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IMPACT OF MULTIPLE SCLEROSIS ON MARITAL LIFE

BY

LYNDA CAROL GRANT ©

A THESIS SUBMITTED TO THE FACULTY OF GRADUATE STUDIES AND RESEARCH IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PHILOSOPHY.

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Dedicated to the memory of

my Mom and Dad,

Vi and Alec Grant

ABSTRACT

In this research the impact of multiple sclerosis (MS) on marital life was explored. In phase one, open-ended interviews were conducted and short questionnaires were mailed to volunteer participants. They were asked to respond to the question, "In what ways has MS impacted on your marital life?" In phase two the statements gathered were sorted into homogeneous groups by 14 psychologists. The sorts were statistically analyzed using multidimensional scaling and cluster analysis (concept mapping) in order to identify themes. Analysis of patient data resulted in 11 themes: positive impact on marital life, coping and adaptation, sexual issues, financial issues, role of spirituality, lifestyle changes, negative impact on marital life, insecurity, emotional reaction, and anxieties/fears. Analysis of partner data resulted in 9 themes: lifestyle changes, uncertainty about the future, financial issues, emotional reaction, feeling burdened, sense of losing spouse, stresses, changes in approach to life, and positive impact. In phase three separate incident surveys were developed for MS patients and partners to determine the applicability/significance of the items. This data provided a broad, multidimensional perspective on the impact of MS on marital life. Frequency data were calculated for all demographic variables and each of the 97 patient survey items and the 98 partner survey items. T-tests were calculated to determine if items were differentially endorsed based on demographics. There was a great variation in the endorsement rates of the individual items highlighting the uniquely individual and complex nature of the impact of MS on marital life. Cluster #2 (Coping and Adaptation) from the patient concept map had the largest number of patient-endorsed statements perceived to be applicable to them. Cluster #9 (Positive Impact) had the largest number of statements that were perceived by partners to be applicable to them.

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CHAPTER 1: INTRODUCTION

Statement of the Problem

Chronic illness is an event we usually view from a distance. We are thankful and relieved that we and our loved ones have been spared. We feel sympathy for those afflicted but our lives remain essentially untouched.

Although entire families are affected by chronic illness, it is typically the spouse that becomes the primary caregiver, and is required to take on the additional roles of his or her ill partner (Rolland, 1994). The well spouse has needs and struggles which are often overlooked and little understood. The focus of therapy is usually, if not always, on the ill family member. There are stressors which occur due to the day to day living arrangements that need to be made and carried out, as well as psychological stress that is an inevitable part of coping with the chronic illness of a loved one. In long-term disabling illness, emotional adjustments are complicated and prolonged, and may cause more distress than the physical effects of the disease. When an individual develops a chronic illness, the life of the marital partner is disrupted and changes are inevitable in the marital relationship.

The impact of neurological disease can be immense. Couples in which one partner has a neurological disease face changes in interpersonal dimensions and strain on the bonds of commitment (DesRosier, Catanzaro & Piller, 1992). Multiple sclerosis (MS) is the most common neurological disorder affecting young couples (Matthews, 1993). The focus of the present study is to explore the effects of multiple sclerosis on the marital relationship.

Multiple sclerosis (MS) is the most common disease of the central nervous system and is one of the most common chronic disabilities among young adults in

Canada. An estimated 50,000 Canadians have MS (Fact Sheet, MS Society of Canada, 1996). MS involves the progressive erosion of the myelin sheaths that surround fibers in the central nervous system. Both the brain and spinal cord are involved. Nerve conduction takes place along the myelin sheaths and cannot occur normally when the sheaths erode. The result may be vision problems, numbness, loss of balance, extreme fatigue, tremors, and even paralysis. Urinary symptoms occur in the majority of MS patients and are typically conjoined with bowel and sexual complaints (Halbreich, 1993; Lechtenberg, 1995). Depression is also common in MS patients (Halbreich, 1993). Psychosocial and vocational problems complicate the lives of many MS patients, and because of it's unpredictability, MS is a disease that tends to cause considerable stress (LaRocca, Kalb & Kaplan, 1987).

The physically disabling symptoms of MS are the most noticeable. However, dementia is not as rare in MS as was previously believed. Studies (Peyser, Edwards & Poser, 1980; Rao, Hammeke & McQuillen, 1984) have shown that about 50% of MS patients have intellectual impairment, as measured by formal psychometric testing. It appears however, that only 20% have functionally significant deficits. Most of those with significant intellectual impairment have advanced disease, but significant dementia occasionally occurs early in the disease. Lesions in the frontal lobe can lead to unrestrained and tactless behavior, mood changes, blunted feelings, boastfulness, and grandiose, obstinate, egocentric behavior (Rao, Reingold, Ron, Lyon-Caen & Comi, 1993). The person with frontal lobe damage often displays behavior best described as callous unconcern. The emotional and intellectual changes caused by the cognitive damage cause extreme stress in marriages (Lechtenberg, 1995).

Individuals with MS and their partners face a unique set of stressors and challenges as they seek to adapt to a chronic illness with an unknown cause, few medical therapies, and an uncertain prognosis that almost always includes some degree of functional disability (Stuifbergen, 1992). The onset of MS is usually between the ages of 20 and 40 years when individuals typically have heavy work and family responsibilities. Each individual's experience with MS and the associated demands of the illness are unique because the pattern of demyelinating lesions can produce numerous combinations of functional abnormalities.

Few studies have investigated the effects of MS on the marital relationship. It is common knowledge that the reported cognitive, affective, and physical changes require significant adjustments on the parts of those with the disease and those in relationships with them. There is surprisingly little research about how to discern the issues of concern to couples. Studies that have appeared address specific issues such as spousal social support (Foote, Piazza, Holcombe, Schienbert & Reznikoff, 1990; DesRosier et al., 1992; Gulick, 1994; Stuifbergen, 1992; Wineman, 1990), coping (O'Brien, 1993; White, Catanzaro & Kraft, 1993; Gulick, 1995; Wineman, O'Brien, Nealon & Kaskel, 1993), spousal caregivers (O'Brien, 1993A, O'Brien, 1993B; Murray & Stewart, 1994; Cockerill & Warren, 1990), chronic sorrow in helping spouses (Hainsworth, Burke, Lindgren & Eakes, 1993; Hainsworth, 1993), and marital adjustment (Rodgers & Calder, 1990).

Chronic illness is becoming a greater problem in our society due to advances in medical science and technology that have prolonged the lives of many chronically ill persons (Rolland, 1994). Rolland states that the family perspective on health care is part of an intellectual and technological movement toward holistic and ecosystem approaches to medicine that consider people within their particular social contexts. The patient's quality of life is determined partially by the maintenance of family relationships throughout the chronic illness (Salmond, 1987). Social support, particularly spousal support, has been cited by several authors (Gillis, Rose, Hallburg & Martinson, 1989; Strauss & Glaser, 1975; Winterhalter, 1992) as an integral part of the care of chronically ill patients.

The increase in the incidence of chronic illness and the associated need for long-term health care unfortunately have come at a time when resources to pay for health services are depleting. Consequently, policy makers and health care professionals increasingly look to the spouses and family as a resource (Montgomery, Gonyea & Hooyman, 1985). It is now expected that the burden of managing a chronic illness will rest with the diagnosed individuals and their families except in times of medical crisis (Corbin & Strauss, 1984).

As dissatisfaction with health care services grows among families and individuals affected by chronic illness, it is imperative that spouses also be considered as the "client" (Butcher, 1994). Chronic illness can be effectively managed only if the relationships among family members, particularly spousal relationships, are taken into account (Strauss & Glaser, 1975). Traditionally, care has focused on the individual and has included the family only informally as the unit of care (Anderson & Tomlinson, 1992). However, because the entire family is affected by chronic illness, it is time to move beyond the individual approach.

From a theoretical systems perspective, the adult partners are the executive unit of the family and their responses to a chronic illness provide the foundation for the responses of the family system and it's individual members. The meaning and adjustment to the diagnosis within the partner relationship is influenced by each individual partner's perception of that meaning within the dyad (Germino, Fife & Funk, 1995). The marital partners must somehow integrate the changes brought on by the illness. This may include challenging long held assumptions; changing the way they view themselves and their partners; reexamining their life, relationship and values; and addressing fears and concerns (Lewis, Woods & Hough, 1989).

Little research exists in this area of MS and marital life but there is a small and growing literature on the effects of spouse perceptions of the impact of chronic illness on the marital relationship. Although no literature of this sort exists in the area of multiple sclerosis, the literature for other chronic illnesses such as chronic pain, cancer, arthritis, renal disease, cardiology, diabetes, spinal cord injury, brain injury, and Alzheimer's disease exists and will be reviewed in the next chapter.

The review of the literature related to marital relationships in MS couples reveals a need to examine the unique experiences of married individuals from their perspective. The current study utilized indepth qualitative interviews with individual marital partners, and open-ended questionnaires, combined with a concept mapping method. This approach compliments previous studies which have focused on specific theoretically defined concepts.

The present exploratory study was undertaken to gain a better understanding of the perceptions of the impact of MS on the marital relationship from the individual perspectives of the MS patient and the partner. Specifically, the objectives are i) to identify the issues, ii) to determine underlying themes and to identify these themes, iii) to determine the prevalence of these issues among couples in which one partner has MS.

Overview of the Concept Mapping Method

Concept mapping is a methodological approach which combines qualitative and quantitative strategies. It combines phenomenological and quantitative research strategies and actively involves research participants in item generation and data gathering (Daughtry & Kunkel, 1993).

Concept mapping is a set of statistical methods used to cluster variables into their underlying themes. This method is particularly appropriate for applications in which researchers are seeking to clarify the domain and determine the constituent variables which underlie a phenomenon as experienced by a population of interest (Daughtry & Kunkel, 1993; Trochim, 1989). Kunkel (1991) suggests that concept mapping methods can lead to a greater understanding of the perceptual themes underlying psychological phenomena. He states that concept mapping adds objectivity to qualitative data that has typically been analyzed using nonstatistical approaches. Concept mapping allows for the understanding of psychological issues and constructs as they are experienced by participants rather than as defined by researchers (Daughtry & Kunkel, 1993).

In concept mapping, researchers first pursue participants' perspectives about their experiences of the phenomenon of interest. This is accomplished by asking an open-ended question or conducting a phenomenological probe such as an interview (Giorgi, 1985). Consequently, concept mapping provides an analysis of qualitative data in a manner that allows confidence in the results because of the inherent objectivity in the method. At the same time, this approach gives us a fresh look at the participant's perspective.

Another advantage of the concept mapping method is that it allows the raw data to be grouped and organized by many sorters. This reduces the potential for bias or subjectivity that can occur when qualitative data are sorted and grouped by an individual researcher. Finally, concept mapping results in a graphic representation which demonstrates at a glance all of the major relevant concepts and their interrelationships (Trochim, 1989).

Purpose of the Study

The purpose of the present study was to gain a better understanding of the individual spouse's perceived impact of MS on the marital relationship. The investigation allowed research participants to reflect on their experience of MS in regard to their spousal relationship in a way that is unconstrained by the researcher's previous conceptions. This study combined indepth qualitative interviews and open-ended questionnaires with a more quantitative methodological approach, concept mapping, to understanding the nature and organization of the elements of the experience of MS in the marital context. Rather than adhere to conceptually or diagnostically based a priori formulations, the intent of this investigation was to obtain a relatively unconstrained description of the ways in which MS is perceived to affect the spousal relationship. Concept mapping allows the research participants to collaborate in clarifying the organization and salience of the various elements of their experience.

The outcome of this investigation will be useful for assessing the problematic issues arising in MS couples, and aid in the creation of effective counselling approaches. The statements generated in this study could be used in the development of a scale to aid in psychological treatment plans. The hope is that the information obtained in this study will be useful to counselors to assist clients to work through MS related relationship issues in order to attain their highest level of functioning. Review of the psychosocial literature reveals the limited availability of research to guide psychological practice as it relates to helping individuals with MS and their partners.

Assumptions and Limitations

Volunteer participants for the interviews and the open-ended questionnaires were chosen using a non-probability sample of convenience utilizing a snowball technique. The lack of random sampling and the use of volunteer participants at the initial data gathering state could have created a potential selection bias.

The survey sample of MS couples consisted of the participants from phase one of the study as well as MS patients and their partners whose names were provided from a number of physicians. Consent was obtained from the Alberta College of Physicians and Surgeons. Volunteer participants were also contacted through advertisements in local newspapers and the community service television channels. Some volunteers were contacted through support groups in Alberta, British Columbia, and the Washington, D.C. area in the United States. Problems with generalization could have developed if the volunteer sample differed in terms of perceived marital difficulties from the general population of MS couples.

There is also recognition that couples who are coping poorly may be underrepresented in this study, since they may fail to take the time to respond to survey research. Subjects who choose to return their questionnaires may be atypical of the population at large.

In addition, the Likert-type scale used on the survey can be vulnerable to response sets by the subjects. Finally, consistency in the manner the survey was completed is not under the researcher's control, possibly adding unknown biases. For example, if the two partners filled out the surveys together rather than independently, the meaning of the results could be altered.

Conclusion

Variables included in quantitative studies reflect the issues that researchers believe are important. These issues are not necessarily the issues perceived to be relevant by chronically ill multiple sclerosis (MS) patients and their partners. The operational definitions of variables set by a chosen questionnaire do not provide the whole picture of emotional and marital adjustment. A more qualitative approach is necessary to better understand the dynamics involved in relationships in which one partner has MS.

No research utilizing qualitative interviews combined with concept mapping has been applied to the problem of understanding the effects of MS on the marital relationship. Results from this type of investigation will complement existing literature related to couples and MS. Having a clearer understanding of the physical as well as cognitive-emotional issues that affect MS couples will contribute to the ability to provide more effective marital counselling.

The format for this thesis is as follows: Chapter 2 consists of a review of the literature. The MS literature is reviewed providing information on etiology, epidemiology and symptoms (physical, emotional, and cognitive). A section discussing cognitive impairment in MS is included, as well as a review of the few studies which address MS spouses and marital relationships. Literature is reviewed on the perceived effects of various chronic illnesses on couples. As well, a general overview of the concept mapping methodology is described.

Chapter 3 provides a detailed description of the method used in this investigation. In Chapter 4, the results are presented in the form of the concept maps, as well as the results of the incidence study. Finally, Chapter 5 consists of a summary and discussion of the major aspects of the overall research study.

CHAPTER 2: REVIEW OF THE LITERATURE

The following literature review develops the background and rationale for this study on the effects of multiple sclerosis on the marital relationship. This is accomplished by reviewing four broad areas. It begins with a general discussion of the disease of multiple sclerosis in order to acquaint the reader with the nature of the disease. This is followed by a brief synopsis of the research done in the area of marital life and multiple sclerosis. Then there is a discussion and summary of the research on the effects of various chronic illnesses on marital life. The final section introduces and explicates the concept mapping method utilized in this study.

Multiple Sclerosis: the Disease

Multiple sclerosis (MS) is the most common of the neurological diseases characterized pathologically by central nervous system (CNS) demyelination (Halbreich, 1993; Lechtenberg, 1995). MS involves the progressive erosion of the myelin sheaths that surround fibers in the central nervous system which includes the optic nerves, brain and spinal cord. Nerve conduction takes place along myelin sheaths and cannot occur normally when inflammation destroys patches of the myelin. This can result in vision problems, numbness, loss of balance, extreme fatigue, tremors, and even paralysis. Spontaneous recovery from symptoms may occur and last from months to years. However, MS is often progressive and further disability results from characteristic unpredictable attacks.

Despite decades of intensive scientific study, neither the cause nor the pathogenesis of MS is known. However, its impact is obvious and is a major source of severe disability in the young adult population. An estimated 50,000 Canadians have MS (Multiple Sclerosis Society of Canada - fact sheet, 1996). The physical and psychological effects of an unpredictable disease with a wide clinical expression strain relationships (Lechtenberg, 1995). The general discussion of MS reviews the salient features including the epidemiology, symptoms, prognosis, diagnosis and treatment of MS.

Epidemiology and Pathogenesis

MS is a disease that differentially effects white females: the female to male ratio and the white to black ratio are both nearly 2:1 (Halbreich, 1993). MS does not affect all ethnic groups uniformly. MS is rare among Orientals, black Africans, and North American Indians and Inuit. The onset of MS typically occurs in the age range of 17 years to the early 30's. Onset is rare before the age of 15 and decreases in frequency after the age of 45 years (Lechtenberg, 1995).

MS has a prevalence of approximately 100/100,000 in most parts of the UK, Northern Europe, Northern USA, and Canada (Compston & Sadovnick, 1992). A north-south frequency gradient exists in Europe but does not strictly follow geographical rules since the disease is more prevalent in Italy than in European countries of comparable latitude such as Spain, Southern France, and Greece. The frequency of MS decreases in a northwest to southeast direction in North America.

Canada is recognized as a high-risk zone for MS. The province of Alberta has a particularly high rate. Svenson et al. (1994) estimate the prevalence rate for Alberta at 216.7 per 100,000 (173.1 for males; 260.3 for females) population. The prevalence rate for Alberta is among the highest reported in the world suggesting that the province appears to be an excessive risk area relative to other global locations. Although statistically a high risk area there is no evidence to explain the higher level of incidence.

From the time that Charcot first commented on the geographical distribution of MS, it has been referred to as a disorder distributed in both time and place (Charcot, 1877). The uneven geographical distribution of MS has provided considerable interest for epidemiological study since the geographical parameters are thought to reflect underlying causes (Sadovnick & Ebers, 1993). MS distribution suggests an aetiological role for both genetic and environmental factors but these are not yet fully characterized.

To explain the geographical distribution of MS, considerable effort has been focused on traditional environmental factors. However, significant and consistent differences in the frequency of MS amongst peoples who are geographically close but genetically distant continue to be reported and support the idea that genetic factors influence the distribution of the disease. Large scale epidemiological studies favor environmental factors as dominant in the interplay between race and place in determining the frequency of MS (Poser, 1987). The geographical distribution links MS to colder climates as it is more common in areas farther from the equator. Caucasians appear to have a genetically determined susceptibility to the disease. It is thought that environmental factors, likely a viral infection, affecting the individual in puberty, activates the genetic susceptibility (Poser, 1987).

Symptoms

Multiple sclerosis is manifested by a variety of symptoms affecting different individuals to differing degrees. MS symptoms can be categorized as primary, secondary, or tertiary. The primary symptoms reflect the effects of a discrete plaque of demyelination on neurological function. Examples are visual loss from optic neuritis, ambulation or gait difficulties, bladder, bowel and sexual dysfunction, sensory problems, fatigue, and dementia. Secondary symptoms are the non-neurological complications that occur directly as a consequence of primary symptoms. These include urinary tract infection, pressure sores from immobility, and aspiration pneumonia. Tertiary symptoms are the psychological and sociological ramifications of the disease on the patient and family (Halbreich, 1993). The primary, secondary, and tertiary symptoms of MS, all have a significant impact on marital life (Halbreich, 1993).

Primary Symptoms

Vision is often affected in people with MS. Visual problems result from either lesions of the optic nerves or from pathways subserving extraocular muscle movements. Inflammation and demyelination in the optic nerve results in blurring or loss of vision, as in retrobular neuritis. Usually only one eye is affected and once inflammation subsides, vision usually returns. Double vision is caused by weakness in the eye muscles leading to incoordination of the eyes (Lechtenberg, 1995).

Symptoms resulting in altered gait include a combination of weakness, stiffness, heaviness, imbalance, and numbness. Paralysis, spasticity, cerebellar ataxia, or sensory loss may be responsible for the symptoms. The earliest signs of gait impairment are complaints of easy fatigability or difficulty with running. As symptoms progress, a 'foot drop' is evident - a dragging of one or both lower limbs (Scheinberg & Smith, 1987). Symptoms fluctuate and many worsen under conditions such as high temperature. Equilibrium may be defective and falling is frequent. If the disease is progressive, gait may become hazardous and walking aids may become necessary. For some, gait becomes impossible and the use of a wheelchair becomes inevitable.

Patients with symptomatic spasticity may also report spasms of the lower limbs, causing pain particularly at night, interfering with sleep. (Halbreich, 1993).

Cerebellar disturbances are among the most common symptoms of MS. Cerebellar ataxia is the most frequent cause of gait problems. Loss of balance and tremors in the arms and legs are caused by demyelination in the cerebellum (Schapiro, Harris, & Lenling, 1987). Speech difficulties are another category of symptoms that are a result of disturbances in the cerebellum. Difficulties usually involve slower speech with diminished fluency and slurring of words. Slurring may occur especially if the muscles of the tongue and throat are also affected by nerve transmission and if tremors of the lips, tongue, or jaw are occurring (DeLoya, Arndt & Schapiro, 1987).

Urinary symptoms occur in the majority of MS patients and are typically conjoined with bowel and sexual complaints. Frequency and urgency of urination are the most common problems. Urinary symptoms are a direct result of the neurological lesions of MS (Halbreich, 1993)`.

Bowel complaints are at least as common as urinary symptoms, the most frequent complaint being constipation (Glick, Meshkinpoor & Haldeman, 1982). Demyelination in the brain and/or spinal cord can disrupt the nerve impulse transmission responsible for the digestive system muscles. Also many patients control irritative urinary symptoms by reducing fluid intake resulting in constipation (Schapiro, 1987).

Sexual complaints are as frequent as bladder and bowel complaints. The most frequent problem for males is impotence and for females is decreased libido (Kalb, LaRocca & Kaplan, 1987). Sexual problems may relate to the psychological ramifications of the disease as well as to the effects of the neurological lesions. (Stanager, Stanager & Jensen, 1992).

Sensory symptoms are almost universal in MS. Sensations are described as "vibration", "bands", "tingling", or "pins and needles". For some, the sensations can be sharp and aching. Pain is not rare in MS (Clifford & Trotter, 1984) and occurs in about 20% of the cases. Pain may be in the form of trigeminal neuralgia, a severe stabbing pain on one side of the face. The most common pain is described as a "burning" pain occurring throughout the extremities (burning dysesthesias). Another common sensory symptom is numbness which occurs when nerves that transmit sensation fail to conduct information properly (Schapiro, 1987). Lesions in the brain stem area are responsible for the dizziness and vertigo experienced by some people with MS (Schapiro, 1987).

Up to 77% of people with MS name fatigue as a symptom (Coulthard-Morris & Vollmer, 1995). Descriptions of the fatigue include a "washed out", "exhausted", or "totally lacking energy" sensation. People with MS experience a great deal more fatigue than the average person. The deep overwhelming fatigue experienced is usually most prominent in the mid to late afternoon and is worsened by physical exercise and hot, humid conditions. Fatigue is one of the major symptoms associated with unemployment in the MS population (Coulthard-Morris & Vollmer, 1993).

Dementia is not as rare in MS as was previously believed. Peyser et al. (1990), Rao, Leo, Bernardin, and Unuerzagt (1991) and LaRocca, Kalb, and Kaplan (1987) have estimated that as many as 43-65% of MS patients have MS related intellectual impairment, as measured by formal psychometric testing. However, only about 20% have functionally significant deficits. Unlike the chronic progressive, and irreversible global impairment associated with Alzheimer's disease, the cognitive disturbances associated with MS are generally milder. They do not affect all patients, do not progress predictably, and generally do not affect all cognitive functions uniformly. Often intellectual changes are very subtle (Rao, et al., 1991).

Disturbances in memory are the most frequently reported form of cognitive impairment in MS (Beatty, 1993). Other common findings are impaired abstract reasoning, problem solving, and verbal fluency (Rao et al., 1984).

Rao et al. (1991) describe the neuropsychological profile of MS as consistent with a "subcortical dementia". Along with the slowed information processing and poor memory retrieval, some MS patients experience mood disturbances and disturbed executive functions. Neuropsychological deficits of MS may be associated particularly with demyelination of white matter pathways emanating from the prefrontal cortex. Frontal lobe damage is associated with unrestrained and tactless behavior, mood changes, blunted feelings, callous unconcern, boastfulness, grandiose, obstinate and childishly egocentric behavior (Stuss & Benson, 1984). There appears to be suppression or actual inability to produce imaginative or original thinking and a diminished spontaneity and initiative. Careless work habits, distractibility, apathy, dullness, indifference, and slowness of thought are often part of the frontal lobe syndrome. Throughout all of the frontal lobe symptoms there is almost constantly a striking lack of insight, and patients ignore or actively deny many of their difficulties (Stuss & Benson, 1984).

