E	M	S
PS	---	.25**	-.02	.30**	-.29**	.001	-.03	.13
SSI	---	---	.33**	.06	-.09	.13	.07	.55**
MAS	---	---	---	.22**	.17*	.15	.24**	.14
IS	---	---	---	---	-.10	-.04	.05	.04
SR	---	---	---	---	---	.56**	.62**	-.08
E	---	---	---	---	---	---	.68**	.06
M	---	---	---	---	---	---	---	.11
S	---	---	---	---	---	---	---	---

Note. PS = Perceived Severity of Illness; SSI = Social Support and Involvement;

MAS = Medical Access and Support; IS = Illness Status;

SR = Self-Reliance; E = Equanimity; M = Meaningfulness;

S = Spirituality

** $p < .01$, two tailed; * $p < .05$, two-tailed.

Despite those previously reported significant findings, there were also a number of unexpected and puzzling findings

1. There was not a significant relationship between spirituality and resilience (i.e., self-reliance, equanimity and meaningfulness).
2. There was not a significant relationship between social support and involvement and resilience (i.e., self-reliance, equanimity and meaningfulness).
3. There was not a significant relationship between medical access and support and self-reliance and equanimity.
4. There was not a significant relationship between perceived severity of illness and equanimity and meaningfulness.
5. There was not a significant interaction between illness status and resilience (i.e., self-reliance, equanimity and meaningfulness).
6. There was not a significant relationship between spirituality and self-reliance, equanimity and meaningfulness after controlling for social support and involvement, medical access and support, illness status and perceived severity of illness.
7. There was not a significant interaction effect between perceived severity of illness and spirituality on equanimity.
8. There was not a significant interaction effect between illness status and spirituality on equanimity.

One possible explanation for these findings may reside in the measurements used in this study, namely Spirituality Perspective Scale (SPS), Contributing Factors Questionnaire (CFQ) and Resilience Scale (RS). Perhaps the SPS did not measure the “inherent complexity of spirituality” (Kutsunai, 2000), and the CFQ did not tap the dimensions of contributing factors that may reflect a relationship to resilience, resulting in non-significant results.

Relationship to Previous Literature

The results of the present study indicated a significant positive correlation between medical access and support and meaningfulness. That is, individuals who rated medical support and access as important had increased sense of meaningfulness (i.e., awareness that their lives had purpose and meaning) whereas those who rated medical support and access as less important had a decreased sense of meaningfulness. These findings were consistent with prior research on the positive relationship between medical support and resilience among long-term survivors of AIDS (Rabkin et al., 1993) and medical support and effective coping among individuals with cancer (Kyngas et al., 2001).

Results also indicated a significant negative correlation between perceived severity of illness and self-reliance. Individuals with MS who had a more severe perception of illness had decreased belief in their own selves and their capabilities, suggesting that they may be less able to depend on themselves, less capable of handling many things at a time, and less able to recognize their

strengths. It was not surprising though that individuals with a more severe perception of illness reported less self-reliance than individuals with a less severe perception of the illness. Accordingly, Resnick and Hutton (1987) found a significant negative relationship between severity or more disabled perception of illness and resilience in adolescents with cerebral palsy. It is important to mention that the findings in the present study were generated from a sample of individuals with RRMS whereas previous studies had used samples of individuals with disabilities or other illnesses, but not necessarily MS.

The influential role of spirituality was noted when the interaction effect between spirituality and illness status and spirituality and perceived severity of illness on resilience was examined. Findings indicated that those with high levels of spirituality and more severe perception of illness had increased levels of self-reliance and meaningfulness. Likewise, those with high levels of spirituality who were experiencing a relapse had increased levels of self-reliance and meaningfulness. The positive influence of spirituality and its “healing effects” has been documented. Spirituality gives a sense of purpose in life, a sense that has been reported as absent prior to the onset of an illness, a new understanding of trust, and a greater sense of self-sufficient (McCull et al., 2000). As reported earlier, spirituality has been found to be positively related to overall psychosocial adaptation, that is, low level of spirituality was related to lower levels of psychosocial adaptation (McNulty et al., 2004).