Emotional disturbances have been found to be highly prevalent among MS patients (Minden & Schiffer, 1990; Mahler, 1993; Garland & Zis, 1991). Neurologically based emotional symptoms include euphoria, pathological laughing and weeping, and depression.

Euphoria is an exaggerated or inappropriate sense of well being. There is no consensus on the prevalence of euphoria in MS with estimated rates ranging from a high of 63% to a low of 0% (Minden & Schiffer, 1990; Mahler, 1992; Beatty, 1993). Patients who are euphoric, compared to those who are not, are more likely to have cerebral involvement, enlarged ventricles, cognitive function, and more social disability. There is consensus that euphoria is a neurologically based emotional state, produced by demyelination, and not a psychological process (Minden & Schiffer, 1990; Mahler, 1992; Beatty, 1993).

Emotional lability (pathological laughing and weeping) in MS patients involves only the display of emotion and not a subjective emotional state experienced by the patient. MS patients may laugh or weep with slight provocation, regardless of their underlying mood (Minden & Schiffer, 1990). The emotional lack of control is likely caused by disconnection of diencephalic or brain-stem centers from the right frontal hemisphere.

Depression is the most common emotional disturbance in MS, occurring in 15-30% of patients (Gilcrest & Creed, 1994). The aetiology of depression in MS is still uncertain, and the relative contributions of neurological disorder, cognitive deficits and social stresses are debated (Devins & Eland, 1987; Rao, et al., 1993; Minden & Schiffer, 1990; Moller et al., 1994). A number of controlled studies indicate that lifetime prevalence rates for significant depressive illness are higher for patients with MS (40 to 50%) than for patients with a variety of comparable medical and neurological diseases (Schubert et al., 1993; Minden & Schiffer, 1990; Acorn & Anderson, 1990). This finding suggests the cause, although unclear, is probably due to the interaction of biological, psychological, and social factors.

Secondary Symptoms

Secondary symptoms are those that arise as a direct result of the neurological disturbances. Secondary problems include urinary tract infection, fibrous contracture of muscles, pressure sores, and aspiration pneumonia (Halbreich, 1993).

Urinary tract infection results when there is an obstruction of urinary flow and an elevated residual urine (Halbreich, 1993). Spasticity can lead to irreversible shortening of muscles (fibrous contractures). The fibrous contractures can lead to ankylosis of adjacent joints (Halbreich, 1992). Pressure sores are primarily the consequence of sustained pressure. Superficial skin lesions can develop into deep ulcerations which frequently require surgical management (Halbreich, 1993). Aspiration pneumonia results from cerebellar disturbances that affect the oral-pharyngeal phase of swallowing. Aspiration pneumonia is a potentially life-threatening complication that tends to be associated with advanced disease (Halbreich, 1993).

Tertiary Symptoms

Tertiary symptoms include psychosocial and vocational problems that complicate the lives of MS patients. MS causes considerable stress (LaRocca et al., 1987), and the ability of MS patients to cope with this stress appears to be associated with premorbid coping strategies and their internal and external support systems. Patients with inadequate support systems tend to lose their ability to cope and adapt socially and psychologically to the changing impact of the disease (DesRosier et al., 1992; Foote, Piazza, Holcombe, Paul & Daffin, 1990; Gulick, 1994).

Prognosis

Establishing a prognosis for an individual with MS is a tenuous exercise. MS is a disease whose course ranges from primarily benign, with as few as one or two neurological episodes, to totally devastating, with total incapacity within a few months of onset. Although future prospects cannot be predicted, certain patterns of presenting signs and symptoms seem to have predictive power. Patients with initial sensory symptoms involving the posterior columns of the spinal cord have a more favorable prognosis than those with pyramidal involvement. The latter are more likely to develop a more malignant clinical course (Sanders, Bollen & Vandervelde, 1986).

There are two broad general categories of MS which are thought to influence the clinical course of the disease. The exacerbating-remitting type is characterized by episodes of clear-cut worsening. The chronic-progressive type is characterized by disability that gradually mounts and remissions, if any, are not complete (Schapiro, 1987).

About 20% of patients with MS have a "benign type" of remitting-relapsing MS in which they experience only a few exacerbations and almost complete remission. They have a normal life span of relatively unencumbered physical activity. The clinical course cannot be predicted early in the disease, but a benign course is more likely to develop in females diagnosed in their twenties, with sensory rather than motor symptoms (Paty & Poser, 1984).

Another 25% have the relapsing-remitting type which is like the benign course except the attacks have more manifestations. However, remission is nearly always complete and the MS usually does not manifest significant disability even after many years (Schapiro, 1987).

Forty percent of MS patients fall into the relapsing progressive type which is characterized by clearly defined exacerbations with incomplete recovery during remission. Fifteen percent of the MS population experience a chronic progressive course in which there is a slow but steady progression of neurological impairment. Severe disability can result in only a few years (Halbreich, 1993).

Although it is not possible to reliably determine the eventual outcome of an individual with MS, some features of the history and physical examination can help. For example, frequent exacerbations, especially during the early phase of the illness, tend to be associated with a worse outcome. When exacerbations are gradual in onset, the outcome is also less favorable. A chronic progressive course, either from the onset or after a relapsing-remitting phase is a strong predictor of an unfavorable prognosis (Halbreich, 1993). Positive signs for a favorable prognosis include onset at an earlier age (prior to age 35); complete recovery from an initial acute attack; and predominately sensory as opposed to motor symptoms.

The single most important prognosticating instrument is the Extended Disability Status Scale of Kurtzke (1983). This is an ordinal scale that assigns an estimate of disability based on physical examination. The scale is a good general reflection of global impairment. Used over a period of years, it gives a general sense of the type of disease and prognosis for a given patient.

Diagnosis

Despite the advent of new laboratory and radiological techniques, there is no specific diagnostic test for MS. The diagnosis remains a clinical one, relying on the ability to demonstrate the existence of white matter lesions in the central nervous system. According to Poser and Aisen (1987), to conclusively diagnose MS, there must be evidence of two or more lesions in the CNS that are in different locations and which developed at different times. For an accurate diagnosis, the history of symptoms is obtained from the patient and a thorough neurological examination is initiated. Some specialized procedures are used to aid in the diagnosis of MS (Halbreich, 1992).

The MRI (magnetic resonance imaging), because of its sensitivity in visualizing plaques of MS, has become the single-most important advance in diagnosis. However, MRI abnormalities alone cannot be used to support the diagnosis of MS. Another imaging technique, the computer-assisted tomography (CAT scan) can verify the presence of multiple lesions, and rule out other conditions such as tumors.

Evoked potentials (EPs) have been used for many years to demonstrate the presence of white matter lesions. An EP is the electrical manifestation of the brain's response to an external stimulus. Clinical interpretation is based on the presence or absence of appropriate EP waves and their latencies. Optic nerve involvement is common in MS. Therefore visual evoked potentials are particularly useful because each optic nerve can be tested independently (Lechtenberg, 1995).

Cerebrospinal fluid (CSF) is examined to confirm a diagnosis of MS. A spinal tap/lumbar puncture is performed, whereby a needle is inserted in the spinal column and some cerebrospinal fluid is withdrawn. This fluid contains more lymphocytes (white blood cells) and more protein in people with MS (Halbreich, 1993).

A diagnosis of clinically definite MS requires a history of two attacks and clinical evidence of two separate lesions of the CNS. The final diagnosis is determined by the patient's reported symptomatic history, a neurological examination and the specialized diagnostic procedures described above.

Treatment

There is no known cure for MS and little is known about prevention or overcoming exacerbations. Treatments available attempt to reduce the existing disability by treating the symptoms and decreasing the duration and severity of attacks (Matthews, 1985).

Steroids are often used to shorten or decrease the severity of an MS attack. Oral prednisone and ACTH have immunomodulatory and anti-inflammatory properties. Steroids reduce the swelling in the lesions which reduces some of the symptoms (Troiano, Cook & Dowling, 1990).

The treatment approach for patients with chronic progressive MS differs from that for patients with exacerbating disease. Because of the predictably downhill course, a more aggressive treatment approach is warranted. Active chronic progressive MS is usually treated with relatively intense immuno-suppression drugs such as cyclophosphamide, azathioprine, and cyclosporin. It is believed that the person's own immune system (the lymphocytes) may be responsible for the demyelination in the CNS (Lechtenberg, 1995). Use of the immunosuppressant drugs decreases the number of lymphocytes and reduces damage to the myelin (Halbreich, 1992).

A relatively new and still experimental therapy for MS is the use of interferons which are naturally occurring glycoproteins produced by the body in response to viral challenges. Beta interferons act on the immune system and modify some of its effects. Betaseron was found to reduce the number of MS attacks by one-third and cut down the severity of attacks by about 50 percent (MS Ontario, 1993). The goal of treatment by beta interferon is disease stabilization in early relapsing-remitting MS. Clinical trials of Betaseron for secondary progressive MS were schedule to begin early in 1996 (MS Canada, 1996).

Multiple Sclerosis and Marital Life

Few studies have investigated the effects of MS on marital life. Physical, cognitive, and affective changes brought about as a result of the disease require significant adjustments on the parts of those with the disease as well as those in relationship with them. However, surprising little research has explored the effects of MS on marital life. Studies that have appeared, address specific issues such as spousal social support and coping, spousal caregiving and marital adjustment.

Wineman, O'Brien, Nealon, and Kaskel (1993), examined how each spouse's perception of illness uncertainty in MS influences the emotional well-being of the couple measured by family satisfaction. Wineman et al. (1993) concluded that in order to manage a chronic illness such as MS, and to make the needed modifications in daily life, both the MS spouse and the partner must come to terms with the illness trajectory. Corbin and Strauss (1988) describe illness trajectory as the course and progression of the illness and its effect on the lives of those it touches. Coming to terms with the illness trajectory of MS may be uncommonly difficult because of the unpredictable and changing nature of the disease process.

The uncertainty experienced by persons with MS and the accompanying disabilities that affect motor, sensory, cognitive, and interpersonal functions create a need for social support over the long chronic illness trajectory. Kahn and Antonucci (1980) define social support as interpersonal transactions that include one or more key elements such as affect, affirmation, and aid. Affective transactions include expressions of liking, admiration, respect, or love. Affirmative transactions include expressions of agreement or acknowledgment of the rightness of some act. Transactions involving direct aid or assistance include the provision of material things, money, information, time, and entitlements.

A substantial body of research suggests that social support may affect both physical and psychological health through its stress-mediating and/or stress-buffering role (Heitzmann & Kaplan, 1988; Foote, Piazza, Holcombe, Paul & Daffin, 1990). Perceived social support that leads the person to believe that he or she is cared for, loved and esteemed, appeared to be the buffer that enables chronically ill individuals to cope with the demands of their illness. During an illness, the spouse generally provides the most help and satisfies the need for social support. The spousal system provides affection, companionship, and acts as an ego-restoring center in times of social and psychological crisis (Blood & Wolfe, 1980).

Results of a study by Stuifbergen (1992) indicated that spouses emerged as one of the most important sources of support for individuals with MS. Spouses were reported to be the most frequent provider of support for managing the physical demands of the illness as well as providing emotional support. In this study partners reported that the spouse with MS had been one of their major sources of support in dealing with their own problems. Individuals with MS reported that the emotional support from spouses was helpful in coping with their thoughts and feelings about the experience of MS.

The presence of spouses among persons with MS was found by Zeldow and Pavlou (1984) to provide support which preserved MS subjects' sense of well-being in the face of physical disability and life stress. Gulick (1994) collaborated this finding with his finding of an interaction between marital status and MS duration. Persons with MS who had spouses perceived higher average levels of aid while those without partners perceived lower average levels of aid over the illness trajectory, emphasizing the important role that spouses play in meeting the increasing demands of persons with chronic illness. The value of spousal support was further illustrated in Gulick's (1994) study whereby men, but not women, when they had spouses, perceived that the average amount of loss was less severe.

It is hypothesized that adjustment to MS is affected by coping behavior (Foley, Bedell, LaRocca, Schienbert & Reznikoff, 1987). McNett (1987) found that perceived availability of social support significantly influenced coping effectiveness. Wineman (1990) suggested that people's perception of a supportive social network gave them a feeling of belonging, which helped them to cope with the needs that arise while living with an unpredictable, chronic disease. Perceived unsupportiveness was associated with both an increase in depression and a lower sense of purpose. Less perceived social support was associated with longer periods of illness and higher levels of functional disability.

Coping is behavior directed toward managing internal and environmental demands, or both, that tax or exceed a person's resources (Lazarus & Folkman, 1984). Lazarus and Folkman (1984) suggest that people who generally feel supported seem to have a greater propensity to initiate healthy and adaptive coping behavior. They theorized that social support is an antecedent that influences coping behavior. Other research suggests that perceived spousal social support is a crucial factor in coping with the demands of physical illness and disability (McIvor, Riklan & Reznikoff, 1984; Weinert, 1983; O'Brien, 1993a).

The social dependency accompanying chronic illness creates an increased need for social support. Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek, and

Wiener (1984) note that chronic illness requires the spousal caregiver to do all the things that the ill person cannot do, such as personal care, monitoring symptoms, carrying out regimens, shopping, and transportation. The impact of a neurological disease such as MS on caregivers can be immense. The many physical, social, and emotional disabilities associated with MS result in social dependence on spouses during the long illness trajectory. The presence of dependency needs in individuals with chronic illness can have an adverse effect on the health of spouses and significant others. Caregiving can be so overwhelming that caregivers suffer many emotional and physical problems including chronic fatigue, interrupted sleep, insufficient rest, and depression (Decker & Young, 1991).

Spousal caregivers are an important and often neglected aspect of the life, happiness and positive outcome in MS patients. Several researchers have addressed the issues of caretaker stress and coping strategies among spouses of MS patients (O'Brien, 1993; White et al., 1993; Gulick, 1995; Cockerill & Warren, 1990; DesRosier et al., 1992).

O'Brien (1993b) found a significant inverse relationship between health-promotion behavior of the caregiver spouse and dependency needs of the care recipient suggesting that caregiving spouses may be neglecting their own health as their spouse becomes more dependent upon them. Spousal caregivers who experience physically and emotionally exhausting daily chores of providing care may not have sufficient energy to meet their own needs for health-promotion practices.

Coping among spousal caregivers of MS patients has been addressed in a number of studies (O'Brien, 1993c; Gulick, 1995; White et al., 1993; DesRosier, et al., 1992; Cockerill & Warren, 1990). O'Brien (1993c) found significant correlation between caregiver stress and caregiver coping behavior, suggesting that as stress in the caregiver role increases, there is an increase in the use of various forms of coping behavior, both problem focused and emotion focused. Gulick (1995) also studied the coping strategies of spouses of persons with MS in meeting the challenges of living and caring for someone with MS. Gulick concluded that meeting the increasing dependency needs of persons with MS, as well as one's own needs, requires the use of systematic and creative problem-solving strategies. These included obtaining accurate information about MS and MS-related services; open communication with the afflicted person, family and health professionals; and using assistive devices. Other coping strategies included maintaining a positive attitude, utilizing humor, religion, and thinking about the good things in life.

The women in DesRosier and Catarzano's (1992) study who were primary caretakers of their MS-disabled husbands described themselves as angry and frustrated because of the social isolation created by their caregiver responsibilities. Never having time away from the husband strained the marital relationship and threatened the supportive nature of the relationship. These women found it necessary to have personal time and space away from their husband. They coped by setting aside a place in their homes that was just for them. They also learned to declare time out for themselves.

White et al. (1993) suggested that marital or family counselling may provide help for spouses of MS persons, by providing an opportunity for them to discuss their perceived burden. Respite care was also recommended to help protect the ability of the spousal caretaker to continue the role as primary caretaker. A 1990 study by Cockerill and Warren found that caregivers of individuals with MS underutilized available respite services and felt uncomfortable with the options available to them.

Although the need for respite is clear, spousal caregivers must be informed about the options and must feel comfortable using them.

The effects of caregiving are highly personal and related to the caregivers' perceptions of the situation, their physical and mental health, and their incorporation of the partner's illness into their own lives (Corbin & Strauss, 1988). Feelings associated with caregiving are loneliness, depression, frustration, and mental exhaustion.

Hainsworth (1995) explored chronic sorrow in spouse caregivers of individuals with MS. Chronic sorrow is defined as a pervasive sadness that is permanent, periodic and progressive in nature. Chronic sorrow is not the same as depression, but is rather a normal state associated with chronic or life-threatening conditions that cause lifestyle disruption. Hainsworth found that 80% of the caregivers in the study experienced chronic sorrow.

The impact of a chronic illness such as MS can be as devastating for the spouse as it is for the afflicted person. Both must sacrifice personal goals and pleasures if the marriage is to be maintained. A healthy marriage offers security and a sense of being loved and worthwhile. This is perhaps the most important social context within which the psychological aspects of chronic illness can be managed. Rodgers and Calder (1990) examined the relationship of marital adjustment and level of disability to emotional adjustment. Findings indicated that emotional adjustment was significantly related to perceived level of marital adjustment, but no relationship was found for level of disability. Further analysis suggested that although marital adjustment was an important resource for emotional adjustment, MS can have negative effects on both marriage partners.

Research on Other Chronic Illnesses and Marital Life

A review of the literature indicates a growing interest in the relation between marriage and physical illness. A wide range of variables has been studied including psychological symptoms of spouses, stress in caregiving, death following bereavement, marital satisfaction, and the effects on marriage of specific illnesses such as cancer, chronic pain, arthritis, renal disease, coronary heart disease, and head injury/brain damage. As outlined earlier in this section, the symptoms of MS can be predominantly physical, predominantly cognitive, or a combination of both. For this reason, chronic illnesses reviewed include some physically disabling chronic illnesses as well as primarily cognitively impairing conditions such as head injury/brain damage. The chronic illnesses reviewed are those which affect the same age group as MS.

Prior studies are important because they provide data about the importance of interpersonal relationships in physical illnesses (Carter & Carter, 1994). Marriage has consistently been regarded as providing general support against illness or as a specific buffer that neutralizes stress produced by illness (Carter & Carter, 1994). However, marriage may not always be supportive and may be a source of conflict and strain, which increases stress and reduces the level of available support for both the ill and well spouse (Coyne & Bolger, 1990).

Marital adjustment has frequently been found to improve as a result of illness (Lichtman et al., 1987), which suggests that interactions can be facilitated by illness. However, this is certainly not the case in all marriages. Devitalization of the marriage may result when illness override occurs due to the worsening of the effects of the illness or treatment and the erosion of the resilience of the coping system over time (Carter & Carter, 1994). The task of interacting with and caring for the ill spouse may be so affected by the nature of the illness that preexisting interactions are outweighed and gradually replaced by newer ones, which are determined by the demand characteristics of the illness.

Many recent studies have been carried out on the effects of various chronic illnesses on marital life. Life-threatening illnesses such as cancer may precipitate marital crises in vulnerable relationships. Several researchers have attempted to identify factors that predict strain in cancer couples (Sales & Biegel, 1992; Zabora & Smith, 1991; Peteet & Greenberg, 1995). A number of recent articles addressed the effects of breast cancer on the marital relationship (Given & Given, 1992; Carter & Carter, 1993; Zahlis & Shand, 1993; Northhouse, et al., 1995). These studies indicated that breast cancer and mastectomy have strong psychological consequences not just for the wife but for the husband and for their marital relationship as well. Neither diagnosis nor treatment necessarily results in marital schism, but in many circumstances diagnosis and treatment affect seriously, and perhaps even permanently, marital interactions at a level that is psychologically very important. Researchers have found that spouses of cancer patients undergoing surgical treatment, exhibited higher levels of distress than did the cancer patients (Keitel, Zeuon, Rounds, Petrelli & Karakousis, 1990; Davis-Ali, Chesler & Chesney, 1993; and Germino, Fife & Funk, 1995). These same researchers hypothesized that spouses experienced heightened feelings of helplessness in addition to the sadness and fear experienced by many patients. Given the critical nature of support provided by a spouse, the strain on the marriage and the underlying threat of divorce or separation can create a great fear of abandonment in patients who are already facing major losses (Northhouse & Peters-Golden, 1993). Kristjanson and Ashcroft (1994) suggest that couples who have a poor relationship before a cancer diagnosis will have greater difficulty adjusting after mastectomy. Those who have an empathetic relationship, good communication, and satisfactory sexual adjustment before diagnosis will fare better.

Dar, Beach, Barden, and Cleeland (1992) studied cancer pain in the marital system. In recent years, several studies have documented the role of the marital relationship in relation to chronic pain (Kerns, Haythornthwaite, Southwick & Giller, 1990; James & Lange, 1992; Feinauer & Steele, 1992; Turk, Kerns & Rosenberg, 1992; Paulson & Altmaier, 1995). Chronic pain has been noted to have serious negative consequences on marriage. The consequences of chronic pain such as role change, financial strain, and sexual dysfunction, can lead to marital frustration and despair. However, perhaps more important, is the influence of the marital relationship on the chronic pain cycle. Several investigators have noted that although support from the spouse has been shown to be important in reducing depression in people with chronic pain, the spouse, as a primary source of social contingencies, may serve as a discriminative cue and selective reinforcer for the behavioral expression of pain (Kerns et al., 1990; Turk et al., 1992; Feinauer & Steele, 1992; Paulson & Altmaier, 1995). Thus, spousal support can influence the chronic pain patient in both beneficial and detrimental ways.

Similar results were found in a study of arthritis patients (Schiaffino & Revenson, 1995). Spousal social support was shown to increase self-esteem, life satisfaction, and coping, and lessen depressive symptoms in arthritis populations. At the same time, spouse solicitousness (exhibiting excessive concern, taking over a task) was associated with increased pain behavior, helplessness, and a greater negative impact of pain. Reich and Zautra (1995) also studied rheumatoid arthritis couples. They found that spouses tend to assume responsibilities for their ill partners' household duties soon after their illness begins. This has short-term positive benefits but over the longer term, loss of such responsibilities tends to become related to poorer adjustment. Poor psychological adjustment to rheumatoid arthritis for both partners has been consistently found to be associated with negative marital interaction (Manne & Zautra, 1990; Hawley, Wolfe, Cathey & Roberts, 1991).

Marital interaction and its effects upon psychological adjustment has recently been examined in men with coronary heart disease (Yates, 1995). The Yates study indicated that spouses were providing significantly greater quantities of emotional support and tangible aid than were health care providers, and that patients were more satisfied with spousal support. The emotional support from and satisfaction with spousal support were significantly related to fewer depressive symptoms. King et al. (1993) suggests that because the spouse is the patient's primary emotional supporter, the spouse also has a need for support. This study also found that the esteem-enhancing elements of emotional spousal support are related to positive health outcomes. Thus, the clinical assessment of the marital relationship may be important for predicting patient outcomes. There appears to be a reciprocal nature of adaptation to coronary heart disease, in that the marital relationship and satisfaction are affected by the disease and the disease adjustment is affected by the quality of the marital relationship (Rankin, 1992; Doherty & Power, 1990).

Stress on the marital relationship has also been studied in couples in which one partner is in end-stage renal disease (ESRD). Depression, anxiety, conflict, and suicidal tendencies are found in haemodialysis patients and especially their partners (Gerhardt, 1990; Brock, 1987). Flaherty and O'Brien (1992) assert that in ESRD marital dynamics change drastically and role reversal is the usual pattern. A frequent source of difficulty lies with spouses who live under the responsibility of caring for the patient, which generates much tension in the marital relationship. The dual role imposed upon the healthy spouse of a dialysis patient of taking on the role responsibilities of the sick partners while maintaining his/her own role, causes reduced rest and lowers the physical reserve (Brinker & Lichtenstein, 1981; O'Brien, 1990; Flaherty & O'Brien, 1992).

Recently, numerous articles have been written on the impact of head injury (brain damage) on marital adjustment and stability (Kravetz, Gross, Weiler, Ben-Yakar, Tadir & Stern, 1995; Hall, Karzmark, Stevens, Englander, O'Hare & Wright, 1994; Linn, Allen & Willer, 1994; Resnick, 1993; Peters, Stambrook, Moore, Zubek & Blumenschein, 1992; Kreutzer et al., 1992; Weller, Allen, Liss & Zicht, 1991; and Florian et al., 1991). Liss and Willer (1990) reviewed the literature on traumatic brain injury and marital relationships. Individuals surviving a severe traumatic brain injury (TBI) usually exhibit a range of cognitive and behavioral disabilities including attention and concentration difficulties, memory and information processing deficits, judgment and perception difficulties, and personality changes. These impediments pose numerous difficulties for the spouse. Research findings reviewed by Liss and Willer (1990) demonstrated that spouses react to TBI with feelings of depression, anxiety, isolation, loss, increased stress levels, and diminished social adjustment. Individuals who are brain damaged become more dependent on their spouses and more afraid of being abandoned (Kravetz et al., 1995). Brain damage impacts negatively upon the person with the brain damage, upon the spouse, and upon the relationship between the two individuals (Hall et al., 1994). As the gap in functioning and emotional lability of the couple widens, the feelings of estrangement and marital breakdown increase (Florian, Katz & Lahov, 1991). However, the divorce rate is not particularly high for couples in which there is brain injury. Lezak (1978) suggests that spouses cannot honorably get divorced with a clear conscience due to fond memories, feelings of responsibility, and guilt and fear of social condemnation. These same dynamics may play a role in MS couples in which the individual with MS experiences symptoms of cognitive impairment.

The abundance of literature examining the effects of various chronic illnesses on the marital relationship indicates the importance of studying the relationship between chronic illness and the marital relationship. The dearth of literature in relation to multiple sclerosis and the marital relationship reveals a need for studies such as this study on the impact of MS on the marital relationship. Previous MS studies which examined the marital dyad utilized specific scales or instruments. A more qualitative approach could provide a better understanding of the dynamics involved in the relationship of marriage and MS.

Choosing a Research Method

The strength of qualitative methodology lies in the holistic focus, which allows flexibility and the attainment of a deeper, more valid understanding of a subject than could be achieved through a more rigid approach (Carr, 1994). It allows subjects to bring up issues and topics which the researcher might not have included in a more structured research design. Duffy (1986) argues that a strength of qualitative studies is the interactive relationship between the researcher and subject. As the researcher and subject spend time together, the data are more likely to be honest and valid. A study by Baruch (1981) supports this argument. Findings revealed that time and the subsequent relationship built between the researcher and the subjects were crucial for a genuine understanding of life experience of the subjects.

However, a weakness of a qualitative approach is the possible effect of the researcher's presence on the subjects. The relationship may actually distort findings

(Carr, 1994). Researchers may have difficulty separating their own experiences from those of their subjects resulting in subjectivity (Cormack, 1991).

The reliability of qualitative research is weakened by the fact that the process is under-standardized and relies on the insights and abilities of the researcher, thus making an assessment of reliability difficult (Duffy, 1986). Qualitative research is often criticized for failing to clearly address issues of reliability and investigator bias. There is a need for a more rigorous method of analyzing qualitative research (Morse, 1989).

A qualitative approach appears to be valuable for the exploration of the subjective experiences of MS couples. However, choosing one research methodology over another narrows a researcher's perspective and deprives him or her of the benefits of building on the strengths inherent in a variety of research methodologies (Duffy, 1986). Relying solely on either a quantitative or a qualitative approach has many limitations. A suggested alternative is to combine approaches. Concept mapping is an alternative methodological approach which combines qualitative and quantitative strategies (Daughtry & Kunkel, 1993). Kunkel (1991) states that concept mapping adds objectivity to qualitative data that has typically been analyzed using nonstatistical approaches. The present study combines indepth qualitative interviews and open-ended questionnaires with the concept mapping methodology.

Concept Mapping

This section presents an overview of the concept mapping method. Concept mapping is particularly appropriate for applications in which researchers are seeking to clarify a domain, constituent elements, and the underlying structure of a phenomenon as experienced by the population of interest (Kunkel, 1991; Trochim, 1989b).

Concept mapping techniques were used in this study to examine the individual marriage partner's perception of the influence of one partner having MS.

Background

Concept mapping was first utilized for program planning and evaluation (Trochim, 1989a). However, it has been applied in the study of psychological issues (Fitzgerald & Hubert, 1987). Kunkel (1991) utilized the process of concept mapping to gain a greater understanding of the perceptual themes underlying psychological pathologies. Recent research by Daughtry and Kunkel (1993) used the concept mapping methodology approach to clarify the scope and interrelations among elements of the experience of depression in college students. Trochim, Cook and Setze (1994) utilized concept mapping of a staff's view of a supported employment program for individuals with severe mental illness. Concept mapping has been shown to be an effective technique for research in the field of counselling psychology and appears to be well suited to exploring the issues and underlying themes that couples with MS perceive to be affecting their marital relationship.

Method

Concept mapping is a structured conceptualization process which consists of three main components. First a specified group of subjects generate ideas or statements about a specific research question. Second, the interrelationships between the ideas or statements are sorted into sets containing a common theme. Finally, multivariate statistical analysis of the card sorts results are conducted to determine the underlying categories and the concepts generated are depicted in the form of a picture or map which represents the ideas of interest (Trochim, 1989b).

Concept mapping adds objectivity to the study of more qualitative types of data that have typically been analyzed using non-statistical approaches (Kunkel, 1991). The process allows the objective categorization of items along thematic lines using statistical techniques (Trochim, 1989a). The clustering of the qualitative data into themes is accomplished by the participants rather than defined by the researcher. Therefore, this methodological approach allows for a careful evaluation of the participant's perspective regarding a specific phenomenon (Daughtry & Kunkel, 1993).

A further advantage of the concept mapping method is that the data are grouped by many sorters which reduces the potential for bias and subjectivity that can be present when qualitative data are sorted and grouped by an individual researcher. Objective statistical analysis of the card sort groupings further reduces bias in that the researcher looks beyond his/her own subjective interpretation. Rosenberg and Kim (1975) stated that this method makes it unnecessary for the respondents or the researchers to specify any of the psychological dimensions that provide a basis for judgments of similarity. Underlying themes are identified from the structures obtained by scaling and clustering. Therefore, the respondents' judgments are uncontaminated by an investigator's preconceptions.

The concept mapping method results in a graphic representation which shows all of the major ideas and their interrelationships (Trochim, 1989a). It has practical utility in that it suggests statistically and visually the organized principles implicit in the sorting (Daughtry & Kunkel, 1993).

Kunkel (1991) concluded that the statistical rigor of concept mapping adds objectivity and validity to the interpretation of the experiences of participants. Therefore this approach appears to be well suited to the study of the experiences of couples in which one partner has MS.

Six specific steps are utilized in the development of concept maps (Trochim, 1989b): 1) preparation (the selection of participants and development of the focus of the study); 2) the generation of statements; 3) the structuring of statements; 4) the representation of statements in the form of a concept map; 5) the interpretation of the map; and 6) the utilization of the map.

1) Preparation

There are two prepatory steps necessary before beginning the concept mapping process: choosing who will participate and deciding on the specific focus for conceptualization (Trochim, 1989b). A decision must be made regarding who the participants will be. Concept maps have been developed using a wide variety of relevant people, small homogeneous groups, and random sampling schemes (Trochim, 1989b). Trochim (1989b) states that there is no set number of participants, and has worked with groups as large as 80 people. However, more commonly 10-20 people are involved in his investigations. Next, it is important to clearly define the focus of the study by carefully wording the research question in a clear and simple manner in order to avoid confusion (Trochim, 1989b).

2) Generation of Statements

The actual beginning of the concept mapping process is the generation of a set of statements or ideas based on the participants' perceptions about the research question. Ideally, the set of statements generated should represent the entire conceptual domain for the topic of interest. The statements can be generated through a one-question questionnaire, through interviews, or "through a brainstorming process whereby the selected group of subjects state in sentence form all their ideas and perceptions about the research question (Trochim, 1989b). The compatibility of utilizing a qualitative interview approach with concept mapping was explored by Wiener et al. (1994). These researchers concluded that interviews, besides generating the statements that are diverse and complete, also assist the researcher in learning about the context in which the mapping occurs and helps in determining the number of clusters that best summarizes the data. Interviewing also helps the researcher to label the resulting clusters and interpret the resulting themes. Combining qualitative interviewing and quantitative concept mapping provides the opportunity to gather rich qualitative data in which there is increased confidence in the results.

The statements from the participants are collected and combined. Redundant statements are removed and the remaining statements are further reviewed and reduced until all that remains is an inclusive subset of statements that capture the essence of the phenomena but retain the participants' language. Usually, a maximum of 100 statements are maintained because it has been found that more than 100 statements is extremely difficult to sort into theme groups (Trochim, 1989b).

3) Categorization of Statements

Initially, to identify interrelationships between statements, a card sorting procedure is conducted on the set of statements. Each statement is printed on a separate index card and the cards arranged in random order. The sorting participants are chosen, who may be but are not restricted to, the same individuals who participated in the generation of the statements. A complete set of statements is given to each sorter who is asked to sort the statements into groups having a common theme or idea. Sorters are told to sort the statements in a way that makes sense to them. Although there are no restrictions on the number of groups or the number of statements placed in each group (Trochim, 1989b), there are some restrictions: "each statement can only be placed in one pile; all statements cannot be placed into a single pile; and all statements cannot be put into their own pile" (Trochim, 1986b, p.5).

The sorting procedure is easy for the participants to understand and takes little time to accomplish. The unstructured sorting procedure is appropriate because a large number of items can be accommodated (Willer & Romney, 1988).

Multidimensional scaling (MDS) is performed on the card-sort data which has been collected from the sorting participants (Davidson, Richards & Rounds, 1986). The MDS suggests statistically and visually the organizational principles implicit in the sorting process. The next step is to utilize cluster analysis to identify the similar groups of sorted items (Borgen & Barnett, 1987). The item groups determined by individual sorters are thus considered in combination and common categories emerge and are identified (Miller, Wiley & Wolfe, 1986).

4) Representation of Statements

Initially, the results of the individual sorts are put into a square table or binary similarity matrix in which the values of the matrix are either zero or one. Next, individual sort matrices are combined resulting in a group similarity matrix composed of many rows and columns as there are statements. This matrix is the relational structure of the conceptual domain and provides all the information on how the statements were grouped by the participants (Trochim, 1989b).

Multidimensional scaling is the first statistical procedure carried out on the sort data in Trochim's (1989) concept mapping system. MDS techniques are applied to the similarity matrix using a nonmetric two-dimensional solution which locates each statement as a separate point on a map (the point map). Statements that are closer to each other are more likely to have been sorted together more frequently and therefore be related to the same concept. Next, the statements are grouped into clusters which represent higher order conceptual groupings of the original data set of statements. Finally, maps which overlay the averaged ratings by point or cluster are constructed (Trochim, 1989b).

5) Interpretation of Maps

Each group of statements, or themes, derived from the statistical analysis can be visually inspected and given a label which serves to describe the contents of that group. As part of this interpretation process, sorters can be asked to have input by reading through the set of statements in each cluster and coming up with a word or phrase that seems to describe the data (Trochim, 1989b). After the themes are labeled, the statements are qualitatively classified into hierarchical concepts. Novak and Gowin (1984) have found this process to be useful for some data sets.

The final result is a visual representation, or map, of the concepts developed in the analysis of the internal relationships among the sorted statements. Conceptually similar clusters are closer together on the cluster map. The final map provides an easy to understand summary of the conceptualization process (Trochim, 1989b).

6) Utilization of Maps

According to Trochim (1989b) the results of the concept mapping process can be used to plan or evaluate treatment programs and provide an understanding of the issues of interest from the participants' perspective. Each category grouping can be conceived as a measurement construct which can provide direction for future research. The concept mapping pictorial form helps people to understand and retain the essential issues more easily and can therefore be utilized for communication and educational purposes. Maps can be verified by distributing them to a number of the individuals who participated in the sorting or are familiar with the area being examined. This process helps to establish the validity of the concepts identified.

Application to Current Research

The six steps in the development of concept maps will be applied in this research as follows: 1) participants were couples in which one partner has a diagnosis of MS. The focus was on the perception of the individual partners of how MS has affected the marital relationship; 2) the perceptual statements were extracted from qualitative open-ended interviews with each marital partner and also open-ended questionnaires mailed to other MS patients and their partners; 3) the statements were sorted into themes by 14 people; 4) concept maps were generated using Trochim's (1993) Concept Mapping computer software program; 5) concept maps were interpreted; 6) the potential utility of the maps was discussed.

CHAPTER 3: METHODOLOGY

Introduction

A review of the literature related to marital relationships in MS couples revealed a need for examining the unique experiences of married individuals from their perspective. This approach complements previous studies which have focused on specific theoretically defined concepts. This study was undertaken to gain a better understanding of the individual partners' perceptions of the impact that MS has on their marital life. Specifically, the objectives were: i) to identify the issues, ii) to determine and identify the underlying themes that are specific to MS, iii) to determine the incidence of these issues among couples in which one partner has MS.

The concept mapping method was used in this study. Concept mapping is a structured conceptualization process which combines qualitative and quantitative strategies. The concept mapping process consists of three main components. First, statements are generated about specific research questions by a specific group of subjects. Second, the statements are analyzed and sorted into themes which indicate the interrelationships between the statements. The concept mapping software (Trochim, 1989) applies multivariate techniques to this information to determine the underlying categories. Finally, the concepts are depicted in the form of a picture or map which represents the sorters' conceptualization of the original statements and themes. Because the map depicts the sorters' conceptualization of the ideas, the researcher's biases in interpreting the results are minimized.

This study was conducted in three phases. Phase one involved the collection and organization of experiential data. MS couples were interviewed and the responses analyzed to extract statements representing the perceptions of the interviewees. Open-ended questionnaires were completed by several other MS couples to ensure the saturation points for reported experiences was attained. Phase two entailed the structuring of the statements into themes, illustrated by concept maps. In Phase three, an incidence study was conducted to determine to what extent the identified issues are of concern to MS couples.

Phase One: Generation of Statements

The first step in concept mapping is to generate a set of statements that represent the focus of the research question. Phase one of the study required statements from a sufficient number of patients and their partners to ensure the saturation point for reported experiences was attained. To address the research questions, couples in which one partner has a diagnosis of multiple sclerosis were interviewed. The purpose of these interviews was to ascertain how MS is perceived to influence the marital relationship. Interview transcripts were analyzed to obtain statements that represent the distinct perceptions of the participants. Open-ended questionnaires were completed by several other individual partners in relationships in which one partner had an MS diagnosis.

Participants

Volunteer participants were chosen using a nonprobability sample of convenience using a snowball technique. The researcher contacted MS couples she knew as well as MS couples who were asked to volunteer by friends and colleagues of the researcher. Several physicians provided the names and addresses of MS patients. Several of these patients and their partners completed the short open-ended questionnaire. These couples were invited to participate and were asked for the names of other couples who might be willing to volunteer. Care was taken to include representatives from a variety of age groups, MS symptoms, and levels of disabilities.

Participants completed a consent form (Appendix A) that informed them of the purpose of the study. The form stated that the interview would be audio-taped and material from the interviews would be transcribed. Participants were informed that at the conclusion of the study the tapes would be erased. Participants were assured that they could discontinue the interviewing process and have tapes erased at any time. Participants were also asked to complete a demographic questionnaire (Appendix B). Ethical approval to conduct the research was obtained from the Department of Educational Psychology Research and Ethics Committee. Verbal approval was obtained from the Alberta College of Physicians and Surgeons to contact physicians to provide names of possible research participants.

Interviews

Volunteers participated in unstructured interactive interviews in which they were asked to respond to the question: "In what ways has MS affected your marital life?" Husbands and wives were interviewed separately. Each interview was approximately one hour. Participants were given a choice of locations, either in the researcher's office or in their homes. Other open-ended questions spontaneously followed the lead responses of the interviewees. The advantages of giving the participant control over the interview situation are made clear in a project by Davis (1992) in which participants were confused by being asked to answer by selecting forced choices that did not match their situations. Probes and encouragement were occasionally used in order to obtain fuller responses. Unstructured interviews are used when the researcher knows very little about the topic and is learning about the topic as the interview progresses and as subsequent interviews ensue (Morse & Field, 1995). The important point is that participants often know better than the researcher exactly what is and what is not relevant to the topic. The purpose of interviewing is not to influence the response by preconceived categories but to access the perspective of the person being interviewed (Patton, 1990).

The use of general, open-ended questions as well as employing probing and encouragement is an appropriate method for understanding experiences in descriptive exploratory studies (Morse & Field, 1995; Patton, 1990; and Becker, 1986). Bogdon and Bilken (1982) state that the interview should resemble a conversation between two trusting friends rather than a formal survey by an authority.

Individual interviews concluded when no new topics or themes were presented. Typically, participants would begin to reiterate previously discussed material indicating that the issues had been adequately covered and that saturation had been reached. Before concluding each interview, participants were given an opportunity to introduce new information. Participants were asked if they could be contacted again if more questions arose.

With respect to the number of interviews needed, the domain was considered to be adequately sampled when fewer than three unique perceptions were identified. At this point data was considered to be redundant, and the number of interviews deemed adequate to sample the research domain. Eight individual MS patients and eight partners were interviewed.

Interview Analysis

The interviews were transcribed and analyzed to distill an inclusive subset of statements that captured the essence of the participants' perceptions about how MS has affected their marital life. Care was taken to maintain the language of the participants. The transcriber and secondary coder was asked to sign an oath of confidentiality (Appendix I).

The author consulted with two other psychologists to examine the statements to determine that they maintained the participant's language and adequately reflected the perceptions of the participants. In addition, the statements were analyzed to ensure they were credible and clearly grounded in the material from which they were reduced.

Next, the statements were scrutinized for redundancies and a list of unique statements compiled. Changes from the verbatim retention in the final list of statements were kept to a minimum. However, each item was equated for tense consistency with a procedure used by Daughtry and Kunkel (1993). All modifications made in the statements were intended to maximize the interpretability of the concept map "through equating the level of abstraction and providing parallel grammatical structure for each item." (p.318).

Open-ended Questionnaires

Open-ended questionnaires were utilized in addition to interviews to ensure that statements were obtained from a sufficient number of MS patients and partners to ensure that all areas of their experience were identified. A package was sent to all volunteer participants. Each package contained a letter explaining the nature of the study, instructions for writing out the statements about the ways that MS affected marital life (Appendix D), and a demographic information form (Appendix B). Potential participants were informed that the decision to become involved in this research was completely voluntary, and were instructed not to sign their names in order to ensure confidentiality. The covering letter informed the participants that the return of the questionnaire was viewed as consent to participate in the project.

Kidder (1981) articulated some advantages of the open-ended questionnaire method of data collection. The open-ended method avoids the creation of a mind-set for the answering participants. Participants may feel more inclined to express themselves since there is complete neutrality and anonymity. Interviewer bias is eliminated and sufficient time is permitted for respondents to consider their answers.

Eighty packages were sent out. A total of 40 patient response forms (50%) and 27 partner response forms (33.8%) were completed and returned. Once the forms were returned, descriptive statistics on the interview and questionnaire participants were computed and are summarized in Table 1.

Two master lists of patient and partner statements of the ways in which MS has impacted on their marital life were compiled. As each response form of patient's and partner statements was returned, the specific statements were compiled to formulate the patient master list and the partner master list. A total of 545 statements were generated by 40 patients (Appendix J). A total of 456 statements were generated by 27 partners (Appendix K).

Each entire statement list was edited to remove any specific allusions to persons, gender or positions, to correct errors in grammar and spelling, to eliminate statements not related to the research question or that seemed ambiguous or vague, and to split up phrases which had more than one response. Care was taken to retain

Table 1 Characteristics of Interview and Short Questionnaire Participants

MS Patients

Variable	**Mean**	**Range**
Age	45.21 years	23-72 years
Years Married	18.65 years	1-51 years
Years since MS diagnosis	11.52 years	0.3-36 years
Age at onset of MS	31.54 years	14-60
Variable	**Options**	**Percent**
Gender	Male	31.6%
	Female	68.4%
Employment status	Outside home	20.6%
	Homebound employment	17.6%
	Homemaker	44.1%
	Student/trainee	2.9%
	Other	14.6%
Disease Course	Chronic Progressive	64.5%
	Remitting/Relapsing	29.0%
	Benign	6.4%
Symptoms	Physical	23.6%
	Emotional	7.9%
	Cognitive	10.5%
	Physical and Emotional	18.4%
	Physical and Cognitive	5.3%
	Physical/Emotional/Cognitive	31.6%
Level of Education	Grade School	7.9%
	Some High School	13.2%
	High School	18.4%
	Business/Technical School	18.4%
	Some college	18.5%
	College degree	28.9%
	Some grad/professional school	5.3%
	Graduate School	7.9%

Partners

Variable	**Mean**	**Range**
Age	44.77 years	23-64
Years Married	19.10 years	1-51
Variable	**Options**	**Percent**
Gender	Male	65.4%
	Female	34.6%
Employment Status	Outside home	72%
	Homebound employment	12%
	Homemaker	4%

Table 1 (continued)

Variable	Options	Percent
	Other	12%
Level of Education	High School	26.9%
	Business/technical school	30.8%
	Some college	7.7%
	College degree	26.9%
	Some grad/professional school	3.8%
	Graduate school	3.8%

the essential meaning of the statement. This editing process was to ensure that the statements were clear, concise, and singular in focus.

The second edit of the patient and partner lists was to remove redundant statements. The listing of statements by the second participant was reviewed and compared to the statement list of the first participant. Any new statements were added to the new master list. Any duplicated statements were eliminated. This process was repeated with each person's statement list until redundancy or saturation was reached. Redundancy or saturation was judged to be reached when no new statements were presented by three consecutive participants. Patients' reported statements were judged to be redundant after the 22nd participant (Appendix L) and the final list of 97 patient statements was considered complete. Partners' reported statements were judged to be redundant after the 25th participant and the list of partners' statements was considered complete (Appendix M). The final listing of partner statements contained 98 statements.

The master lists of statements contained items from both male and female participants. Comparisons of the statements found no gender differences. The final lists of patient and partner statements were each randomly numbered to ensure confidentiality.

To ensure the validity of the editing process, the original master lists and the first and second edited lists were evaluated by two chartered psychologists. They were instructed to see if the final lists captured the essence of the original statements and to ensure that the statements were not gender biased. They also verified that deleted statements duplicated earlier responses in the statement set. Recommended changes were considered and incorporated when deemed appropriate.

Phase Two: Structuring of Statements

Following the compilation of the list of statements encompassing the perceptions of the impact of MS on marital life, the second research question was addressed. The first objective of Phase two was to sort the statements into distinct categories. The sorting task was completed by 14 psychologists. Trochim (1989b) has noted that it is not necessary to have the same participants involved in each phase of the procedure.

The second objective of Phase two was to analyze the thematic groupings to develop a concept map of the categories. A detailed outline of the sorting procedures is provided in this section.

Sorting

To prepare the data set for the concept mapping procedure, the volunteer sorters were asked to sort the statements generated from the interviews and open-ended questionnaires into theme groups. Each of the statements was placed on a sheet of paper. The two complete sets of statements were given to each volunteer with a cover letter and instructions to sort the statements into groups which contain common themes (see Appendixes E and F). The sorters were instructed to use their own judgment to determine whether the statements fell into themes based on similarity of content and meaning and to group the statements into themes.

A cover letter was used to inform the sorters about the purpose and nature of the research and stated that the return of the sorts would be viewed as consent to participate. They were told that they could withdraw their participation at any time. The sorters were instructed to make as many groups as they wished and that statements could be kept separate if they did not seem to fit into any group. In addition, the volunteer sorters were instructed that statements could not all be placed in individual piles of one item each, or one pile containing all the items. Sorters were told that if they chose to, they could assign a name to each group.

The sorters were informed that the task would require approximately 45 minutes to complete. To ensure anonymity, the sorters were asked not to sign their names.

Data Analysis and Mapping of Concepts

The data analysis was based on the general procedure outlined by Trochim (1989b) and utilized most recently by Trochim, Cook, and Setze (1994). Trochim's (1993) Concept Mapping computer software program was used to accomplish the concept mapping procedure.