Limitations

These findings may be interpreted with caution because of several limitations. First, there are limitations that may affect the generalizability of the findings. That is, although a response rate of 44% was acceptable for survey research, there was the possibility of bias due to non-response. In other words, it can not be assumed that those who did not complete the questionnaires shared similar views as those who completed the questionnaires in the study. In addition, the use of a convenient sample and the restricted geographical area from where the data was collected may limit the generalizability of the findings. In other words, the sample was restricted to members of a regional chapter of the National MS Society, individuals participating in a support group and individuals receiving treatment from a neurology clinic in the Northern Virginia area. Thus, the sample may have been biased toward more resilient highly educated individuals with greater access to resources. Therefore, these findings may not reflect those individuals with MS who have less education.

Second, the data was obtained by means of self-report measures. Thus, social desirability may have influenced participants' responses. For example, participants may have responded in a way that they appeared more spiritual and more resilient.

Third, this study does not explore the preventive aspect of resilience, but instead incorporates the variable as an outcome.

Implications of the Study

Despite the limitations noted above, this study addressed important issues and generated stimulating implications for practice, training and future research.

Implications for Practice

The present research confirmed the importance of incorporating spirituality in the field of counseling with target populations consisting of those with a chronic illness or severe disability. Consistently with prediction, high levels of spirituality were related to significant higher level of self-reliance and meaningfulness for individuals who rated their symptoms as more severe and for those experiencing a relapse. Thereby, there are clinical implications based on the findings of this study. Health professionals should explore the possible importance of spirituality for those individuals experiencing a relapse and those who have a more severe perception of illness. Furthermore, those with chronic illnesses could be made aware of the benefits of having higher spiritual perspectives for enhancing their level of resilience. This study indicated that for those individuals in relapse and for those reporting an increased severity or progression of illness, level of self-reliance and sense of purpose and meaning increased, with increased spiritual perspectives. Therefore, understanding the interactive relation of spirituality and perceived severity of illness and spirituality and illness status (i.e., relapse) could be useful in the care of the chronically ill, especially those living with multiple sclerosis.

Thus, it is recommended for health care professionals to recognize a holistic approach that integrates not only the physiological and the psychological aspect of the person, but also the spiritual component as to incorporate interventions related to spirituality. Since spirituality can be manifested in different expressions, it would be helpful for health professionals to be aware that spiritual beliefs are “intrinsically linked to religious, philosophical, cultural, ethnic, and life experiences (McNulty, Livneh, & Wilson, 2004).

Health professionals should further recognize the spiritual needs of their clients and families as they attempt to cope with the illness. Patients may be asked to explore aspects of their spirituality, and ways of improving or strengthening their spirituality. The patient may be encouraged to think about what gives him/her a sense of peace, meaning, hope, comfort and strength. Also if the person conveys an awareness of spiritual dimension in one’s life, he/she can be further encouraged to get involved in activities that may enhance spirituality, such as, prayer, meditation, devotional singing, and volunteer work (American Family Physician, 2001). Spiritual activities may help patients in finding meaning and purpose in their illness.

Medical support and access to health services was also related to resilience, namely, meaningfulness—the realization that life has purpose and meaning. These corroborated previous findings on the positive relationship between support from physicians and nurses (i.e., the consistency, permanency

and safety) and a greater sense of well-being (Kyngas et al., 2001). Thus, one can speculate that medical support from doctors and nurses and access to services provide the individual with a sense of purpose and meaning. Thereby, health professionals should provide the support that their patients need. In some cases, the patient may need assistance in regards to access to health coverage, billing concerns, prescription, referrals, treatment, or information about the illness. It is important to recognize that increase support from doctors and nurses seem to contribute to resilience in MS.

Implications for Training

Although the Council for the Accreditation of Counseling Related Educational Programs (CACREP, 2001) requires that students in counseling education examine the role of religion and spiritual beliefs in counseling, counseling programs are not integrating religion and spirituality in the training of students (Young et al., 2002). Health educators should train students so that they feel prepared when addressing issues on spirituality, and when feasible, health professionals/educators must continue to receive training and support for their spiritual development. Thus, spirituality needs to be incorporated into the educational curriculum of programs related to human services. For example, counseling programs can offer students seminars, workshops and classes directed to preparing students in becoming more competent in spiritual issues.

Multicultural sensitivity must be taken into account during the training of students

since spiritual perspectives are intrinsically linked to cultural, ethnic and religious differences. The teaching of spirituality must include the uniqueness of individuals, groups, and cultures in regards to expression of spirituality.

In addition, the topic of resilience needs to be included into the educational curriculum of rehabilitation programs as to prepare students in becoming knowledgeable about contributing factors to resilience. It is important for students to understand the role of spirituality as a moderator variable between perceived severity of illness, illness status and resilience in MS. Thus, teaching about resilience; the ability of bouncing back despite adversity may be presented in the form of seminars, classes and workshops. The rehabilitation counselor in training must understand the implications of illness severity and levels of spirituality on resilience.