First, individual matrices (binary symmetric similarity matrices) were computed for each of the sorted items based on groupings compiled by each sorter. Second, the results from all sorters were combined to obtain a group similarities matrix. A two-dimensional nonmetric multidimensional scaling (MDS) procedure was conducted with the data from the group similarity matrix. This procedure resulted in the creation of a point map representing an X-Y coordinate for each statement, so that the distance between points reflected the frequency of items sorted together. Discussions on this statistical technique (e.g., Coxon, 1982; Fitzgerald & Hubert, 1987; Kruskel & Wish, 1978; Schiffman, Reynolds, & Young, 1981) have supported the suitability of MDS for spatially representing latent relations among variables, especially when these relationships are unknown.

For the two-dimensional solution of the MDS analysis a final stress value was computed. The stress value is an index of the stability of the MDS solution. According to Daughtry and Kunkel (1993) the numerical index ranges from zero (perfectly stable) to one (perfectly unstable). The stress index indicates the degree of departure of the observed or calculated similarity from the true or judged similarity among items taken two at a time. A two-dimensional MDS solution is more consistent with the concept mapping approach than one involving three or more dimensions. This MDS configuration is the basis on which to display the clustering results (Kruskel & Wish, 1978).

The data obtained from the MDS similarity matrix was subjected to a hierarchical cluster analysis to group sorted items into internally consistent clusters (Borgen & Barnett, 1987; Everitt, 1980). In this process, the cluster solution was superimposed on the MDS point map which partitioned the MDS map into any number of clusters. No simple mathematical criterion can determine the number of clusters which should be selected. The number of clusters was determined by the researcher with the goal of maintaining the integrity of the MDS results through the absence of overlapping clusters (Trochim, Cook & Setze, 1994). The procedure followed here was to examine an initial cluster solution that averaged about five statements in each cluster. Then successively lower and higher cluster solutions were explored. This resulted in acceptance of a cluster solution that preserved the most detail and yielded substatively interpretable clusters of both patient and partner statements. When this analysis was completed, a point and cluster map was created (Trochim, 1989b). Finally, the researcher designated appropriate sematic labels for each cluster. These "point maps" illustrated the location of all the statements with statements closer to each other expected to be more similar in meaning. Cluster maps were also created that displayed the statement points enclosed by boundaries to form clusters.

Phase Three: The Incidence Study

The objective for Phase three of this study was to determine the extent to which statements generated in the first two phases are relevant among couples in which one partner has MS. To answer this question, the statements identified in Phase one of the study were incorporated into two surveys which were sent to a sample of couples in which one person has MS. The next section presents a description of the sample, the survey, and the procedure that was followed to collect the incidence data.

Sample

The survey was sent to a sample of MS patients whose names were obtained from a number of physicians (one neurologist) in the Edmonton area. Surveys were also sent to volunteers who were contacted through TV and local newspaper advertisements. Many participants from Phase one of the study also agreed to participate in Phase two. Two MS support groups in the Washington, D.C. area recruited volunteers to participate in the survey phase. Both partners were not required to respond. Common law couples were included and divorced individuals who had previously lived in a relationship in which one partner had MS were also invited to respond. Two surveys were sent to each address so that partners could respond independently. A demographic questionnaire accompanied each survey (Appendix B).

A total of 170 pairs of surveys were sent out in Alberta, British Columbia and the Washington, D.C. area. A response time of 10 weeks was allowed. A total of 84 patient surveys and 71 partner surveys were returned within the response period, which represents a return rate of 49.4% for patients and 41.8% for partners.

Descriptive statistics on the survey participants were computed and are summarized in Table 2. These demographic characteristics indicated that respondents represented a wide sample of MS couples.

Description of the Sample

The average age of MS patients completing the survey was approximately 45 years with a range of 28 to 74 years. The partners ranged from 24 to 74 years, with an average age of 46 years. The average number of years living with the present partner was 19 years for both patients and partners with a range of 1 to 55 years. For both patients and partners, the average number of years of formal education was 13 with a range of 8 to 27 years. The average number of years since diagnosis was approximately 10 with a range of .3 to 42 years.

The sample was somewhat skewed toward female patients and male partners which is characteristic of MS, as it differentially affects females at a ratio of 2 to 1. The sample for patients was 71.4% female and 28.6% male. Sixty-four percent of partner respondents were male and thirty-six percent were female.

Table 2 Characteristics of the Incidence Survey Participants

MS Patients (n=84)

Variable	**Mean**	**Range**
Age	45.65 years	28-74
Years with present partner	19.48 years	1-55
Years since MS diagnosis	10.46 years	0.3-42 years
Years of formal education	13.64 years	8-27 years
Marital satisfaction	4.15	1-5
Variable	**Options**	**Percent**
Gender	Male	28.6%
	Female	71.4%
Marital Status	Married	80.7%
	Separated/Divorced	15.7%
	Other	3.6%
Disease Course	Chronic progressive	51.4%
	Remitting relapsing	36.1%
	Benign	8.3%
	Unknown	4.2%
MS Symptoms	Physical	23.8%
	Cognitive	1.2%
	Physical and emotional	17.9%
	Physical and cognitive	17.9%
	Emotional and cognitive	3.6%
	Physical/emotional/cognitive	35.7%
Employed outside the home?	yes	35.9%
	no	65.1%

Partners (n=71)

Variable	**Mean**	**Range**
Age	46.11 years	24-74 years
Years with present partner	19.43 years	1-55 years
Years of formal education	13.23 years	8-27
Marital satisfaction	4.18	1-5
Variable	**Options**	**Percent**
Gender	Male	64.3%
	Female	35.7%
Marital Status	Married	90%
	Separated/Divorced	2.9%
	Other	7.1%
Employed outside the home?	Yes	71.4%
	No	28.6%

Measures

A two-part questionnaire was developed to obtain the incidence data.

Part one: This section consisted of demographic questions (Appendix B) (e.g., gender, age, marital status, employment status, and socio-economic status) and MS-specific questions (e.g., years since diagnosis, age at onset, disease course, and prominent symptoms).

Part two: Part two of the questionnaire consisted of the statements derived from the interview transcripts and from the open-ended questionnaires. This instrument was designed to assess the issues that evolved from Phases one and two of the study. Each item consisted of a statement related to the effect of MS on marital life. Respondents were asked to rate how much, if any, the statement is representative of their own experience. A six-point scale was used ranging from "not at all" to a "very much", and a "not applicable" category.

Procedure

The questionnaires were mailed to the sample described previously. A cover letter was included informing prospective participants about the purpose and nature of the research, and information about what was required of respondents. Return of the questionnaire was viewed as consent to participate in the research (Appendix G). It was noted that participation could be withdrawn at any time and confidentiality would be ensured. Participants were asked not to sign their name. Respondents were instructed to return the questionnaire by returning it in the postage paid return envelope. Individuals were instructed to complete the questionnaire independently of their partner and to return the questionnaires in the separate envelopes provided. (See rating instructions for questionnaire in Appendix H).

Data Analysis

Basic descriptive statistics were examined for the demographic variables and MS-related variables found in Part one of the questionnaire. For Part two, an item by item frequency count was completed in order to determine the extent to which the statements about the impact of MS on marital life are experienced by the survey respondents. In addition, group comparisons were conducted based on the demographic variables in Part one. T-tests were completed to determine any significant differences between the respondents in these groupings.

CHAPTER 4: RESULTS

In this study, concept mapping was used to gain an understanding of the impact of multiple sclerosis on marital life of MS patients and their partners. The purpose was to obtain a description of how each individual marital partner perceives that MS impacts on the marriage. Participants' collaboration was sought to clarify the organization and salience of the various elements of their experiences, rather than adhere to conceptually or diagnostically based a priori formulations. In this way investigator bias was minimized. The aims of this research were to 1) identify the issues, 2) determine and identify underlying themes specific to MS patients and their partners, 3) determine the incidence of the issues among couples in which one partner has MS. The research was designed in three phases to answer these research questions.

Phase One

In Phase one statements were derived from interview transcripts of 16 people, 8 MS patients and their partners. In addition, patients (n=40) and partners (n=27) were asked to generate statements using the open-ended prompt "In what ways has MS impacted on your marital life?" This process generated 545 patient statements and 456 partner statements. Each master list was edited to remove redundant, irrelevant or ambiguous statements. The reported perceptions of patients were judged to be redundant after the 22nd participant. Partners' perceptions were judged to be redundant after the 25th respondent. The resulting master lists consisted of 97 statements for patients and 98 statements for partners. These lists of statements are presented in Tables 3 and 4 respectively. These statements were used for the concept mapping process in Phase two of the study to determine if the perceived experiences identified by the participants fell into underlying themes.

Phase Two

The conceptual sorting process commenced with a sorting task in which the 97 patient statements were sorted by 14 psychologists who are associates of the researcher. The same 14 people sorted the 98 partner statements. The multidimensional scaling analysis (MDS) and hierarchical cluster analysis were conducted on the sorted similarity data. Two-dimensional concept maps were constructed to graphically display the patients' and partners' statements.

The two-dimensional solution of the MDS analysis indicated a final stress value of .31 for MS patients and .29 for partners. These stress values indicate reasonably stable solutions. Daughtry and Kunkel (1993), in a study looking at the experience of depression in college students, obtained a stress value of .27. In a study examining staff views of a program of supported employment for individuals with severe mental illness, Trochim, Cook, and Setze (1994) accepted a final stress value of .31 for a two-dimensional solution of the MDS analysis.

The point map (two-dimensional configuration) of the 97 patient statements is presented in Figure 1, while the 98 partner statements are displayed in Figure 2. Since the concept mapping way of presenting data may be unfamiliar to many, a detailed explanation follows. Each statement is represented by a dot or "point" with the number beside identifying the statement. The MDS solution determines the placement of points which spatially represents a matrix of proximities, judged to be similar or dissimilar among the items (Kruskel, 1981). The distance between the points reflects

Table 3

<u>Final Master List of Patient Statements</u>

1. We are closer because of MS
2. We stay home a lot.
3. We have more conflict in our marriage due to MS.
4. More sharing of the running of the household.
5. More sharing of the raising of children.
6. I don't have the energy to do some things.
7. When we go on holidays we tend to just rest and relax.
8. My partner is worried that I'll embarrass him/her.
9. The uncertainty of MS causes a lot of stress and anxiety in our lives.
10. I'm more conscious of trying to make the best of things now.
11. We make a conscious effort to find things we can still share.
12. We enjoy closeness without a sexual relationship.
13. My partner couldn't come to terms with living with an invalid.
14. We decided not to have children because of MS.
15. I didn't tell people I had MS.
16. Thinking and memory problems have been the most difficult to deal with.
17. I've tried to stay looking and seeming as normal as possible.
18. I don't want to be a burden on anyone.
19. When I think of a way out I think of suicide.
20. I feel guilty about having MS.
21. Because MS is unpredictable I worry about the future.
22. It's important not to dwell on your MS.
23. I'm frustrated to be continually losing something.
24. I worry about becoming totally dependent on my partner.
25. Living with MS is a learning process for both of us.
26. We no longer argue the way we used to.
27. I had to give up a lot of my previous types of recreation.
28. Lack of a sexual relationship has been a major loss.
29. It's difficult to keep the marital relationship and caretaker relationship separate.
30. I'm resentful that my partner has more control.
31. I worry that I'm hanging on to the relationship because of the caregiving.
32. I want a better future for my partner.
33. Finances are more of an issue because of MS.
34. With MS what you were to each other is changed.
35. I needed my partner to say we'll manage.
36. We never talked about the MS.
37. My partner withdrew from me.
38. I was afraid that I could lose my family.

Table 3 (continued)

39. My partner didn't cope well.
40. I have a lot of anger at the disease.
41. I didn't want to anger my partner because I needed a lot of help.
42. I felt that I had none of my roles left.
43. MS causes financial burden.
44. I feel emotionally alone.
45. Our sexual relationship was strained.
46. Physically I was able to have a sexual relationship.
47. I tried to keep my kids and family normal.
48. I rely on other people.
49. The marriage relationship has become less and less.
50. If my partner had taken the caretaker role I wouldn't be as capable as I am.
51. We might be together now only because I an financially dependent.
52. I feel devalued because of the MS.
53. I feel unequal to my partner.
54. MS affected the relationship because it affected me so much.
55. My partner worries about me.
56. I covered up to the extent that my partner didn't think anything was wrong.
57. We bought a bungalow, one floor plan.
58. My partner is supportive.
59. Adjustments have to be made sexually.
60. For me spirituality/religion is an anchor.
61. I am careful with my partner because I need the security of the relationship.
62. I feel like I've let my partner down.
63. I think my partner protects me by not telling me how he/she feels.
64. We spend a lot of time apart.
65. I'm more dependent on my partner.
66. MS stops me traveling to the extent that my partner wants to.
67. We don't make plans for the future.
68. My partner has his/her own friends.
69. I have to be flexible in planning ahead.
70. We take every day one at a time.
71. I turned myself over to God.
72. I have to live a very controlled lifestyle.
73. My partner had to be the sole breadwinner.
74. It's difficult to have time to myself.
75. I have trouble keeping my spirits up.
76. Often arguments over activity.
77. Spouse gets impatient over dull life.
78. Made us focus on priorities.
79. MS has enabled me to spend more time with my partner.
80. Forced us to work on our communication skills.

Table 3 (continued)

81. My unpredictable mood swings cause undue stress.
82. Has made me appreciate my partner more.
83. Requires different positions when making love.
84. Reduced amount and quality of our sex life.
85. Has reduced my feelings of desirability and attractiveness.
86. Has eliminated spontaneity in our lives.
87. Many of our long terms goals are unattainable.
88. It is impossible to continue with most activities, hobbies we previously enjoyed together.
89. Increased anxiety that I should lose my partner through separation or death.
90. My partner works all day then comes home and works too.
91. I feel my partner stays under obligation.
92. Spouse runs away from the problem.
93. Spouse does not understand what I'm going through.
94. MS has shown me that our marriage is not as secure as I thought it was.
95. Previous problems are just magnified now.
96. I am disappointed that my partner has not been as supportive as I thought he/she would be.
97. Our marital troubles cause me stress which I believe has worsened my MS.

Table 4

Final Master List of Partner Statements

1. We have to plan our days, our weeks ahead of time.
2. I have to do all the driving for the children.
3. I feel like everybody depends on me.
4. In a sense I have lost my spouse.
5. I feel MS has contributed to my own illness.
6. MS changed my outlook on life.
7. I'm frustrated by the uncertainty of not knowing what will be ahead.
8. We had to adapt the house to accommodate the wheelchair.
9. There were a lot of added expenses.
10. The physical and emotional needs of the ill spouse come first.
11. I miss some of the activities we used to do together.
12. I needed a support group to help understand my feelings.
13. It was no longer the two of us raising the family.
14. I feel like I have to do everything.
15. It's made us much more aware of having a healthier lifestyle.
16. MS has made us closer in our relationship.
17. We understand each other better.
18. Fatigue plays a big role in our lives.
19. We take time for ourselves independently.
20. We try to maintain a positive attitude towards life.
21. Much of the household responsibilities are on my shoulders.
22. The shock of diagnosis strained the relationship.
23. My partner really needs me.
24. Caregiving creates a lot of stress.
25. We're more careful in expressing our feelings.
26. We no longer fight the way we used to.
27. Caring for my partner has given me a sense of fulfillment.
28. We no longer feel like equals.
29. The pace of our life has slowed down.
30. MS makes it difficult to plan for the future.
31. We find ways to adapt so we can still do some things we enjoy.
32. At times I feel very begrudging for the things I'm doing for my partner.
33. I feel hurt and resentful we longer have a sexual relationship.
34. We're aware of the preciousness of what we have.
35. We've learned about each other's strengths and weaknesses.
36. Conversation seems to be centered on the needs of the person with MS.
37. The most impactful part of MS has been the emotional.

Table 4 (continued)

38. I'm constantly driven crazy by the unpredictability.
39. The person that I'd married no longer existed in many ways.
40. It takes an incredible amount of emotional awareness and energy to cope.
41. It's difficult to cope with all the expectations placed on me.
42. I find I need space away from my partner.
43. We can no longer do a lot of the things we used to do.
44. I feel I always need to evaluate how my partner is feeling before I talk to him/her.
45. We don't make decisions together any more.
46. I think of myself as a back-up to do whatever my partner cannot do.
47. I believe it's important to allow my partner dignity.
48. I have to screen out what is illness related from what is personality related.
49. I often feel guilty because my partner is ill.
50. With MS I cannot look at my partner and assume he or she is fine.
51. It's very stressful dealing with a chronic illness.
52. We no longer have a sexual relationship.
53. Evening social events are a thing of the past.
54. I have been able to put my own fear into perspective more.
55. My strong faith is a resource.
56. I try not to burden my partner.
57. I can't be straight forward in my feelings.
58. I don't share with people what I'm going through.
59. I no longer have somebody to talk things over with.
60. Our sexual life was greatly affected.
61. I had to take over handling all the finances.
62. I feel it is my duty to take care of things.
63. We have to live near appropriate doctors and hospitals.
64. Days are often long and boring.
65. Reduced companionship.
66. Spouse's thinking and memory problems cause poor communications.
67. Reduced greatly my free time to do many little things.
68. More sharing of responsibilities.
69. I had to learn to live more day by day.
70. I am constantly concerned about my partner's health.
71. I didn't tell people so there was a lot of covering up.
72. I feel depressed a lot of the time.
73. I feel I have to be stronger and more independent.
74. I fear my partner being totally dependent on me.
75. I feel insecure about the future.
76. There was a shattering of our dreams for the future.

Table 4 (continued)

77. I withdrew from people.
78. I feared that my partner would no longer be able to work.
79. Financially it's been difficult.
80. I'm impressed with how my spouse has coped with the disease.
81. One area of conflict is I try to do too much for my partner.
82. I get angry and annoyed about having to live with MS.
83. We have had to make some decisions we wouldn't have made without the MS.
84. Purchased new house that was an open floor plan.
85. Entertaining much less because my partner gets too tired.
86. We've refocused on priorities in life like health, friends, and family.
87. I'm more supportive of my spouse.
88. Made us more aware of other people's problems.
89. Keep a quiet home for rest periods.
90. I have to do many activities on my own.
91. Roles have changed.
92. Traveling more difficult.
93. We spend more time together.
94. It shattered our dreams about having children.
95. We've had to plan financially more for the future.
96. Time together is in sedentary activities.
97. Stressful relationship because of constant and unpredictable change.
98. Embarrassed about my partner's behavior around other people.

the frequency with which the items were sorted together. Thus, points relatively close together on the maps represent items often placed together in the sorts.

Several pairs of statements fell virtually in the same place on the maps. The premises underlying the analysis assume that these items should be located in proximity of each other. For example, on the patient map (see Figure 1) statements #37 (My partner withdrew from me) and #92 (Spouse runs away from the problem) are located close together, as expected given their conceptual similarity. Statement #95 (We've had to plan financially more for the future) on the far left side of the partner map (see Figure 2) lacks conceptual similarity to statement #56 (I try not to burden my partner) on the far right side of the partner map.

A hierarchical cluster analysis with Wards (1963) algorithm was conducted on the MDS solution as a basis for defining the conceptual domain of both the MS patients' and partners' perceptions of how MS has impacted on their marital life. Ward's algorithm is a minimum variance clustering technique which according to Trochim (1989b) generally gives more sensible and interpretable solutions than other approaches.

An important task at this stage of the research was to determine how many clusters the statements should be grouped into for the final solution. The partitioning of statements can produce any number of clusters. There is no simple mathematical criterion for selecting the number of clusters for the final result. Discretion must be used in examining different cluster solutions to prevent fragmentation or over generalization of the statements. The goal was to arrive at a true partitioning of the space, where there are no overlapping clusters (Trochim, Cook & Setze, 1994). Trochim (1989b) recommended a procedure in which numerous cluster solutions are analyzed in sequence in order to determine what grouping made sense for the

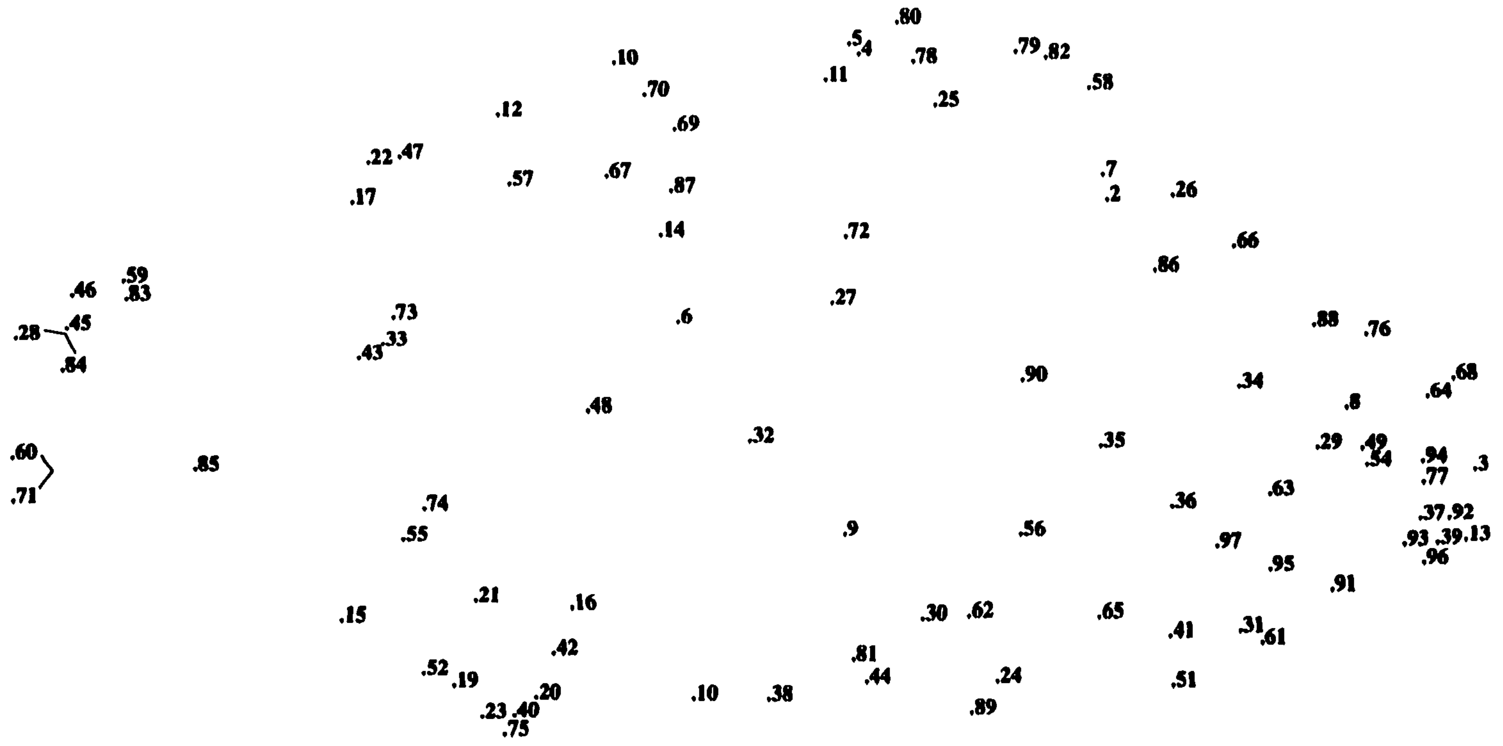

Figure 1. Point map of 97 patient statements.

Figure 2. Point map of 98 partner statements.

statements in the conceptualization. Interpretation of the results of the concept mapping analysis followed a structured process. First the initial 19-solution cluster map for MS patients was examined along with 14 and successively lower (13,12,11,10,9,8,7,6) cluster solutions to arrive at a final cluster solution. Second, the initial 19-cluster maps for partners was evaluated with successively lower (14,13,12,11,10,9,8,7,6) cluster solutions to determine a final partner map. At each level a judgment was made about whether the split or merger seemed substantively reasonable.

The computer program also computed a "bridging index" which assists the researcher in determining the number of clusters and the subsequent cluster naming procedure (Trochim, 1993). A bridging index (which ranges from 0.0 to 1.0) was calculated for each statement. Lower values represented statements often sorted together and higher values represent statements frequently sorted with items further away on the map A higher value suggests that the item is a "bridge" or linking item having been sorted with various statements on the map. A lower bridging index denotes statements more central for the meaning of the cluster (Trochim, 1993).

In addition, the computer program also produced an average bridging index for each cluster. Statements were judged to be more coherent if the cluster had a low bridging index. Clusters with a high bridging index are typically "linking" clusters between adjacent clusters (Trochim, 1993). The appropriate number of clusters, for both the MS patient and partner maps, were determined after careful consideration of cluster solutions ranging from 19 to 6. A detailed discussion of this process follows along with descriptions of each cluster of the final maps. Please note that no attempt was made to compare MS patient and partner statements or their possible interrelationships. Each set of statements was regarded as a separate data set.

The Patient Concept Map

The computer program was set to initially produce a cluster solution that was one-fifth of the total number of statements. This resulted in an initial cluster solution of 19 clusters. It was immediately apparent that the 19-cluster solution as well as the 14-cluster solution were too discrete. The clusters contained too few items and appeared to overlap conceptually. Therefore, further reduction of the cluster solutions was considered appropriate.

Next, the 6-cluster solution was examined. These clusters appeared to be too general and contained more than one theme. For example, cluster #3 included sexual issues, financial constraints, and the role of spirituality. This solution was rejected in favor of a more sensible and interpretable partition of the multidimensional space. It was now evident that the final cluster solution was between 7 and 13 clusters.

Successive cluster solutions were examined and cross-referenced to determine the most appropriate number of clusters. The seven cluster solution improved upon the 6-cluster solution in that personal emotional reactions (cluster 6) were now separated from fears about the future (cluster 7). The cluster bridging index for each (.30 and .26, respectively) remained close to what it was when they were grouped together (.28).

The 8-cluster solution separated a large cluster into two themes pertaining to perceived personal losses and change in lifestyle. The 9-cluster solution separated out the themes of negative impact on the marital relationship from insecurity about the relationship. At this point most of the clusters were conceptually coherent. The exception was cluster #3 which included sexual issues, financial constraints and spiritual issues. The 10-cluster solution separated out the sexual issues from the financial/spiritual issues. The final splitting of this cluster resulted in an 11 cluster solution which separated financial and spiritual issues. Further increases in the cluster solution failed to improve the structure of the configuration. Consequently, further analysis was deemed unnecessary and it was concluded that the 11-cluster solution provided the most useful and concise description of the patient data set. The 11-cluster solution concept map for patients is displayed in Figure 3.

Description of the Patient Cluster Map

Description of the concept map and each cluster includes informed conjecture about how participants sorted the items. Labeling the clusters was somewhat subjective but was guided by the following procedure. Items in each cluster with the lowest bridging indexes were deemed to be most indicative of the thematic content of the cluster. Subsequent items were considered to be more central or less central to the theme (according to the respective bridging indexes). Clusters were named according to the reflected content of the central items as much as possible. In order to reduce the subjective bias in the labeling process, labels provided by the sorters were examined and an attempt was made to utilize actual words found in the central statements.

The upper portion of the map (clusters 1 and 2) seemed to be related to positive changes in the relationship as well as coping and adaptation to MS. The middle clusters (3,4,5,6, and 7) are related to perceived losses and changes in lifestyle. The clusters at the bottom of the map (8,9,10,11) related to the more negative emotional reactions and negative impact of MS on the relationship. The left side of the map (clusters 2,3,4,5, and 10) appeared to be related to the personal impact that MS had on the individual while the right side seemed more related to the impact on the

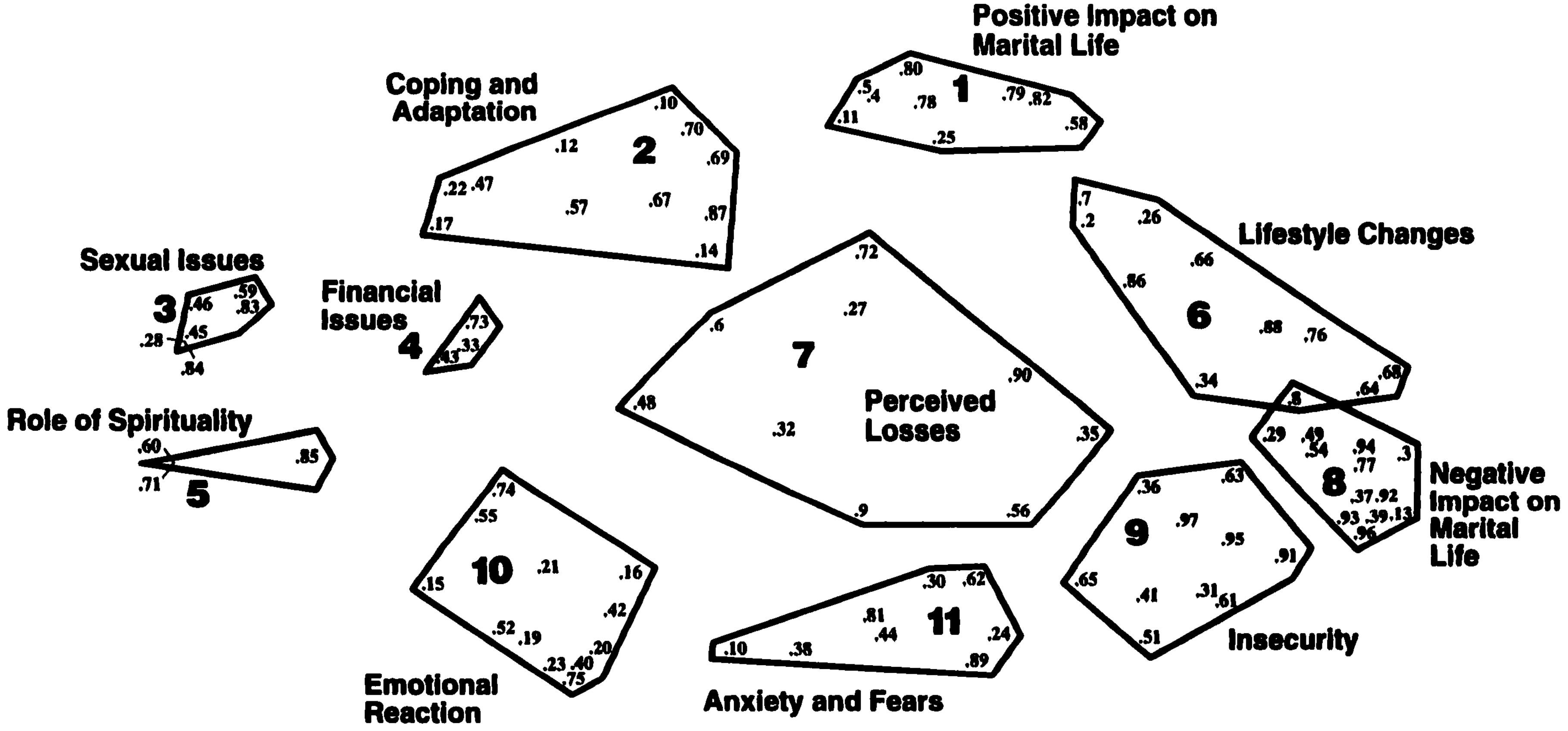

Figure 3. Eleven solution cluster map of 97 patient statements.

marital relationship. Cluster #7 "Perceived Losses" was positioned centrally on the concept map. Perceived Losses can be seen to relate to the other clusters and may serve as a central cluster around which the others revolve. The items of each cluster in the 11-solution patient concept map, along with their accompanying bridging indexes and labels are displayed in Table 5. A detailed interpretation of each cluster of the patient map and their interrelationships follows.

Cluster #1 - Positive Impact on Marital Life

Cluster #1, located at the top of the concept map, contained items related to positive influences that MS was perceived to have on the marital relationship. Some statements were quite general such as, "We are closer because of MS" (#1). Some statements focused on specific areas such as, "More sharing of the running of the household" (#4), and "More sharing of the raising of children" (#5). Part of this theme focused on an appreciation of the partner evidenced by statements such as, "My partner is supportive" (#58), "Has made me appreciate my partner more" (#82), and "MS has enabled me to spend more time with my partner" (#79).

Other statements included in this category emphasized perceived changes imposed by MS such as, "Forced us to work on our communication skill" (#80), "Living with MS is a learning process for both of us" (#25), "Made us focus on priorities"(#72), and "We make a conscious effort to find things we can still share" (#11).

Cluster #2 - Coping and Adaptation

Cluster #2 which is adjacent to cluster #1, focused on coping, adapting, and planning for the future. The majority of statements in this cluster pertained to the

Table 5

Cluster Items and Bridging Indexes for the Eleven Solution Concept Map of Multiple Sclerosis Patients

Statements	**Bridging Index**
Cluster #1 - Positive Impact on Marital Life	
1. We are closer because of MS	0.04
4. More sharing of the running of the household.	0.05
78. Made us focus on priorities.	0.05
80. Forced us to work on our communication skills.	0.05
5. More sharing of the raising of children.	0.06
79. MS has enabled me to spend more time with my partner.	0.07
82. Has made me appreciate my partner more.	0.12
25. Living with MS is a learning process for both of us.	0.13
11. We make a conscious effort to find things we can still share.	0.14
58. My partner is supportive.	0.37
Cluster average	0.11
Cluster #2 - Coping and Adaptation	
70. We take every day one at a time.	0.15
69. I have to be flexible in planning ahead.	0.16
87. Many of our long terms goals are unattainable.	0.17
14. We decided not to have children because of MS.	0.21
67. We don't make plans for the future.	0.21
10. I'm more conscious of trying to make the best of things now.	0.22
57. We bought a bungalow, one floor plan.	0.31
12. We enjoy closeness without a sexual relationship.	0.38
22. It's important not to dwell on your MS.	0.40
17. I've tried to stay looking and seeming as normal as possible.	0.44
47. I tried to keep my kids and family normal.	0.44
Cluster average	0.28
Cluster #3 - Sexual Issues	
46. Physically I was able to have a sexual relationship.	0.00
28. Lack of a sexual relationship has been a major loss.	0.04
45. Our sexual relationship was strained.	0.04
84. Reduced amount and quality of our sex life.	0.04
59. Adjustments have to be made sexually.	0.17
83. Requires different positions when making love.	0.17
Cluster average	0.07

Table 5 (continued)

Cluster #4 - Financial Issues	
33. Finances are more of an issue because of MS.	0.39
43. MS causes financial burden.	0.39
73. My partner had to be the sole breadwinner.	0.45
Cluster average	0.41
Cluster #5 - Role of Spirituality	
60. For me spirituality/religion is an anchor.	0.41
71. I turned myself over to God.	0.41
85. Has reduced my feelings of desirability and attractiveness.	0.46
Cluster average	0.43
Cluster #6 - Lifestyle Changes	
2. We stay home a lot.	0.20
7. When we go on holidays we tend to just rest and relax.	0.21
64. We spend a lot of time apart.	0.22
86. Has eliminated spontaneity in our lives.	0.26
66. MS stops me traveling to the extent that my partner wants to.	0.28
76. Often arguments over activity.	0.28
68. My partner has his/her own friends.	0.29
88. It is impossible to continue with most activities, hobbies we previously enjoyed together.	0.30
34. With MS what you were to each other is changed.	0.33
26. We no longer argue the way we used to.	0.43
50. If my partner had taken the caretaker role I wouldn't be as capable as I am.	0.46
Cluster average	0.30
Cluster #7 - Perceived Losses	
72. I have to live a very controlled lifestyle.	0.28
27. I had to give up a lot of my previous types of recreation.	0.31
35. I needed my partner to say we'll manage.	0.32
56. I covered up to the extent that my partner didn't think anything was wrong.	0.34
9. The uncertainty of MS causes a lot of stress and anxiety in our lives.	0.36
90. My partner works all day then comes home and works too.	0.40
6. I don't have the energy to do some things.	0.42
32. I want a better future for my partner.	0.47
48. I rely on other people.	0.56
Cluster average	0.38

Table 5 (continued)

Cluster #8 - Negative Impact on Marital Life	
93. Spouse does not understand what I'm going through.	0.04
13. My partner couldn't come to terms with living with an invalid.	0.06
92. Spouse runs away from the problem.	0.06
96. I am disappointed that my partner has not been as supportive as I thought he/she would be.	0.06
37. My partner withdrew from me.	0.09
77. Spouse gets impatient over dull life.	0.10
39. My partner didn't cope well.	0.12
3. We have more conflict in our marriage due to MS.	0.14
94. MS has shown me that our marriage is not as secure as I thought it was.	0.14
49. The marriage relationship has become less and less.	0.18
54. MS affected the relationship because it affected me so much.	0.18
8. My partner is worried that I'll embarrass him/her.	0.20
29. It's difficult to keep the marital relationship and caretaker relationship separate.	0.23
Cluster average	0.12
Cluster #9 - Insecurity	
91. I feel my partner stays under obligation.	0.11
31. I worry that I'm hanging on to the relationship because of the caregiving.	0.13
61. I am careful with my partner because I need the security of the relationship.	0.13
41. I didn't want to anger my partner because I needed a lot of help.	0.18
95. Previous problems are just magnified now.	0.19
65. I'm more dependent on my partner.	0.21
63. I think my partner protects me by not telling me how he/she feels.	0.23
97. Our marital troubles cause me stress which I believe has worsened my MS.	0.23
36. We never talked about the MS.	0.24
51. We might be together now only because I an financially dependent.	0.26
Cluster average	0.19
Cluster #10 - Emotional Reactions	
40. I have a lot of anger at the disease.	0.04
23. I'm frustrated to be continually losing something.	0.05
75. I have trouble keeping my spirits up.	0.07

Table 5 (continued)

20. I feel guilty about having MS.	0.11
19. When I think of a way out I think of suicide.	0.12
52. I feel devalued because of the MS.	0.15
42. I felt that I had none of my roles left.	0.24
16. Thinking and memory problems have been the most difficult to deal with.	0.32
21. Because MS is unpredictable I worry about the future.	0.41
74. It's difficult to have time to myself.	0.48
15. I didn't tell people I had MS.	0.54
55. My partner worries about me.	1.00
Cluster average	0.30
Cluster #11 - Anxieties and Fears	
24. I worry about becoming totally dependent on my partner.	0.22
38. I was afraid that I could lose my family.	0.24
89. Increased anxiety that I should lose my partner through separation or death.	0.24
30. I'm resentful that my partner has more control.	0.25
62. I feel like I've let my partner down.	0.25
18. I don't want to be a burden on anyone.	0.26
53. I feel unequal to my partner.	0.28
81. My unpredictable mood swings cause undue stress.	0.30
44. I feel emotionally alone.	0.33
Cluster average	0.26

theme of changes in orientation toward the future such as, "I have to be flexible in planning ahead" (#69), "We don't make plans for the future" (#67), "Many of our long term goals are unattainable" (#87), "We decided not to have children because of the MS" (#14), and "We take every day one at a time" (#70).

Coping strategies associated with this theme emphasized the importance of normalizing the situation. Statements included, "I've tried to stay looking and seeming as normal as possible" (#17), "I've tried to keep my kids and family normal" (#47), "It's important not to dwell on your MS" (#22), and "I'm more conscious of trying to make the best of things now" (#10).

Physical adaptations identified included, "We bought a bungalow, one floor plan" (#57) and "We enjoy closeness without a sexual relationship" (#12).

Cluster #3 - Sexual Issues

This cluster had the lowest cluster average bridging index (.07) of the 11 cluster on this map. This value indicated that the items formed a discrete, coherent cluster. Statements all related to changes in relating sexually such as, "Lack of a sexual relationship has been a major loss" (#28), "Our sexual relationship was strained" (#45), "Reduced amount and quality of our sex life" (#84), "Physically I was able to have a sexual relationship" (#49), "Adjustments have to be made sexually" (#59), and "Requires different positions when making love" (#83).

Cluster #4 - Financial Issues

Items in this cluster were located on the far left side of the concept map. The theme reflected the financial issues that patients perceived as being due to their MS. Items such as, "Finances are more of an issue because of MS" (#33) and "MS causes financial burden" (#43) reflect this theme. Also in this cluster was the statement "My partner had to be the sole breadwinner" (#73).

Cluster #5 - Role of Spirituality

Located closely to the Financial Issues cluster and the Changes in Sexual Relationship Cluster, was a small cluster with two items related to spirituality. The items that reflected the role of spirituality were, "For me spirituality/religion is an anchor" (#60) and "I turned myself over to God" (#71). Another statement "Has reduced my feelings of desirability and attractiveness" (#85), does not seem to fit into this category. The bridging index of .46 indicates that this item was frequently sorted into different clusters.

Cluster #6 - Lifestyle Changes

The items with the lowest bridging values and likely the most representative of this cluster were, "We stay home a lot" (#2), "When we go on holidays we tend to just rest and relax" (#7), "We spend a lot of time apart" (#64), and "Has eliminated spontaneity in our lives" (#86). This cluster was located in the upper right section of the cluster map and seemed to relate to lifestyle changes. Statements in this cluster reflected physical restrictions such as, "MS stops me traveling to the extent that my partner wants to" (#66), and "It is impossible to continue with most activities, hobbies we previously enjoyed together". Patients also expressed changes in the marital lifestyle such as "We no longer argue the way we used to" (#26), "With MS what you were to each other is changed" (#34), "Often arguments over activity" (#76) and "My partner has his/her own friends" (#68).

Cluster #7 - Perceived Losses

Cluster #7 was located in the center of the map and had the highest bridging index (.38) of all of the clusters, suggesting that many of the items were sorted in different categories. Some of the items with lower bridging indexes appear to refer to lifestyle changes and thus to fit with cluster #6. For example, "I have to live a very controlled lifestyle" (#72), and "I had to give up a lot of my previous types of recreation" (#27). On further examination, however, it is evident that statements in this cluster are all in the first person and refer mostly to perceived losses rather than changes in lifestyle of the couple. Examples are, "I didn't have the energy to do some things" (#6), "I rely on other people" (#48), "I needed my partner to say we'll manage" (#35), "The uncertainty of MS causes a lot of stress and anxiety" (#9), and "I covered up to the extent that my partner didn't think anything was wrong" (#56).

Cluster #8 - Negative Impact on Marital Life

Located at the bottom right side of the concept map, this cluster was very stable with an average cluster bridging index of .12. Some statements specifically focused on the negative reaction of the spouse such as, "My partner couldn't come to terms with living with an invalid" (#13), "Spouse runs away from the problem" (#92), "My partner withdrew from me" (#37), "My partner didn't cope well" (#39), "Spouse gets impatient over dull life" (#77), and "My partner is worried that I'll embarrass him/her" (#8).

Other statements were more general such as, "We have more conflict in our marriage due to MS" (#3), "MS has shown me that our marriage is not as secure as I thought it was" (#97), "The marriage relationship has become less and less "(#49), "MS affected the relationship because it affected me so much" (#54), and "It's difficult to keep the marital relationship and caretaker relationship separate" (#29).

Cluster #9 - Insecurity

Items with the lowest bridging indexes and thus most representative of the cluster theme were, "I feel my partner stays under obligation" (#91), "I worry that I'm hanging on to the relationship because of the caregiving" (#31), "I'm careful with my partner because I need the security of the relationship" (#61), and "I didn't want to anger my partner because I needed a lot of help" (#41). Two statements address the dependency issues directly: "I'm more dependent on my partner" (#65) and "We might be together now only because I am financially dependent" (#51). Other statements in this cluster are more general and related less directly to the overall theme of the cluster. These include, "Previous problems are just magnified now" (#95), "We never talked about the MS" (#36), "I think my partner protects me by not telling me how he/she feels" (#63), and "Our marital troubles cause me stress which I believe has worsened my MS" (#97).

Cluster #10 - Emotional Reactions

Clusters 10 and 11 are both dominated by items representative of affective elements. Cluster 10 emphasizes the personal emotional reactions to the disease while the theme of cluster 11 revolves around anxieties and fears.

Statements with the lowest bridging indexes in cluster 10 were: "I have a lot of anger at the disease" (#40), "I'm frustrated to be continually losing something" (#23), "I have trouble keeping my spirits up" (#75), "I feel guilty about having MS"

(#20), "When I think of a way out I think of suicide" (#19), and "I feel devalued because of the MS" (#52).

Cluster #11 - Anxieties and Fears

Items in this cluster were located in the central lower section of the concept map between clusters 9 and 10. Lower bridging index statements were "I worry about becoming totally dependent on my partner" (#24), "I was afraid that I could lose my family" (#38), "Increased anxiety that I could lose my partner through separation or death" (#89), and "I don't want to be a burden to anyone" (#18). Other statements in this cluster were of a more general emotional nature such as, "I'm resentful that I've let my partner down" (#62), and "I feel unequal to my partner" (#53).

The Partner Concept Map

As with the patient concept map the concept mapping program initially produced a cluster solution one-fifth of the total number of statements. This initial cluster solution of 19 clusters contained clusters too conceptually discrete and visually fragmented. The 14-cluster solution contained too few items and appeared to overlap conceptually. Due to the difficulty in interpretation of these cluster solutions, further reduction was considered appropriate.

The 6-cluster solution was examined next. These clusters were quite general and contained more than one theme. For example, cluster #1 included both changes in lifestyle necessary when one partner has multiple sclerosis and also changes in future dreams. Therefore this solution was rejected. Now it was evident that the final cluster solution was between 7 and 13 clusters for partners.

The 7-cluster solution was an improvement over the 6-cluster solution because the changes in lifestyle (cluster #1) was now separated from changes in future dreams (cluster #2). However, cluster #2 also contained statements pertaining to finances.

The next choice was the 8-cluster solution. Some clear and consistent themes were emerging. For example, on the right side of the map, stresses felt by the partner were now separated out from "feelings of having lost their partner". The cluster bridging index for these clusters (0.44 and 0.52) remained close to their merged value of 0.47.

The 9-cluster solution split cluster #2 into statements pertaining to finances and changes in future dreams. Successive cluster solutions were examined and the inspection of the remaining cluster solutions failed to improve the structure of the configuration. Consequently, the decision was made to accept the 9-cluster solution (see figure #4) as the one that provided the most clear and concise description of the partner data set.

Description of the Partner Concept Map

The first examination of the partner concept map attempted to identify implicit dimensional axes around which the points may be configured. Unlike the patient map, the partner concept map did not have a central cluster around which themes revolved.