Finally, health educators must teach their students about the importance of assisting patients in receiving access to services—health insurance coverage and benefits, and recognizing the specific needs of their patients. Thus, health professionals must be mindful of resources and services needed by their patients and make appropriate referrals when needed.

Implications for Future Research

Even with its limitations, this study addressed important issues and generates stimulating questions to be focused on more systematically in future research. It is recommended that future research uses a more representative sample. Results generated from this research derived from a sample of participants from a specific geographical area who participated in specific activities. In addition, the sample consisted of a fairly homogeneous group in that 90.8% of participants were white, 86.2% were females, and 66.5% had a college degree. Thus, it is recommended to compare results derived from this sample with those derived from other samples of individuals with relapsing-remitting multiple sclerosis pooled from the general population.

In addition, there were a number of unexpected findings. For example, there was not a significant relationship between spirituality and resilience (i.e., self-reliance, equanimity and meaningfulness). It has been suggested that perhaps the Spiritual Perspective Scale (SPS) may not measure the “inherent complexity of spirituality” (Kutsunai, 2000). Thus, it is recommended that future research includes additional measures of spirituality other than the SPS. In addition, findings indicated that there was not a significant interaction effect between perceived severity of illness and equanimity and between illness status and equanimity. Thus, future research should look at the variable equanimity and determine why it was not significantly related to the independent variables.

Moreover, it is recommended that future research incorporates a more precise instrument to measure contributing factors to resilience. In the present study, the question addressing contributing factors asked for participants to indicate their opinion about the degree of importance, but it did not indicate if the person had access to those identified contributing factors. In other words, the person may have rated certain factors as important, but he/she may not have access to such factors (e.g., social support, medical access). Thus, the question about contributing factors would need to be reworded to make the meaning more relevant and precise.

Furthermore, it is suggested that future research includes qualitative research, so that participants can freely report on contributing factors to resilience, as well as define and identify specific components of spirituality, for example, praying, meditation, reading and inspirational literature as opposed to generating conclusions when spirituality is defined in general terms.

Conclusions

The purposed of this study was to examined the possible relationship between spirituality, contributing factors (i.e., social support and involvement and medical access and support), perceived severity of illness (less severe, more severe), illness status (remission, relapse) and resilience (i.e., self-reliance, equanimity, meaningfulness). This study also examined the influence of spirituality as a moderator variable between perceived severity of the illness and

resilience, and illness status and resilience. In summary, the results of this study indicated that medical access and support was significantly positively related to meaningfulness. In other words, individuals who attributed medical access and support from nurses and doctors as important had increased purpose in life and an increased sense of having something for which to live for. Perceived severity of illness was significantly negatively related to self-reliance, thus, individuals who had a more severe perception of the illness had decreased belief in themselves and their capabilities, and they were less able to recognize their strengths and limitations. There was a significant interaction effect between perceived severity of illness and spirituality on self-reliance, and there was a significant interaction effect between perceived severity of illness and spirituality on meaningfulness. Similarly, there was a significant interaction effect between illness status and spirituality on self-reliance, and there was a significant interaction effect between illness status and spirituality on meaningfulness. In other words, as the disease progress and the person experiences relapses, spirituality plays an important role in terms of resilience (i.e., self-reliance, meaningfulness). Individuals with more severe perception of illness and experiencing a relapse who had higher levels of spirituality had increased belief in themselves and their capabilities (self-reliance), and increased sense of having something for which to live for (meaningfulness) compared to those with lower levels of spirituality.

APPENDIX A

Introduction Letter

Help others living with MS

I am a Ph.D. candidate in Counseling Education Program at the University of Maryland, College Park. Like you, I am also living with MS. As part of my Ph.D. requirements I am conducting a study to examine aspects related to adjustment in MS. The information I am gathering will help people like us understand factors relating to adjustment and will help health professionals identify strategies that could promote positive adjustment.

30 Minutes to Complete Questionnaire

I am hoping you will help. By spending 30 minutes completing the enclosed multiple choice survey, you will add knowledge and make a valuable contribution to the literature on adjustment in multiple sclerosis. All surveys will be anonymous and data will be aggregated into a single data base without identifiable personal or geographical information. Research materials enclosed in this packet include an informed consent form, a demographic information sheet and a multiple choice questionnaire. You may complete the survey at the site or take the packet home and return the survey by mail using the brown postage paid envelope provided.