The upper portion of the map (cluster 9) contained items that represented more positive aspects of the impact of MS on marital life. In contrast, the left side of the map (clusters 1,2 and 3) focused on the impact that MS has had on lifestyle, future dreams and finances. The lower portion of the map featured items representing the negative impact of MS on the emotional well-being of both partners, as well as stresses specific to the partner of the MS patient, caretaker burden and the feeling of

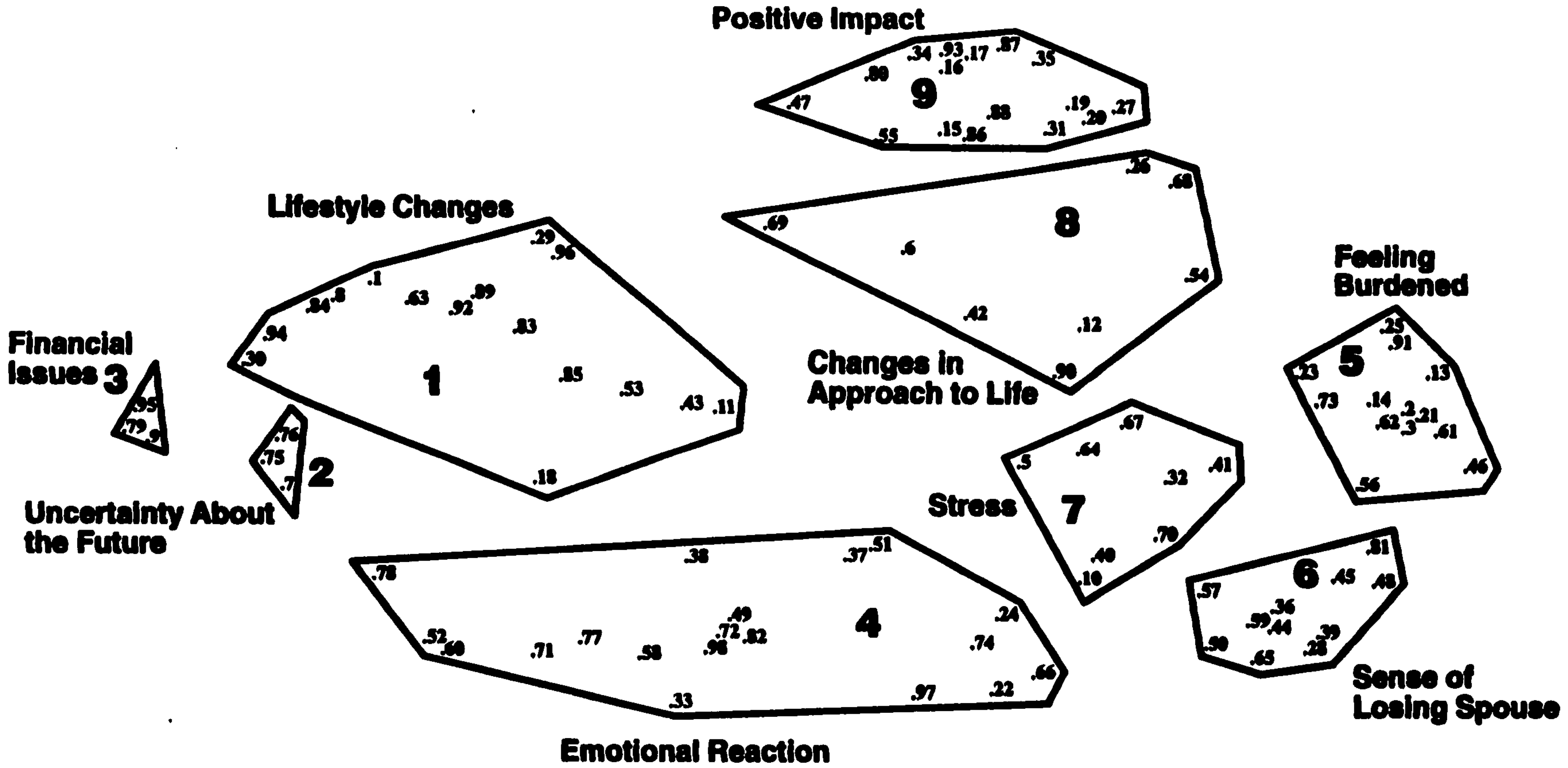

Figure 4. Nine solution cluster map of 98 partner statements

having lost their marital partner. Cluster #8 was between the positive aspects and the more negative aspects. This cluster contained more neutral items pertaining to changes in approach to life.

The procedure previously described for labeling the patient clusters was repeated for the partner clusters. Bridging indexes of the items were used to systematically interpret the concept map of partners of MS patients. The statements in each cluster of the 9-solution partner concept maps with the accompanying bridging indexes and names, are displayed in Table 6. A detailed explanation of each cluster of the partner map follows.

Cluster #1 - Lifestyle Changes

Cluster #1 was located on the far left side of the map. The statements reflected how respondents perceived that MS had impacted on their lifestyle. Some items reflected physical changes that MS necessitated such as, "We had to adapt the house to accommodate the wheelchair" (#8), "Purchased new house that was an open floor plan" (#84), and "We have to live near appropriate doctors and hospitals" (#63). Other items reflected changes in activities due to MS such as, "Traveling is more difficult" (#92),, "We can no longer do a lot of the things we used to do" (#43), "Evening social events are a thing of the past" (#53), and " Time together is in sedentary activities" (#96). A third group of statements in this cluster indicated a change in decisions about the future perceived to be due to MS. Included in this category was, "We have had to make some decisions we wouldn't have made without the MS" (#83), "It shattered our dreams about having children" (#94), and "MS makes it difficult to plan for the future" (#30).

Table 6

Cluster Items and Bridging Indexes for Nine Solution Concept Map of Partners of Multiple Sclerosis Patients

	Bridging Index
Cluster #1 - Lifestyle Changes	
94. It shattered our dreams about having children.	0.42
8. We had to adapt the house to accommodate the wheelchair.	0.45
30. MS makes it difficult to plan for the future.	0.46
84. Purchased new house that was an open floor plan.	0.46
63. We have to live near appropriate doctors and hospitals.	0.47
92. Traveling more difficult.	0.48
1. We have to plan our days, our weeks ahead of time.	0.50
85. Entertaining much less because my partner gets too tired.	0.52
53. Evening social events are a thing of the past.	0.55
89. Keep a quiet home for rest periods.	0.55
29. The pace of our life has slowed down.	0.59
96. Time together is in sedentary activities.	0.60
43. We can no longer do a lot of the things we used to do.	0.61
11. I miss some of the activities we used to do together.	0.66
83. We have had to make some decisions we wouldn't have made without the MS.	0.75
18. Fatigue plays a big role in our lives.	0.83
Cluster average	0.55
Cluster #2 - Uncertainty About the Future	
76. There was a shattering of our dreams for the future.	0.54
75. I feel insecure about the future.	0.60
7. I'm frustrated by the uncertainty of not knowing what will be ahead.	0.70
Cluster average	0.61
Cluster #3 - Financial Issues	
95. We've had to plan financially more for the future.	0.36
9. There were a lot of added expenses.	0.37
79. Financially it's been difficult.	0.37
Cluster average	0.37
Cluster #4 - Emotional Reaction	
72. I feel depressed a lot of the time.	0.44
82. I get angry and annoyed about having to live with MS.	0.45

Table 6 (continued)

49. I often feel guilty because my partner is ill.	0.46
51. It's very stressful dealing with a chronic illness.	0.48
37. The most impactful part of MS has been the emotional.	0.49
98. Embarrassed about my partner's behavior around other people.	0.54
24. Caregiving creates a lot of stress.	0.55
66. Spouse's thinking and memory problems cause poor communications.	0.62
74. I fear my partner being totally dependent on me.	0.62
22. The shock of diagnosis strained the relationship.	0.65
38. I'm constantly driven crazy by the unpredictability.	0.65
97. Stressful relationship because of constant and unpredictable change.	0.74
58. I don't share with people what I'm going through.	0.76
77. I withdrew from people.	0.76
33. I feel hurt and resentful we longer have a sexual relationship.	0.82
71. I didn't tell people so there was a lot of covering up.	0.92
78. I feared that my partner would no longer be able to work.	0.93
52. We no longer have a sexual relationship.	0.96
60. Our sexual life was greatly affected.	0.96
Cluster average	0.67
Cluster #5 - Feeling Burdened	
3. I feel like everybody depends on me.	0.30
14. I feel like I have to do everything.	0.30
62. I feel it is my duty to take care of things.	0.30
21. Much of the household responsibilities are on my shoulders.	0.31
2. I have to do all the driving for the children.	0.40
46. I think of myself as a back-up to do whatever my partner cannot do.	0.42
56. I try not to burden my partner.	0.43
73. I feel I have to be stronger and more independent.	0.48
61. I had to take over handling all the finances.	0.56
13. It was no longer the two of us raising the family.	0.65
23. My partner really needs me.	0.65
91. Roles have changed.	0.72
25. We're more careful in expressing our feelings.	1.00
Cluster average	0.50

Table 6 (continued)

Cluster #6 - Sense of Losing Spouse	
39. The person that I'd married no longer existed in many ways.	0.38
59. I no longer have somebody to talk things over with.	0.38
44. I feel I always need to evaluate how my partner is feeling before I talk to him/her.	0.40
36. Conversation seems to be centered on the needs of the person with MS.	0.41
4. In a sense I have lost my spouse.	0.42
45. We don't make decisions together any more.	0.44
28. We no longer feel like equals.	0.46
50. With MS I cannot look at my partner and assume he or she is fine.	0.46
57. I can't be straight forward in my feelings.	0.46
65. Reduced companionship.	0.46
48. I have to screen out what is illness related from what is personality related.	0.48
81. One area of conflict is I try to do too much for my partner.	0.52
Cluster average	0.44
Cluster #7 - Stresses	
70. I am constantly concerned about my partner's health.	0.44
32. At times I feel very begrudging for the things I'm doing for my partner.	0.46
41. It's difficult to cope with all the expectations placed on me.	0.48
40. It takes an incredible amount of emotional awareness and energy to cope.	0.50
67. Reduced greatly my free time to do many little things.	0.54
64. Days are often long and boring.	0.56
5. I feel MS has contributed to my own illness.	0.57
10. The physical and emotional needs of the ill spouse come first.	0.60
Cluster average	0.52
Cluster #8 - Changes in Approach to Life	
68. More sharing of responsibilities.	0.65
90. I have to do many activities on my own.	0.68
54. I have been able to put my own fear into perspective more.	0.74
12. I needed a support group to help understand my feelings.	0.79
26. We no longer fight the way we used to.	0.79
69. I had to learn to live more day by day.	0.79
6. MS changed my outlook on life.	0.80

Table 6 (continued)

42. I find I need space away from my partner.	0.83
Cluster average	0.76
Cluster #9 - Positive Impact	
16. MS has made us closer in our relationship.	0.00
17. We understand each other better.	0.00
93. We spend more time together.	0.00
35. We've learned about each other's strengths and weaknesses.	0.06
34. We're aware of the preciousness of what we have.	0.08
87. I'm more supportive of my spouse.	0.13
31. We find ways to adapt so we can still do some things we enjoy.	0.18
19. We take time for ourselves independently.	0.19
88. Made us more aware of other people's problems.	0.19
20. We try to maintain a positive attitude towards life.	0.21
15. It's made us much more aware of having a healthier lifestyle.	0.23
86. We've refocused on priorities in life like health, friends, and family.	0.23
27. Caring for my partner has given me a sense of fulfillment.	0.27
80. I'm impressed with how my spouse has coped with the disease.	0.35
55. My strong faith is a resource.	0.36
47. I believe it's important to allow my partner dignity.	0.84
Cluster average	0.21

Cluster #2 - Uncertainty About the Future

Cluster #2 is adjacent to Cluster #1. The theme of this cluster overlaps somewhat with cluster #1 in regard to the statements about the future. However, the theme of cluster #2 more specifically reflects a feeling of uncertainty about the future. The nature of the uncertainty is reflected in the statements, "I'm frustrated by the uncertainty of not knowing what will be ahead" (#7), "I feel insecure about the future" (#75) and "There was a shattering of dreams for the future" (#76).

Cluster #3 - Financial Issues

Financial issues, in cluster #3, is located on the far left side of the map. Although this is a small cluster containing only three statements, in this data set it has one of the lowest cluster average bridging indexes (.37), which indicates that these items were frequently sorted together and form a distinct, cohesive grouping. The statements reflecting the financial theme are, "There were a lot of added expenses" (#9), "Financially it's been difficult" (#79), and "We've had to plan financially more for the future" (#95).

Cluster #4 - Emotional Reaction

Cluster #4 is located at the bottom of the concept map toward the left side. These items identified the emotional impact on the partner of an MS patient. Partners reported "I feel depressed a lot of the time" (#72), "I get angry and annoyed about having to live with MS" (#82), "I often feel guilty because my partner is ill" (#49), and "It's very stressful dealing with a chronic illness" (#51).

Other emotional reactions reported by spouses were, "Embarrassed about my partner's behavior around other people" (#98), "Caregiving creates a lot of stress" (#24), and "I'm constantly driven crazy by the unpredictability" (#38).

Included in this cluster were statements about stress in the relationship such as "The shock of diagnosis strained the relationship" (#22), "Stressful relationship because of constant and unpredictable change" (#97), and "The most impactful part of MS has been the emotional" (#37).

Respondents also reported covering up and withdrawing from people as indicated by the following statements: "I didn't tell people so there was a lot of covering up" (#71), "I withdrew from people" (#77), and "I don't share with people what I'm going through" (#58).

Sexual issues were also included in this cluster. However, the bridging indexes were high which indicates they are bridging items which were often sorted with other clusters. The statements representing sexual issues were, "I feel hurt and resentful we no longer have a sexual relationship" (#33), "We no longer have a sexual relationship" (#52), and "Our sexual life was greatly affected" (#60).

One item reported, "I feared that my partner would no longer be able to work" (#78).

Cluster #5 - Feeling Burdened

The fifth cluster was located on the far right side of the map. The items with the lowest bridging indexes and thus most representative of the cluster theme were, "I feel like everyone depends on me" (#3), "I feel like I have to do everything" (#14), "I feel it is my duty to take care of things" (#62), "Much of the household responsibilities are on my shoulders" (#21), and "I have to do all the driving for the children" (#2).

Partners indicated that they "feel they have to be stronger and more independent" (#73), and they think of themselves "as a backup to do whatever my partner cannot do" (#46).

Other statements in this category suggested changes in relating to the partner such as, "I try not to burden my partner" (#56), "We're more careful in expressing our feelings" (#25), and "My partner really needs me" (#23). Partners reported that "Roles have changed" (#91), "It was no longer the two of us raising the family" (#13), and "I had to take over handling all the finances" (#61).

Cluster #6 - Sense of Losing Spouse

Cluster #6 was located at the bottom right side of the map adjacent to clusters 5 and 7. The essence of this theme was captured in the statements "In a sense I have lost my spouse" (#4), and "The person that I'd married no longer existed in many ways" (#39).

Several statements indicated a shift or change in ways of relating such as, "I no longer have someone to talk things over with" (#59), "I feel I always need to evaluate how my partner is feeling before I talk to him/her" (#44), "Conversation seems to be centered on the needs of the person with MS" (#36), "We don't make decisions together anymore" (#45), and "I can't be straight forward in my feelings" (#57). Partners also expressed that, "We no longer feel like equals" (#28), "With MS I cannot look at my partner and assume he/she is fine" (#50), and "I have to screen out what is illness related from what is personality related" (#48).

One item reported "reduced companionship" (#65) due to MS and another stated "doing too much for my partner causes conflict" (#81).

Cluster #7 - Stresses

As would be expected the "stress on spouse" cluster is located between cluster #5 (Feeling Burdened) and Cluster #4 (the emotional reaction cluster). The essence of this theme is captured by the statements, "I'm constantly concerned about my partner's health" and "The physical and emotional needs of the ill spouse come first" (#10). The stresses caused by the day to day living with MS were indicated by the statements, "It's difficult to cope with all the expectations placed on me" (#4), "At times I feel very begrudging for the things I'm doing for my partner" (#32), and "It takes an incredible amount of emotional awareness and energy to cope" (#40).

Partners reported that MS "Reduced greatly my free time to do many little things" (#67), and another statement expressed that "I feel MS has contributed to my own illness" (#57).

Cluster #8 - Changes in Approach to Life

Cluster #8 is located close to the center of the concept map. The high cluster average bridging index (.76) suggests that many of the statements in this cluster were sorted with various other statements. The statements included in this cluster tended to be more statements of fact which represented either positive or negative impact on marital life. Thus the position of this cluster between cluster #9 (Positive Impact) and cluster #7 (Stresses) seems appropriate.

Statements in cluster #8 included "I have to do many activities on my own" (#90), "More sharing of responsibilities" (#68), and "We no longer fight the way we used to" (#26).

Some statements suggested ways of coping such as, "I had to learn to live more day by day" (#69), "I needed a support group to help understand my feelings"

(#12), and "I find I need space away from my partner" (#42). Statements indicating change included "MS changed my outlook on life" (#6) and "I have been able to put my own fear into perspective more" (#54).

Cluster #9 - Positive Impact

Positive impact statements were located at the center top portion of the concept map. This cluster had the lowest bridging index (.21) of this 9-solution concept map. This value indicated these items were frequently sorted together to form a distinct, cohesive grouping.

The positive impact of MS on marital life was expressed by the statements: "MS has made us closer in our relationship" (#16), "We spend more time together" (#93), and "We understand each other better" (#17).

Positive changes in relating to each other were indicated as well. Examples of this are, "We've learned about each other's strengths and weaknesses" (#35), "I'm more supportive of my spouse" (#87), and "We take time for ourselves independently" (#19).

Partners also suggested that MS contributed to a changing of awareness as indicated by the following statements: "We've become aware of the preciousness of what we have" (#34), "Made us more aware of other people's problems" (#88), "It's made us more aware of having a healthier lifestyle" (#15), and "We've refocused on priorities in life like health, friends, and family" (#86).

Positive coping was expressed by the statements, "We find ways to adapt so we can still do some things we enjoy" (#31), "We try to maintain a positive attitude towards life" (#20), and "My strong faith is a resource" (#53).

One statement indicated a positive attitude toward the ill spouse, "I'm impressed with how my spouse has coped with the disease" (#80). Another indicated that, "Caring for my partner has given me a sense of fulfillment" (#27).

Phase Three: Incidence Survey

Concept mapping, like many research approaches, involves a compromise between breadth and depth of understanding (Daughtry & Kunkel, 1993). The data gathered, organized, and interpreted in Phase one and two of the study address the first two objectives of the study. There is reasonable confidence that the data has captured the issues and underlying themes of the impact of MS on marital life.

A limitation of this method is that the incidence of each statement is not determined for the entire sample of patients. Phase three addresses the third objective of the study. In Phase three, incidence surveys were developed from the patient statements (Appendix P) and from the partner statements (Appendix Q). These surveys sought to determine the extent that a sample of MS patients, and a sample of partners perceived the identified areas to be relevant to their lives. It was also hoped to determine if these perceptions differed based on gender, age, disease course, symptoms present, length of marriage, years since diagnosis, education, employment, and marital satisfaction rating.

MS Patient Incidence Survey

To address the third research objective, a survey instrument was developed and mailed to research participants. The survey consisted of two parts: the demographic questionnaire and a questionnaire consisting of the statements derived from the interview transcripts and open-ended questionnaire. Participants were asked to rate each item on a 6-point Likert response scale to determine how relevant the statement was to their personal experience of the effects of MS on marital life. The scale ranged from "not at all" to "very much" and also included a not applicable category. Frequency data was calculated for each of the patient statements (Appendix R).

Frequency Data

Appendix R contains the summary statistics of the responses for each statement, frequencies for each response as well as item means and standard deviations are presented.

The top ranked statements - statements in which the mean was 3.0 or higher - are presented in Table 7. There were a total of 32 statements in this category. Also presented in Table 7 are statements in which the mean was less than 2.5. There were a total of 29 statements in this category.

The statement most frequently endorsed by patients was statement #18, "I don't want to be a burden on anyone" (86.3%). Eight of the top ten statements were positive and adaptive. For example, "I've tried to keep my kids and family normal" (85.1%), "I've tried to stay looking and seeming as normal as possible" (83.5%), "My partner is supportive" (78.1%), "Has made me appreciate my partner more" (77.0%) and "It's important not to dwell on your MS" (72.0%). A total of 36 statements had means greater than 3.00.

Statements that received the least frequent agreement were: "We might be together now only because I am financially dependent" (10.6%), "I worry that I'm hanging on to the relationship because of the caregiving" (9.0%), "My partner is worried that I'll embarrass him/her" (13.5%), "When I think of a way out I think of suicide" (14.1%), "Spouse runs away from the problem" (14.3%), "Often arguments

Table 7

Item Means and Percentages of Patient Endorsed Statements

Statement (statements with means above 3.0)	**% Patient Endorsed Items** **mean**	 **1 and 2**	 **4 and 5**
18. I don't want to be a burden on anyone.	4.44	5.1	86.3
47. I tried to keep my kids and family normal.	4.43	4.5	85.1
17. I've tried to stay looking and seeming as normal as possible.	4.24	7.6	83.5
58. My partner is supportive.	4.22	10.9	78.1
22. It's important not to dwell on your MS.	4.15	10.7	72.0
82. Has made me appreciate my partner more.	4.05	13.5	77.0
25. Living with MS is a learning process for both of us.	3.99	9.4	66.7
27. I had to give up a lot of my previous types of recreation.	3.96	17.9	70.5
10. I'm more conscious of trying to make the best of things now.	3.94	14.1	70.5
6. I don't have the energy to do some things.	3.86	10.5	61.8
35. I needed my partner to say we'll manage.	3.75	21.9	65.7
24. I worry about becoming totally dependent on my partner.	3.72	21.1	59.2
70. We take every day one at a time.	3.65	23.0	59.5
23. I'm frustrated to be continually losing something.	3.58	20.6	54.8
69. I have to be flexible in planning ahead.	3.58	19.3	56.4
21. Because MS is unpredictable I worry about the future.	3.55	25.1	50.1
57. We bought a bungalow, one floor plan.	3.54	35.4	62.5
78. Made us focus on priorities.	3.51	23.0	51.3
46. Physically I was able to have a sexual relationship.	3.42	25.7	51.3
55. My partner worries about me.	3.39	28.0	54.6
11. We make a conscious effort to find things we can still share.	3.32	29.2	47.2
2. We stay home a lot.	3.30	27.6	41.1
32. I want a better future for my partner.	3.26	32.9	45.7
12. We enjoy closeness without a sexual relationship.	3.24	30.5	52.5
40. I have a lot of anger at the disease.	3.13	41.6	42.9
43. MS causes financial burden.	3.13	37.3	41.3
60. For me spirituality/religion is an anchor.	3.10	42.3	46.5

Table 7 (continued)

7. When we go on holidays we tend to just rest and relax.	3.08	30.1	33.3
4. More sharing of the running of the household.	3.03	35.2	37.9
81. My unpredictable mood swings cause undue stress.	3.01	35.6	38.4
33. Finances are more of an issue because of MS.	3.00	44.7	44.7
84. Reduced amount and quality of our sex life.	3.00	44.4	45.8
(Patient-endorsed items with means less than 2.5)			
83. Requires different positions when making love.	2.48	53.1	27.4
67. We don't make plans for the future.	2.45	55.1	26.1
53. I feel unequal to my partner.	2.44	55.7	24.3
29. It's difficult to keep the marital relationship and caretaker relationship separate.	2.39	59.1	24.6
36. We never talked about the MS.	2.39	59.3	22.2
39. My partner didn't cope well.	2.34	62.2	21.6
95. Previous problems are just magnified now.	2.34	63.3	25.0
97. Our marital troubles cause me stress which I believe has worsened my MS.	2.30	64.8	28.2
3. We have more conflict in our marriage due to MS.	2.29	64.4	19.1
14. We decided not to have children because of MS.	2.29	67.8	29.0
49. The marriage relationship has become less and less.	2.29	60.9	24.6
15. I didn't tell people I had MS.	2.26	59.4	23.0
61. I am careful with my partner because I need the security of the relationship.	2.26	60.3	19.1
56. I covered up to the extent that my partner didn't think anything was wrong.	2.22	63.7	24.6
30. I'm resentful that my partner has more control.	2.15	70.8	23.6
38. I was afraid that I could lose my family.	2.14	65.7	18.6
74. It's difficult to have time to myself.	2.12	63.6	20.8
13. My partner couldn't come to terms with living with an invalid.	2.11	69.3	21.0
77. Spouse gets impatient over dull life.	2.11	68.9	18.9
96. I am disappointed that my partner has not been as supportive as I thought he/she would be.	2.07	67.1	21.5
94. MS has shown me that our marriage is not as secure as I thought it was.	2.06	68.1	21.7
37. My partner withdrew from me.	1.97	73.2	16.9
91. I feel my partner stays under obligation.	1.92	73.3	16.9

Table 7 (continued)

76. Often arguments over activity.	1.91	74.3	5.5
92. Spouse runs away from the problem.	1.87	74.3	14.3
19. When I think of a way out I think of suicide.	1.86	71.8	14.1
8. My partner is worried that I'll embarrass him/her.	1.82	73.0	13.5
31. I worry that I'm hanging on to the relationship because of the caregiving.	1.66	82.1	9.0
51. We might be together now only because I an financially dependent.	1.58	80.7	10.6

over activity" (5.5%), and "I feel my partner stays under obligation" (16.9%). A total number of 8 statements had means less than 2.00 and a total number of 29 statements had means less than 2.5.

The data was also organized by cluster to determine how patients had responded to categories of items. Table 8 contains a listing of the means, and standard deviations of each item by cluster as well as by cluster means. Results indicate that cluster #2 (Coping and Adaptation) had the greatest number of patient-endorsed statements with means greater than 3.00. Eight out of the 11 statements contained in this cluster had means greater than 3.00. Eighty-five percent of patients endorsed the statement, "I tried to keep my kids and family normal" (#47) and 83.5% said "I've tried to stay looking and seeming as normal as possible" (#17). About 72% of patients said "It's important not to dwell on your MS" (#22), while 70.5% said "I'm conscious of trying to make the best of things now" (#10). Sixty-two percent of patients stated that "We bought a bungalow - one floor plan", while approximately half the respondents (56% and 52% respectively) "had to be flexible in planning ahead" (#14) and "enjoy closeness without a sexual relationship" (#12). Fifty-nine percent of patients indicated that "We take one day at a time" (#70).

Cluster #1 (Positive Impact on Marital Life) was endorsed second by patients, with six statements with means over 3.00. Seventy-eight percent of patients said their partners were supportive (#58), while 77% said that MS has made them appreciate their partner more (#82). Sixty-six percent responded that living with MS was a learning process (#25) and 51% said that MS made them focus on priorities (#78). Forty-seven percent of patients indicated that they make a conscious effort to find things they can still share (#11). Thirty-seven percent said there was more sharing of the running of the household after MS (#4).

Table 8

Item Means and Percentages of Patient-Endorsed Statements by Cluster

Statement	% Patient Endorsed Items		
	mean	1 and 2	4 and 5
Cluster #1 - Positive Impact on Marital Life			
1. We are closer because of MS	2.90	41.4	38.6
4. More sharing of the running of the household.	3.03	35.2	37.9
5. More sharing of the raising of children.	2.81	40.5	30.7
11. We make a conscious effort to find things we can still share.	3.32	29.2	47.2
25. Living with MS is a learning process for both of us.	3.99	9.4	66.7
58. My partner is supportive.	4.22	10.9	78.1
78. Made us focus on priorities.	3.51	23.0	51.3
79. MS has enabled me to spend more time with my partner.	2.60	43.9	26.1
80. Forced us to work on our communication skills.	2.95	43.8	39.7
82. Has made me appreciate my partner more.	4.05	13.5	77.0
Cluster means	3.34	29.1	49.3
Cluster #2 - Coping and Adaptation			
10. I'm more conscious of trying to make the best of things now.	3.94	14.1	70.5
12. We enjoy closeness without a sexual relationship.	3.24	30.5	52.5
14. We decided not to have children because of MS.	2.29	67.8	29.0
17. I've tried to stay looking and seeming as normal as possible.	4.24	7.6	83.5
22. It's important not to dwell on your MS.	4.15	10.7	72.0
47. I tried to keep my kids and family normal.	4.43	4.5	85.1
57. We bought a bungalow, one floor plan.	3.54	35.4	62.5
67. We don't make plans for the future.	2.45	55.1	26.1
69. I have to be flexible in planning ahead.	3.58	19.3	56.4
70. We take every day one at a time.	3.65	23.0	59.5
87. Many of our long terms goals are unattainable.	2.61	46.9	29.2
Cluster means	3.47	28.6	56.9

Table 8 (continued)

Cluster #3 - Sexual Issues			
28. Lack of a sexual relationship has been a major loss.	2.83	48.5	44.0
45. Our sexual relationship was strained.	2.95	45.2	38.4
46. Physically I was able to have a sexual relationship.	3.42	25.7	51.3
59. Adjustments have to be made sexually.	2.85	44.7	38.8
83. Requires different positions when making love.	2.48	53.1	27.4
84. Reduced amount and quality of our sex life.	3.00	44.4	45.8
Cluster means	2.92	43.6	41.0
Cluster #4 - Financial Issues			
33. Finances are more of an issue because of MS.	3.00	44.7	44.7
43. MS causes financial burden.	3.13	37.3	41.3
73. My partner had to be the sole breadwinner.	2.59	53.2	29.7
Cluster means	2.91	45.1	38.6
Cluster #5 - Role of Spirituality			
60. For me spirituality/religion is an anchor.	3.10	42.3	46.5
71. I turned myself over to God.	2.98	46.0	42.8
85. Has reduced my feelings of desirability and attractiveness.	2.81	47.5	33.3
Cluster means	2.96	45.3	40.9
Cluster #6 - Lifestyle Changes			
2. We stay home a lot.	3.30	27.6	41.1
7. When we go on holidays we tend to just rest and relax.	3.08	30.1	33.3
26. We no longer argue the way we used to.	2.66	43.8	23.3
34. With MS what you were to each other is changed.	2.51	56.2	28.8
50. If my partner had taken the caretaker role I wouldn't be as capable as I am.	2.67	49.2	31.8
64. We spend a lot of time apart.	2.60	50.7	27.4
66. MS stops me traveling to the extent that my partner wants to.	2.51	56.7	28.3
68. My partner has his/her own friends.	2.76	47.2	37.2
76. Often arguments over activity.	1.91	74.3	5.5
86. Has eliminated spontaneity in our lives.	2.79	49.3	32.9

Table 8 (continued)

88. It is impossible to continue with most activities, hobbies we previously enjoyed together.	2.71	48.6	30.6
Cluster means	2.68	48.5	29.1
Cluster #7 - Perceived Losses			
6. I don't have the energy to do some things.	3.86	10.5	61.8
9. The uncertainty of MS causes a lot of stress and anxiety in our lives.	2.91	40.2	35.1
27. I had to give up a lot of my previous types of recreation.	3.96	17.9	70.5
32. I want a better future for my partner.	3.26	32.9	45.7
35. I needed my partner to say we'll manage.	3.75	21.9	65.7
48. I rely on other people.	2.75	49.4	24.7
56. I covered up to the extent that my partner didn't think anything was wrong.	2.22	63.7	24.6
72. I have to live a very controlled lifestyle.	2.91	37.5	28.8
90. My partner works all day then comes home and works too.	2.88	41.8	40.3
Cluster means	3.17	35.1	44.1
Cluster #8 - Negative Impact on Marital Life			
3. We have more conflict in our marriage due to MS.	2.29	64.4	19.1
8. My partner is worried that I'll embarrass him/her.	1.82	73.0	13.5
13. My partner couldn't come to terms with living with an invalid.	2.11	69.3	21.0
29. It's difficult to keep the marital relationship and caretaker relationship separate.	2.39	59.1	24.6
37. My partner withdrew from me.	1.97	73.2	16.9
39. My partner didn't cope well.	2.34	62.2	21.6
49. The marriage relationship has become less and less.	2.29	60.9	24.6
54. MS affected the relationship because it affected me so much.	2.52	57.8	24.0
77. Spouse gets impatient over dull life.	2.11	68.9	18.9
92. Spouse runs away from the problem.	1.87	74.3	14.3
93. Spouse does not understand what I'm going through.	2.70	48.6	30.0

Table 8 (continued)

94. MS has shown me that our marriage is not as secure as I thought it was.	2.06	68.1	21.7
96. I am disappointed that my partner has not been as supportive as I thought he/she would be.	2.07	67.1	21.5
Cluster means	2.20	65.1	20.9
Cluster #9 - Insecurity			
31. I worry that I'm hanging on to the relationship because of the caregiving.	1.66	82.1	9.0
36. We never talked about the MS.	2.39	59.3	22.2
41. I didn't want to anger my partner because I needed a lot of help.	2.52	56.5	21.7
51. We might be together now only because I an financially dependent.	1.58	80.7	10.6
61. I am careful with my partner because I need the security of the relationship.	2.26	60.3	19.1
63. I think my partner protects me by not telling me how he/she feels.	2.83	47.9	33.8
65. I'm more dependent on my partner.	2.86	39.2	32.5
91. I feel my partner stays under obligation.	1.92	73.3	16.9
95. Previous problems are just magnified now.	2.34	63.3	25.0
97. Our marital troubles cause me stress which I believe has worsened my MS.	2.30	64.8	28.2
Cluster means	2.27	62.7	21.9
Cluster #10 - Emotional Reactions			
15. I didn't tell people I had MS.	2.26	59.4	23.0
16. Thinking and memory problems have been the most difficult to deal with.	2.94	44.9	39.1
19. When I think of a way out I think of suicide.	1.86	71.8	14.1
20. I feel guilty about having MS.	2.60	51.8	34.6
21. Because MS is unpredictable I worry about the future.	3.55	25.1	50.1
23. I'm frustrated to be continually losing something.	3.58	20.6	54.8
40. I have a lot of anger at the disease.	3.13	41.6	42.9
42. I felt that I had none of my roles left.	2.54	58.1	25.7
52. I feel devalued because of the MS.	2.81	49.4	34.2
55. My partner worries about me.	3.39	28.0	54.6
74. It's difficult to have time to myself.	2.12	63.6	20.8

Table 8 (continued)

75. I have trouble keeping my spirits up.	2.68	52.6	25.1
Cluster means	2.79	47.2	34.9
Cluster #11 - Anxieties and Fears			
18. I don't want to be a burden on anyone.	4.44	5.1	86.3
24. I worry about becoming totally dependent on my partner.	3.72	21.1	59.2
30. I'm resentful that my partner has more control.	2.15	70.8	23.6
38. I was afraid that I could lose my family.	2.14	65.7	18.6
44. I feel emotionally alone.	2.91	42.3	38.4
53. I feel unequal to my partner.	2.44	55.7	24.3
62. I feel like I've let my partner down.	2.59	54.8	27.4
81. My unpredictable mood swings cause undue stress.	3.01	35.6	38.4
89. Increased anxiety that I should lose my partner through separation or death.	2.56	57.8	32.4
Cluster means	2.88	45.4	38.7

Cluster #7 (Perceived Losses) contained four statements with means above 3.00. Seventy percent said that they had to give up a lot of their previous recreation (#27). Sixty-five percent of patients said "I need my partner to say we'll manage" (#35), while 62% said "I don't have the energy to do some things" (#6). The last statement in this cluster with a mean of 3.00 was "I want a better future for my partner" (#32), which was endorsed by 46% of patients.

Two clusters contained three statements that were ranked in the top 32 items. First, from cluster #10 (emotional reactions), 55% said they were frustrated by continually losing something (#23), 50% indicated that because of the unpredictability of MS, they worry about the future (#21), and 43% endorsed the item "I have a lot of anger at the disease". Second, from cluster #11 (anxieties and fears), 86% said "I don't want to be a burden to anyone" (#18), 59% said "I worry about becoming totally dependent on my partner", and 38% indicated "My unpredictable mood swings cause undue stress" (#81).

Three clusters contained two statements that were ranked in the top 32 items. The statements from Cluster #3 (sexual issues) were "Physically I was able to have a sexual relationship" (#46), endorsed by 51% of patients, and "Reduced amount and quality of our sex life" (#84), endorsed by 46% of patients. Second, from cluster #4 (financial issues), 41% said that MS causes financial burden , and 45% said that finances are more of an issue because of MS. The third cluster with two statements with means above 3.0 was cluster #6 (lifestyle changes). Forty-one percent of patients indicated that they stay home a lot (#2), while 33% said when they go on holidays they tend to just rest and relax.

Cluster #5 (role of spirituality) contained only one statement in the top 32. Forty-seven percent of patient respondents said, "For me spirituality/religion is an anchor". Cluster #8 (negative impact on marital life) and #9 (insecurity about the future) contained no statements with means above 3.00.

Eleven out of the 13 statements in cluster #8 (negative impact on marital life) were negatively endorsed by patients and had means of less than 2.5. This indicated that many patients perceived that these statements did not apply to them. Only 13% of respondents said their partner is worried they will embarrass him/her (#8), 14% said their spouse runs away from the problem (#92), and 17% said their partner withdrew from them (#37). Nineteen percent of patients said their "spouse gets impatient over dull life" (#77), and "We have more conflict in our marriage due to MS" (#3). Twenty-one percent indicated that "MS has shown them their marriage was not as secure as they thought" (#94), that they are disappointed that "their partner was not as supportive as they thought he/she would be" (#94), that "their partner couldn't come to terms with living with an invalid" (#13), and that "Their partner didn't cope well" (#39). Twenty-five percent endorsed the statements, "The marriage relationship has become less and less" (#49) and "It's difficult to keep the marital relationship and caretaker relationship separate" (#29).

Cluster #9 (insecurity about the future) contained 7 statements with means less than 2.5. Only 9% of respondents said that, "We might be together now only because I am financially dependent" (#51), and only 10% said, "I worry about hanging onto the relationship because of the caregiving" (#31). Sixteen percent said they felt "their partner stays under obligation" (#91) and nineteen percent said "they were careful with their partner because they needed the security of the relationship" (#61). Twenty-five percent of patients indicated that "they never talked about MS" (#36), and that "previous problems are just magnified now" (#95). Twenty-eight percent said that "their marital troubles cause them stress that they believe has worsened their MS" (#97).

Patients were also asked to rate their level of marital satisfaction. The mean for this question was 4.15 with 77.3% of the patient respondents indicating that they are moderately or very satisfied with their marriage. Eight percent endorsed the neutral category and 14.7% endorsed the moderately or very dissatisfied classification.

Divorced or separated respondents were asked to indicate how much they perceived that MS had been a factor contributing to the divorce or separation. Sixty-two percent of the respondents indicated that they perceived MS to have contributed a fair amount, quite a bit, or was a major factor in their divorce/separation.

Patient Group Comparisons

Respondents to the incidence survey indicated the significant/applicability of each statements to their perceived experience of MS and marital life. A statistical analysis was conducted to determine if the perceived significant/applicability of each statement differed significantly based on gender, age, current marital status, years with current partner, years since MS diagnosis, disease course, MS symptoms, years of education, employment status, and reported satisfaction with the current relationship. Each of these variables were split into two groups and multiple t-tests were conducted on all of the demographic variables and each of the 97 survey statements. T-tests need to be interpreted with caution because the sample was not random. It is also noted that increases in Type I errors typically occur when an increasing number of contrasts are to be computed (Rosenthal & Rubin, 1984). The alpha level to achieve significance was adjusted using the Bonferroni correction, in order to correct for the number of contrasts tested (Rosenthal & Rubin, 1984).

The group categories compared were male versus female, under 45 years old versus over 45 years of age, married versus separated/divorced, less than 20 versus more than 20 years living with present partner, less than 10 years versus more than 10 years since diagnosis, chronic/progressive versus remitting relapsing disease course, physical symptoms only versus physical and emotional and/or cognitive symptoms, more than grade 12 education versus grade 12 or less, employed outside the home versus not employed outside the home, and moderately or very satisfied with the marriage versus neutral or dissatisfied. An alpha level of .05 was used for all statistical tests. Levene's Test for Equality of Variances was utilized in interpreting the t-tests.

Demographics

T-tests were computed comparing the demographic variables with each other. Significant differences were observed in the following areas. Respondents under 45 years of age were more likely to be employed outside the home ($t[74.48]=2.52$, $p<.05$). Respondents older than 45 were more likely to say MS led to divorce/separation ($t[19]=2.49$, $p<.05$). Respondents reporting more than 10 years since diagnosis were less likely to be employed ($t[79.6]=2.29$, $p<.05$), and more likely to say that MS was a factor in their divorce/separation ($t[18.89]=3.56$, $p<.05$).

Patients with a chronic progressive disease course were more likely to be unemployed ($t[62.84]=-3.00$, $p<.05$) and were more likely to be older than 45 ($t[70]=-2.00$, $p<.05$). Male patients were more likely than females to have 13 or more years of education ($t[76.87]=-2.4$, $p<.05$). Patients employed outside the home tended to view MS as significant contributing factor to their divorce ($t[13.38]=-5.87$, $p<.05$).

Patient Survey Statements

A t-test statistic was calculated for each of the 97 statements on each of the split demographic variables.

Gender was the first variable examined. There were approximately twice as many female MS patients as there were males who responded to the survey. This is proportional to the total MS population in which approximately twice as many females as males are diagnosed with MS. However, given that there was not random sampling, all t-test results should be interpreted with caution.

Of the 97 statements that were analyzed, using the Bonferroni corrected level of significance, significant gender differences were observed on 3 items (see Appendix T). Two items were experienced by females as being more applicable to them. Females were more likely to: "Not tell people they had MS" ($\underline{t}[54.1]=-3.53$, $\underline{p}<.05$), and to say "It's difficult to have time to myself" ($\underline{t}[71.16]=-3.49$, $\underline{p}<.05$). Males were significantly more likely to express that their partner is supportive ($\underline{t}[69.9]=3.39$, $\underline{p}<.05$).

Age differences were examined next. Appendix T displays the statement that was found to be significantly different for respondents under 45 years of age compared with those 45 years of age and older. Younger respondents (<45 years old) were more likely to endorse the statement "Physically I was able to have a sexual relationship" ($\underline{t}[74.36]=-4.48$, $\underline{p}<.05$).

Eleven statements demonstrated significant differences when the responses of married MS patients were compared to the responses of divorce/separated MS patients. However, the small number of divorced/separated individual introduced the possibility that the sample may not be representative and, therefore, the results should be interpreted with caution. A complete listing of the 11 statements can be found in

Appendix T. Married MS patients were more likely to endorse positive statements as being more applicable to their experience such as "We are closer because of MS" (t[32.58]=8.16, p<.05), and "My partner worries about me" (t[69]=3.39, p<.05). Married MS patients were statistically more likely to endorse the statement "We decided not to have children because of MS".

Divorced or separated MS patients were much more likely to endorse negative statements such as "My partner couldn't come to terms with living with an invalid" (t[57]=-5.23, p<.05), "My partner didn't cope well" (t[68]=-3.55, p<.05), "The marriage relationship has become less and less" (t[64]=-3.69, p<.05), "Our marital troubles cause me stress which I believe has worsened my MS" (t[66]=-4.46, p<.05), and "MS has shown me that our marriage is not as secure as I thought it was" (t[64]==-4.46, p<.05). Divorced or separated MS patients were also statistically more likely to endorse the statements "MS causes financial burden" (t[69]=-3.79, p<.05), "I feel emotionally alone" (t[72]=-3.53, p<.05), and "Previous problems are just magnified now" (t[62]=-3.39, p<.05).

There were no significantly different means for MS patients who had been with their partner for 20 or more years compared to those who had been with their partner for less than 20 years. One item was found to be significant when those patients diagnosed 10 or more years were compared to those diagnosed less than 10 years ago. Patients diagnosed 10 or more years ago endorsed the statement "We bought a bungalow, one floor plan" (t[41.78]=3.56, p<.05). A comparison between patients with a chronic progressive disease course and those with a remitting relapsing disease course resulted in one statement with a statistically significant difference. Patients with a chronic progressive disease course endorsed the statement "I'm more dependent on my partner" (t[62]=-4.48, p<.05).

One statement was found to be significantly different for patients with cognitive and/or emotional symptoms in addition to physical symptoms than those reporting just physical symptoms. The statement "Thinking and memory problems have been the most difficult to deal with" (t[25.78]=4.02, p<.05) was statistically more frequently endorsed by patients reporting emotional and/or cognitive symptoms.

A comparison of MS patients with more than 12 years of formal education and those with 12 or less years of formal education resulted in no statements which were significantly different. Five statements demonstrated differences when patients employed outside the home were compared to those not employed outside the home. All of these statements were experienced as more relevant to those not employed outside the home. Examples are "I felt I had none of my roles left" (t[61.61]= -5.69, p<.05), "I rely on other people" (t[67.48]=-3.69, p<.05), "I had to give up a lot of my previous types of recreation" (t[44.6]=-3.73, p<.05), "I'm more dependent on my partner" (t[71]=-4.39, p<.05), and "My partner had to be the sole breadwinner" (t[52.94]= -3.61, p<.05)

A final comparison was made on the 97 statements between those patients who reported they were moderately or very satisfied with their marriage and those reporting a neutral response or dissatisfaction with their marriage. As would be expected, those reporting a satisfactory marital relationship were more likely to endorse positive statements such as "We are close because of MS" (t[63]=3.78, p<.05), "My partner is supportive" (t[14.24]=4.35, p<.05), "Made us focus on priorities" (t[66]=3.56, p<.05), and "We make a conscious effort to find things we can still share" (t[65]=3.53, p<.05). Negative statements were significantly more likely to be endorsed by those reporting a neutral response or dissatisfaction with their marriage. Examples include "My partner withdrew from me" (t[12.64]=-4.32, p<.05), "Spouse does not understand what I'm going through" (t[63]=-3.34, p<.05), and "My partner didn't cope well" (t[65]=-4.09, p<.05). Appendix T contains a complete listing of statements with significant mean differences based on marital satisfaction.

Partner Incidence Survey

Frequency Data

Frequency data were calculated for each of the partner statements (Appendix S). Frequencies for each response as well as items means and standard deviations are presented.

The top ranked statements - statements in which the means were 3.0 or higher are presented in Table 9. There were a total of 36 statements in this category. Also presented in Table 9 are statements in which the mean was less than 2.5. There were a total of 34 statements in this category.

The statement most frequently endorsed by partners was statement #47, "I believe it's important to allow my partner dignity" (95.5%). Seven of the top ten statements were positive and adaptive. For example, "I'm impressed with how my spouse has coped with the disease" (81.2%), "We try to maintain a positive attitude towards life" (86.9%), "We're aware of the preciousness of what we have" (66.7%), "My partner really needs me" (68.1%), "We learned about each other's strengths and weaknesses" (69.5%), and "I'm more supportive of my spouse" (62.3%).

Statements that received the least frequent agreement were: "Embarrassed about my partner's behavior around other people" (7.2%), "It shattered our dreams about having children" (11.1%), "I feel MS has contributed to my own illness"

Table 9

Items Means and Percentages of Partner-Endorsed Statements

Statement	**% Patient Endorsed Items**		
(statements with mean above 3.00)	**Mean**	**1 and 2**	**4 and 5**
47. I believe it's important to allow my partner dignity.	4.68	1.5	95.5
80. I'm impressed with how my spouse has coped with the disease.	4.33	7.2	81.2
20. We try to maintain a positive attitude towards life.	4.32	4.2	86.9
18. Fatigue plays a big role in our lives.	4.01	14.4	72.4
34. We're aware of the preciousness of what we have.	3.94	13.0	66.7
70. I am constantly concerned about my partner's health.	3.94	15.9	72.4
23. My partner really needs me.	3.93	18.8	68.1
10. The physical and emotional needs of the ill spouse come first.	3.87	12.9	65.8
35. We've learned about each other's strengths and weaknesses.	3.84	14.4	69.5
87. I'm more supportive of my spouse.	3.81	17.3	62.3
31. We find ways to adapt so we can still do some things we enjoy.	3.67	18.8	62.3
88. Made us more aware of other people's problems.	3.60	20.5	55.8
56. I try not to burden my partner.	3.51	22.3	55.3
86. We've refocused on priorities in life like health, friends, and family.	3.47	22.1	52.9
92. Traveling more difficult.	3.41	34.8	50.7
93. We spend more time together.	3.41	23.5	48.5
37. The most impactful part of MS has been the emotional.	3.38	25.0	50.0
6. MS changed my outlook on life.	3.36	26.9	50.8
46. I think of myself as a back-up to do whatever my partner cannot do.	3.33	33.3	53.6
83. We have had to make some decisions we wouldn't have made without the MS.	3.31	35.2	50.0
21. Much of the household responsibilities are on my shoulders.	3.26	33.8	47.0
15. It's made us much more aware of having a healthier lifestyle.	3.25	34.8	42.0
29. The pace of our life has slowed down.	3.23	39.1	44.9

Table 9 (continued)

51. It's very stressful dealing with a chronic illness.	3.23	36.0	51.6
95. We've had to plan financially more for the future.	3.20	33.3	44.0
11. I miss some of the activities we used to do together.	3.19	35.2	44.1
62. I feel it is my duty to take care of things.	3.19	36.8	47.0
73. I feel I have to be stronger and more independent.	3.18	38.2	48.5
3. I feel like everybody depends on me.	3.17	34.9	45.4
43. We can no longer do a lot of the things we used to do.	3.17	37.5	42.2
90. I have to do many activities on my own.	3.12	37.3	47.8
17. We understand each other better.	3.10	45.3	47.1
89. Keep a quiet home for rest periods.	3.08	37.9	42.4
55. My strong faith is a resource.	3.06	33.9	38.7
16. MS has made us closer in our relationship.	3.03	42.9	45.8
54. I have been able to put my own fear into perspective more.	3.03	37.5	35.9
(statements with mean below 2.50)			
78. I feared that my partner would no longer be able to work.	2.49	60.0	32.3
61. I had to take over handling all the finances.	2.48	62.1	31.8
66. Spouse's thinking and memory problems cause poor communications.	2.48	53.8	26.1
41. It's difficult to cope with all the expectations placed on me.	2.44	51.5	22.0
67. Reduced greatly my free time to do many little things.	2.44	55.9	26.4
57. I can't be straight forward in my feelings.	2.43	59.7	25.4
82. I get angry and annoyed about having to live with MS.	2.43	60.9	26.0
97. Stressful relationship because of constant and unpredictable change.	2.42	56.5	24.6
53. Evening social events are a thing of the past.	2.41	57.4	29.4
2. I have to do all the driving for the children.	2.35	59.4	21.6
8. We had to adapt the house to accommodate the wheelchair.	2.31	66.7	29.4
26. We no longer fight the way we used to.	2.30	60.4	15.1
39. The person that I'd married no longer existed in many ways.	2.29	62.2	21.3

Table 9 (continued)

4. In a sense I have lost my spouse.	2.27	65.7	25.3
33. I feel hurt and resentful we longer have a sexual relationship.	2.23	65.4	19.2
49. I often feel guilty because my partner is ill.	2.19	63.2	22.1
28. We no longer feel like equals.	2.17	63.1	21.6
59. I no longer have somebody to talk things over with.	2.17	65.7	20.4
13. It was no longer the two of us raising the family.	2.12	66.7	23.8
72. I feel depressed a lot of the time.	2.10	68.7	14.9
32. At times I feel very begrudging for the things I'm doing for my partner.	2.09	70.6	20.6
38. I'm constantly driven crazy by the unpredictability.	2.09	68.1	13.0
63. We have to live near appropriate doctors and hospitals.	2.09	71.6	23.8
22. The shock of diagnosis strained the relationship.	1.97	73.9	13.8
65. Reduced companionship.	1.97	73.1	16.5
12. I needed a support group to help understand my feelings.	1.91	71.2	15.2
71. I didn't tell people so there was a lot of covering up.	1.85	72.7	12.1
45. We don't make decisions together any more.	1.80	79.7	10.1
77. I withdrew from people.	1.78	79.1	10.5
64. Days are often long and boring.	1.67	81.9	9.0
5. I feel MS has contributed to my own illness.	1.61	83.3	11.2
94. It shattered our dreams about having children.	1.58	80.6	11.1
98. Embarrassed about my partner's behavior around other people.	1.49	90.0	7.2

(11.2%), "Days are often long and boring" (9.0%), "I withdrew from people" (10.5%), "We don't make decisions together anymore" (10.1%), and "I didn't tell people so there was a lot of covering up" (12.2%). A total number of 10 statements had means less than 2 and all tended to focus on the negative effects of MS. Thirty-four statements had means less than 2.5.