Win \$10 Starbucks Gift Certificate—Reply by _____

As an added incentive, you are invited to enter a random drawing for a chance to win one of ten, \$10 Gift Certificate from Starbucks. This is my way of saying thank you for contributing the multiple sclerosis research. To enter, simply complete the Prize Entry card, seal it in the white envelope provided and return it with the complete study. Your participation in the research as well as the drawing are voluntary. The Prize Entry Cards and questionnaires will be filed separately so that anonymity can be maintained.

Thanks you for Participating!

If you have questions or would like to learn about the results of the study, please contact me at javalde@cuisp.com. Please read the Informed Consent Form for details on procedures, privacy and random drawing specifics. Thank you for your willingness to help with this project; your response will make a difference.

Sincerely,

Carmen Alina DeArmas-Valdes
Ph.D. Candidate, University of Maryland

APPENDIX B

INFORMED CONSENT FORM

Adjustment in Multiple Sclerosis

I state that I am over 18 years of age and wish to participate in a program of research being conducted by Carmen Alina DeArmas-Valdes in the Department of Counseling and Personnel at the University of Maryland, College Park.

The purpose of this research is to examine aspects related to adjustment to multiple sclerosis. The procedure will involve completing three questionnaires and answering ten demographic questions. The first questionnaire asks me to rate the degree of importance of a number of factors (e.g., support from family, friends, access to services), the second and third questionnaires ask questions related to adjustment to MS (e.g., “I usually manage one way or another”, “My belief in myself gets me through hard times; “My spiritual views have had an influence upon my life”).

The completion of the questionnaires and demographic sheet will take approximately 30 minutes. I have the option of either completing the questionnaires and demographic sheet at the site (clinic or support group meeting) or taking them home for completion. After completion, I will use the enclosed postage-paid envelope (brown color) to return the questionnaires, demographic sheet and the informed consent form to the researcher.

My responses to the questionnaires and demographic sheet will be anonymous; they will not have any personally identifiable information. All the information collected in this research is confidential, and the information provided will be grouped with the information provided by others. Although the consent requires my signature, the information I am sending will be kept confidential. The researcher is the only person who handles the envelopes containing the questionnaires, demographic sheet and consent form. Immediately after the researcher receives the envelopes, the researcher will separate the informed consent form from the completed questionnaires, thus, the signed informed consent form will be kept separate from the questionnaires and demographic sheet. The data and informed consent form will be kept in locked files, and the informed consent form will be destroyed after completion of the dissertation.

As a way of compensation for my time, I can enter my name to win 1 of 10 prizes of \$10 dollars gift certificate for Starbucks. My participation is volunteered. If I choose to participate, I will need to complete the Prize Entry Card that is inside the envelope that contains the questionnaires and demographic sheet and return it in the second envelope (white color) provided by researcher. The cards and the questionnaires are kept separately so that anonymity will be maintained. The entry card asks for my name and an address so that if I am one of the winners, the researcher will be able to send me the \$10 dollars gift certificate. The drawing will be held once the researcher receives at least 150 packets from participants (350 packet will be distributed).

There are no known risks related to participation in this study. This study is not designed to help me personally, but it will help the researcher and other health professionals know more about adjustment in multiple sclerosis.

I understand that I am free to ask questions, and I can withdraw from participation at any time without penalty.

If having questions and concerns, I can contact: Carmen Alina DeArmas-Valdes; (telephone) 703-257-5752; (e-mail) javaldes@cuisp.com.

If having questions about my rights as a research subject or wish to report a research-related injury, I can contact: **Institutional Review Board Office, University of Maryland, College Park, Maryland, 20742; (e-mail) irb@deans.umd.edu; (telephone) 301-405-4212.**

Name of Participant:

Signature of Participant:

Date: _____

7. My present situation is best described as (please check one):

In remission

Experiencing a relapse

8. Employment status:

Full time employment

Unemployed

Part-time employment

Homemaker

Disability Benefits

Retired

9. Education:

Less than High School

High School Diploma

Some College

College Graduate (Bachelor degree)

Graduate (Master, Ph.D.)

Other _____

10. Please circle the number that best describes the severity of your illness or MS-related symptoms.

Not Severe

Very Severe

1

2

3

4

5

II. Please indicate your opinion about the degree of importance of the following factors in regards to their contribution to adjustment in MS. Please circle a number from one to seven on the scale provided below. In case of doubt, please circle the number which comes closest to your true opinion.

	Unimportant				Important		
1. Support from my family	1	2	3	4	5	6	7
2. Support from friends	1	2	3	4	5	6	7
3. Support from doctors	1	2	3	4	5	6	7
4. Support from nurses	1	2	3	4	5	6	7
5. Support from a spiritual leader	1	2	3	4	5	6	7
6. Access to health services/treatment	1	2	3	4	5	6	7
7. Access to health insurance coverage	1	2	3	4	5	6	7
8. Access to prescription plan coverage	1	2	3	4	5	6	7
9. Access to home assistance/home health aides	1	2	3	4	5	6	7
10. Involvement in a church/religious organization	1	2	3	4	5	6	7
11. Involvement in recreational activities	1	2	3	4	5	6	7
12. Involvement in a support group	1	2	3	4	5	6	7
13. Involvement in a community organization	1	2	3	4	5	6	7
Other factors (Please specify):							
14. _____	1	2	3	4	5	6	7
15. _____	1	2	3	4	5	6	7
16. _____	1	2	3	4	5	6	7
17. _____	1	2	3	4	5	6	7
18. _____	1	2	3	4	5	6	7

III. Please state the degree to which you agree or disagree with each item by drawing a circle around the number that best describes you.

	Agree				Disagree		
1. When I make plans I follow through with them	1	2	3	4	5	6	7
2. I usually manage one way or another.	1	2	3	4	5	6	7
3. I am able to depend on myself more than anyone else.	1	2	3	4	5	6	7
4. Keeping interested in things is important to me.	1	2	3	4	5	6	7
5. I can be on my own if I have to.	1	2	3	4	5	6	7
6. I feel proud that I have accomplished things in my life.	1	2	3	4	5	6	7
7. I usually take things in stride.	1	2	3	4	5	6	7
8. I am friends with myself.	1	2	3	4	5	6	7
9. I feel that I can handle many things at a time.	1	2	3	4	5	6	7
10. I am determined.	1	2	3	4	5	6	7
11. I seldom wonder what the point of it all is.	1	2	3	4	5	6	7
12. I take things one day at a time.	1	2	3	4	5	6	7
13. I can get through difficult times because I have experienced difficulty before.	1	2	3	4	5	6	7
14. I have self-discipline.	1	2	3	4	5	6	7
15. I keep interested in things.	1	2	3	4	5	6	7
16. I can usually find something to laugh about.	1	2	3	4	5	6	7
17. My belief in myself gets me through hard times.	1	2	3	4	5	6	7
18. In an emergency, I'm someone people generally can rely on.	1	2	3	4	5	6	7
19. I can usually look at a situation in number of ways.	1	2	3	4	5	6	7

20. Sometimes I make myself do things whether I want to or not. 1 2 3 4 5 6 7
21. My life has meaning. 1 2 3 4 5 6 7
22. I do not dwell on things that I can't do anything about. 1 2 3 4 5 6 7
23. When I'm in a difficult situation, I can usually find my way out of it. 1 2 3 4 5 6 7
24. I have enough energy to do what I have to do. 1 2 3 4 5 6 7
25. It's okay if there are people who don't like me. 1 2 3 4 5 6 7

IV. **Introduction and Directions:** In general, spirituality refers to an awareness of one's inner self and a sense of connection to a higher power, nature, others, or to some purpose greater than oneself. I am interested in your responses to the questions below about spirituality as it may relate to your life. There are no right or wrong answers. Answer each question to the best of your ability by marking an "X" in the space above that group of words that best describes you.

1. In talking with your family and friends, how often do you mention spiritual matters?

_____/_____/_____/_____/_____/_____/

Not at all Less than About once About once About once About once
 Once a year a year a month a week a day

2. How often do you share with others the problems and joys of living according with your spiritual beliefs?

_____/_____/_____/_____/_____/_____/

Not at all Less than About once About once About once About once
 Once a year a year a month a week a day

9. My spiritual views have had an influence upon my life.

_____/_____/_____/_____/_____/_____/_____
Strongly Disagree Disagree more Disagree more Agree more Agree Strongly Agree
Disagree than agree than disagree

10. My spirituality is especially important to me because it answers many questions about the meaning of life.

_____/_____/_____/_____/_____/_____/_____
Strongly Disagree Disagree more Disagree more Agree more Agree Strongly Agree
Disagree than agree than disagree

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