The data was also organized by cluster to determine how partners had responded to categories of items. Table 10 contains a listing of the means and percentages for each item by cluster as well as the cluster means. Results indicate that cluster #9 (Positive Changes) had the greatest number of partner-endorsed statements with means greater than 3.00. Fifteen out of the 17 statements contained in the cluster had means greater than 3.00. Three statements in cluster #9 had means greater than 4.00. Ninety-five point five percent of the partners endorsed the statement, "I believe it's important to allow my partner dignity" (#47), 86.9% said "We try to maintain a positive attitude (#20), and 81.2% said "I'm impressed with how my spouse has coped with the disease" (#80). Six statements in this cluster had means above 3.50. Sixty-nine point five percent said that, "We've learned about each other's strengths and weaknesses" (#35), 66.7% endorsed "We're aware of the preciousness of what we have" (#34), and 62.3% reported being "more supportive of my spouse" (#87). About 62.3% said, "We find ways to adapt so we can still do some things we enjoy" (#31), 57.3% said they "spend more time together" (#93), and 55.8% claimed that MS "made us more aware of other people's problems". Table 10 contains the complete list of statement means according to cluster.

Cluster #5 (Feeling Burdened) was endorsed second by partners with seven statements having means over 3.00. Sixty-eight percent of partners said that "My

Table 10

Item Means and Percentages for Partner-Endorsed Statements by Cluster

Statement	**% Partner Endorsed Items**		
	Mean	**1 and 2**	**4 and 5**
Cluster #1 - Lifestyle Changes			
1. We have to plan our days, our weeks ahead of time.	2.72	45.6	32.4
8. We had to adapt the house to accommodate the wheelchair.	2.31	66.7	29.4
11. I miss some of the activities we used to do together.	3.19	35.2	44.1
18. Fatigue plays a big role in our lives.	4.01	14.4	72.4
29. The pace of our life has slowed down.	3.23	39.1	44.9
30. MS makes it difficult to plan for the future.	2.96	41.8	37.3
43. We can no longer do a lot of the things we used to do.	3.17	37.5	42.2
53. Evening social events are a thing of the past.	2.41	57.4	29.4
63. We have to live near appropriate doctors and hospitals.	2.09	71.6	23.8
83. We have had to make some decisions we wouldn't have made without the MS.	3.31	35.2	50.0
84. Purchased new house that was an open floor plan.	2.77	53.5	46.5
85. Entertaining much less because my partner gets too tired.	2.94	44.6	40.0
89. Keep a quiet home for rest periods.	3.08	37.9	42.4
92. Traveling more difficult.	3.41	34.8	50.7
94. It shattered our dreams about having children.	1.58	80.6	11.1
96. Time together is in sedentary activities.	2.85	40.9	36.4
Cluster Mean	2.88	46.1	39.6
Cluster #2 - Uncertainty About the Future			
7. I'm frustrated by the uncertainty of not knowing what will be ahead.	2.82	47.9	38.2
75. I feel insecure about the future.	2.56	51.5	23.5
76. There was a shattering of our dreams for the future.	2.72	50.0	29.4
Cluster Mean	2.70	49.8	30.4

Table 10 (continued)

Cluster #3 - Financial Issues			
9. There were a lot of added expenses.	2.75	46.1	32.3
79. Financially it's been difficult.	2.59	60.3	29.5
95. We've had to plan financially more for the future.	3.20	33.3	44.0
Cluster Mean	2.85	46.6	35.3
Cluster #4 - Emotional Reactions			
22. The shock of diagnosis strained the relationship.	1.97	73.9	13.8
24. Caregiving creates a lot of stress.	2.86	45.4	37.5
33. I feel hurt and resentful we longer have a sexual relationship.	2.23	65.4	19.2
37. The most impactful part of MS has been the emotional.	3.38	25.0	50.0
38. I'm constantly driven crazy by the unpredictability.	2.09	68.1	13.0
49. I often feel guilty because my partner is ill.	2.19	63.2	22.1
51. It's very stressful dealing with a chronic illness.	3.23	36.0	51.6
52. We no longer have a sexual relationship.	2.51	50.8	22.9
58. I don't share with people what I'm going through.	2.88	42.2	37.5
60. Our sexual life was greatly affected.	2.93	49.2	40.3
66. Spouse's thinking and memory problems cause poor communications.	2.48	53.8	26.1
71. I didn't tell people so there was a lot of covering up.	1.85	72.7	12.1
72. I feel depressed a lot of the time.	2.10	68.7	14.9
74. I fear my partner being totally dependent on me.	2.55	57.9	29.0
77. I withdrew from people.	1.78	79.1	10.5
78. I feared that my partner would no longer be able to work.	2.49	60.0	32.3
82. I get angry and annoyed about having to live with MS.	2.43	60.9	26.0
97. Stressful relationship because of constant and unpredictable change.	2.42	56.5	24.6
98. Embarrassed about my partner's behavior around other people.	1.49	90.0	7.2
Cluster Mean	2.41	58.9	25.8
Cluster #5 - Feeling Burdened			
2. I have to do all the driving for the children.	2.35	59.4	21.6
3. I feel like everybody depends on me.	3.17	34.9	45.4
13. It was no longer the two of us raising the family.	2.12	66.7	23.8

Table 10 (continued)

14. I feel like I have to do everything.	2.81	50.0	41.2
21. Much of the household responsibilities are on my shoulders.	3.26	33.8	47.0
23. My partner really needs me.	3.93	18.8	68.1
25. We're more careful in expressing our feelings.	2.59	45.6	23.5
46. I think of myself as a back-up to do whatever my partner cannot do.	3.33	33.3	53.6
56. I try not to burden my partner.	3.51	22.3	55.3
61. I had to take over handling all the finances.	2.48	62.1	31.8
62. I feel it is my duty to take care of things.	3.19	36.8	47.0
73. I feel I have to be stronger and more independent.	3.18	38.2	48.5
91. Roles have changed.	2.94	40.9	40.9
Cluster Mean	2.99	41.8	42.1
Cluster #6 - Sense of Losing Spouse			
4. In a sense I have lost my spouse.	2.27	65.7	25.3
28. We no longer feel like equals.	2.17	63.1	21.6
36. Conversation seems to be centered on the needs of the person with MS.	2.62	50.7	30.4
39. The person that I'd married no longer existed in many ways.	2.29	62.2	21.3
44. I feel I always need to evaluate how my partner is feeling before I talk to him/her.	2.53	53.0	27.9
45. We don't make decisions together any more.	1.80	79.7	10.1
48. I have to screen out what is illness related from what is personality related.	2.82	42.4	36.4
50. With MS I cannot look at my partner and assume he or she is fine.	2.85	47.7	30.8
57. I can't be straight forward in my feelings.	2.43	59.7	25.4
59. I no longer have somebody to talk things over with.	2.17	65.7	20.4
65. Reduced companionship.	1.97	73.1	16.5
81. One area of conflict is I try to do too much for my partner.	2.55	55.0	29.0
Cluster Mean	2.37	59.8	24.6
Cluster #7 - Stresses			
5. I feel MS has contributed to my own illness.	1.61	83.3	11.2
10. The physical and emotional needs of the ill spouse come first.	3.87	12.9	65.8

Table 10 (continued)

32. At times I feel very begrudging for the things I'm doing for my partner.	2.09	70.6	20.6
40. It takes an incredible amount of emotional awareness and energy to cope.	2.90	44.9	42.0
41. It's difficult to cope with all the expectations placed on me.	2.44	51.5	22.0
64. Days are often long and boring.	1.67	81.9	9.0
67. Reduced greatly my free time to do many little things.	2.44	55.9	26.4
70. I am constantly concerned about my partner's health.	3.94	15.9	72.4
Cluster Mean	2.62	52.1	33.7
Cluster #8 - Changes in Approach to Life			
6. MS changed my outlook on life.	3.36	26.9	50.8
12. I needed a support group to help understand my feelings.	1.91	71.2	15.2
26. We no longer fight the way we used to.	2.30	60.4	15.1
42. I find I need space away from my partner.	2.70	49.2	33.3
54. I have been able to put my own fear into perspective more.	3.03	37.5	35.9
68. More sharing of responsibilities.	2.78	43.1	30.7
69. I had to learn to live more day by day.	2.76	43.2	35.8
90. I have to do many activities on my own.	3.12	37.3	47.8
Cluster Mean	2.75	46.1	33.1
Cluster #9 - Positive Impact			
15. It's made us much more aware of having a healthier lifestyle.	3.25	34.8	42.0
16. MS has made us closer in our relationship.	3.03	42.9	45.8
17. We understand each other better.	3.10	45.3	47.1
19. We take time for ourselves independently.	2.91	41.8	34.3
20. We try to maintain a positive attitude towards life.	4.32	4.2	86.9
27. Caring for my partner has given me a sense of fulfillment.	2.70	46.0	27.0
31. We find ways to adapt so we can still do some things we enjoy.	3.67	18.8	62.3
34. We're aware of the preciousness of what we have.	3.94	13.0	66.7

35. We've learned about each other's strengths and weaknesses.	3.84	14.4	69.5
47. I believe it's important to allow my partner dignity.	4.68	1.5	95.5
55. My strong faith is a resource.	3.06	33.9	38.7
80. I'm impressed with how my spouse has coped with the disease.	4.33	7.2	81.2
86. We've refocused on priorities in life like health, friends, and family.	3.47	22.1	52.9
87. I'm more supportive of my spouse.	3.81	17.3	62.3
88. Made us more aware of other people's problems.	3.60	20.5	55.8
93. We spend more time together.	3.41	23.5	48.5
Cluster Mean	3.57	24.2	57.3

partner really needs me" (#23), while 55.3% said "I try not to burden my partner" (#56). Fifty-three percent endorsed "I think of myself as a back-up to do whatever my partner cannot do" (#41), while 47% said "Much of the household responsibilities are on my shoulders" (#21), and "I feel it is my duty to take care of things" (#62). Forty-nine percent agreed with the statement "I feel I have to be stronger and more independent" (#73) and 45.4% said "I feel like everybody depends on me" (#3).

Cluster #1 (Lifestyle Changes) contained six statements with means above 3.00. Seventy-two percent indicated that "Fatigue plays a big role in our lives" (#18) and 50% indicated "We have had to make some decisions we wouldn't have made without the MS" (#83). Forty-five percent endorsed "The pace of our life has slowed down" (#29), while 44.1% said "I miss some of the activities we use to do together" (#11) About 42.2% said "We can no longer do a lot of the things we used to do" (#43), and 42.4% "Keep a quiet home for rest periods" (#89).

One cluster (#8, Changes in Approach to Life) had three statements with means greater than 3.5. Fifty-one percent said "MS changed my outlook on life" (#6), 47.8% endorsed "I have to do many activities on my own" (#90) and 36% said "I have been able to put my own fear into perspective more" (#54).

Two clusters contained two statements that were ranked in the top 36 items (means above 3.00). First, from cluster #4 (Emotional Reactions), 51.6% indicated that "It's very stressful dealing with a chronic illness" (#51) and 50% indicated that "The most impactful part of MS has been the emotional" (#37). Second, from cluster #7 (Stresses), 65.8% endorsed the statement "The physical and emotional needs of the ill spouse come first" (#10), and 72.4% endorsed the statement "I am constantly concerned about my partner's health" (#70).

Cluster #3 (Financial Issues) contained only one statement in the top 36. Forty-four percent said "We've had to plan financially more for the future" (#95). Clusters #2 (Uncertainty About the Future) and #6, (Sense of Losing Spouse) contained no statements with means greater than 3.00.

Twelve statements in cluster #4 (Emotional Reactions) were negatively endorsed by partners and had means less than 2.50. This indicated that partners perceived that these statements did not apply to them very much. Only 7.2% endorsed the statement "Embarrassed about my partner's behavior around other people" (#98), 10.5% reported "I withdrew from people" (#77), 12.1% said "I didn't tell people so there was a lot of covering up" (#71), and 13.8% said that "The shock of diagnosis strained the relationship" (#22). Thirteen percent endorsed the statement "I'm constantly driven crazy by the unpredictability" (#38), 19.2% endorsed "I feel hurt and resentful we no longer have a sexual relationship" (#33), 14.9% said "I feel depressed a lot of the time" (#72), and 22.1% said "I often feel guilty because my partner is ill" (#49). Other cluster #4 statements with means less than 2.5 were: "I get angry and annoyed about having to live with MS" (#82), "Stressful relationship because of constant and unpredictable change" (#97), and "Spouses thinking and memory problems cause poor communications" (#66).

Cluster #6 (Sense of Losing Spouse) had seven statements with means less than 2.50. Only 10.1% said "We don't make decisions together anymore" (#45), 16.5% said they experienced "Reduced companionship" (#65), and 20.4% said "I no longer have somebody to talk things over with" (#59). Twenty-one percent indicated that "The person that I'd married no longer existed in many ways" (#39), 21% said "We no longer feel like equals" (#28), 25% said "In a sense I have lost my spouse" (#4), and 25% indicated "I can't be straight forward in my feelings" (#57).

Cluster #7 (Stresses) contained five out of eight with means less than 2.50. Nine percent endorsed the statement "Days are often long and boring" (#64), 11% felt "MS has contributed to my own illness" (#5), 21% endorsed "At times I feel very begrudging for the things I'm doing for my partner" (#32), 22% said "It's difficult to cope with all the expectations placed on me" (#41), and 26% said MS "Reduced greatly my free time to do many little things" (#67).

Partners were also asked to rate their level of marital satisfaction. The mean for this question was 4.18, with 84% of partners indicating that they are moderately or very satisfied with their marriage. Five percent endorsed the neutral category and 12% endorsed the moderately or very dissatisfied category.

Partner Group Comparisons

A statistical analysis was conducted to determine if partners perceived significance/applicability of each statement varied based on gender, age, marital status, years with partner, years since diagnosis of partner, disease course of partner, MS symptoms of partner, years of education, employment status and reported level of satisfaction with the present relationship. Each of these variables was split into two groups and multiple t-tests were conducted on each of the 98 partner survey statements. T-tests need to be interpreted with caution because of the lack of random sampling in this study. In addition, increases in Type I errors typically occur when an increasing number of contracts are to be computed (Rosenthal & Rubin, 1984).

The group categories compared were: male versus female, under 45 years old versus 45 years and older, married versus separated/divorced, less than 20 years versus more than 20 years living with present partner, less than 10 years versus more than 10 years since diagnosis of partner, chronic progressive versus remitting/relapsing disease course of partner, physical symptoms only versus physical plus emotional and/or cognitive symptoms in partner, more than 12 years of formal education versus grade 12 or less, employed outside the home versus not employed outside, and moderately or very satisfied with the marriage versus neutral or dissatisfied.

An alpha level of .05 was used for all statistical tests. The alpha level to achieve significance was adjusted using the Bonferroni correction to correct for increases in type I errors that occur with increasing numbers of contrasts (Rosenthal & Rubin, 1984). Levene's Test for Equality of Variances was utilized in interpreting the t-tests.

Partner Survey Statements

A t-test statistic was calculated for each of the 98 partner statements on each of the split demographic variables. Gender was the first variable examined. Approximately 64% of partner respondents were male and 36% were female. Given the gender differential for MS in the population, the higher percentage of male partners appears to be proportional. However, the sampling in this study was not completely random, and therefore the t-test results should be interpreted with caution. Of the 98 statements analyzed, significant gender differences were observed on 2 items (Appendix U). Both statements with means that were significantly different with regard to gender were perceived to be more applicable to female partners. In this category were the statements, "In a sense I have lost my spouse" (t[64]=-3.61, p<.05), and "I feared that my partner would no longer be able to work" (t[62]=-3.56, p<.05).

Age differences were examined next and one statement was found to be significantly different for respondents under 45 years of age compared with those 45 years of age and older - "I often feel guilty because my partner is ill" (t[49.89]=-3.40,

$p<.05$). No statements had significantly different means for partners who had been in the present relationship for 20 or more years compared with those in relationships of less than 20 years. However, 11 statements were found to be significantly different for those with partners diagnosed more than 10 years ago compared to those whose partners were diagnosed less than 10 years ago. Displayed in Appendix U are the 11 statements, the means for each group, and the p value. Each of the 11 statements were perceived to be more relevant or applicable to those with a partner diagnosed ten or more years ago. Examples include "Caregiving creates a lot of stress" ($t[61]=3.73$, $p<.05$), "I feel like everyone depends on me" ($t[63]=3.44$, $p<.05$), and "Conversation seems to be centered on the needs of the person with MS" ($t[66]=4.16$, $p<.05$).

A comparison between respondents with partners who have a chronic progressive disease course and those whose partners have a remitting/relapsing disease course resulted in 5 statements with statistically significant differences. For each of the 5 statements, the mean was higher for those with partners with a chronic progressive disease course suggesting that these statements are more applicable to those in that category. The 5 statements were: "We had to adapt the house to accommodate the wheelchair" ($t[37.55]=-4.78$, $p<.05$), "There were a lot of added expenses" ($t[57]=-4.11$, $p<.05$), "I feel like I have to do everything" ($t[58.19]=-3.36$, $p<.05$), "My partner really needs me" ($t[43.87]=-4.30$, $p<.05$), and "Evening social events are a thing of the past" ($t[59]=-3.35$, $p<.05$).

One statement was found to be significantly different for those whose partners reported only physical symptoms. The statement "I'm impressed with how my spouse has coped with the disease" ($t[58.00]=-5.30$, $p<.05$) was statistically more likely to be endorsed by those whose partners had only physical MS symptoms. This result should be interpreted with caution given the small number of respondents who reported only physical symptoms.

A comparison of partners with more than 12 years of formal education and those with 12 or less years of formal education resulted in no statements that were significantly different. Two statements presented in Appendix U demonstrated statistically higher means for those whose partners were not employed outside the home. These statements were: "Keep a quiet home for rest periods" ($\underline{t}[63]=-3.43$, $\underline{p}<.05$), and "We spend more time together" ($\underline{t}[65]=-3.94$, $\underline{p}<.05$).

A final comparison was made on the 98 partner statements between those who reported they were moderately or very satisfied with their marriage and those reporting a neutral response or dissatisfaction with their marriage. However, because of the small size of the neutral/dissatisfied group, these t-tests must be interpreted with caution. Three statements had statistically significant higher means for partners reporting satisfaction with their marriage. These were "We understand each other better" ($\underline{t}[62]=3.50$, $\underline{p}<.05$), "We find ways to adapt so we can still do some things we enjoy" ($\underline{t}[23.28]=3.75$, $\underline{p}<.05$), and "We're aware of the preciousness of what we have" ($\underline{t}[63]=4.02$, $\underline{p}<.05$). Seven statements had significantly higher means for those reporting a neutral response or dissatisfaction with their marriage (see Appendix U). Examples include "At times I feel very begrudging for the things I'm doing for my partner" ($\underline{t}[63]=-4.24$, $\underline{p}<.05$), "The person that I'd married no longer existed in many ways" ($\underline{t}[62]=-3.84$, $\underline{p}<.05$), and "It takes an incredible amount of emotional awareness and energy to cope" ($\underline{t}[16.92]=-3.84$, $\underline{p}<.05$).

Survey Respondents' Additional Comments

At the end of the surveys, both patients and partners were asked to list any areas of their marital experience with MS which were not included in the questionnaire. Although none listed any excluded areas, several wrote some heartfelt comments about their experience. Some examples are included.

One female MS patient wrote: "We've worked so hard to educate ourselves and have a good life. I'm angry that none of it matters, since our material and emotional lives, and those of our children hang on the whims of a capricious and destructive disease that I am powerless to fight. I love every day that I can get up, think straight, drive to work and come home again, exhausted. At the end of each day I can say I have done my best for my husband and children by continuing to honor all my roles as well as I can. I hope and pray that I will be able to continue to do so."

A male MS patient included this statement: "At first we were very disappointed at not being able to go on planned trips or evenings out, but eventually we learned to make all plans conditional on my condition, and therefore only be slightly disappointed at missing things because of MS. My wife has been truly understanding and supportive. Where I used to help with the household chores, now she does them all herself without complaining. She attends a monthly support group with me to enhance her understanding, as well as reading books and articles. She's always concerned about how I'm doing and even gives me my Betaseron shots. Without all the big (and little) things she does in such a caring manner, I would have great difficulty in coping emotionally and physically with MS (especially in our sexual relationship)".

Another female patient wrote: "My life is full of blessings: my faith, my wonderful husband, 4 healthy happy grown children, 3 grandchildren (so far), a family business, a peaceful home and friends. A person can choose what he puts his mind on and I choose to dwell on the positives. If I'm slow and awkward so what! When I get to Heaven, I won't have MS any more!"

Although the difficulty in writing was apparent by the handwriting, another wrote: "My husband and I were married after my diagnosis, so he knew what conditions he was going to be dealing with. My love for my husband is doubled because of the way he understands me and my disease. I don't have MS, WE have MS."

And yet another wrote: "I believe my husband thinks if he doesn't talk about it and he ignores it long enough my MS will go away. When I have 2 or 3 very good days, he forgets I have MS."

Several partners also wrote comments on the back of the survey. Both male and female partners appeared to have a need to express the difficulties of having a partner with MS. I sensed from the writings of these people their need to share their experience with someone who they perceived would be interested. For many of them, they don't want to burden friends and family. These people do not complain but instead do whatever they need to do to help alleviate the difficulties their partners experience due to MS. They cope with taking on the additional roles that their partners can no longer fulfill and they do this within the isolation of their homes. The following quotes stand alone. They illuminate the partner experience in a very profound and personal manner.

"We learned to cope slowly as my husband was ill with a bowel disease for many years prior to MS diagnosis. I do need to work two jobs and pick up extra hours whenever I can. My husband worked in a highly paying position, and lost his income and has had to return to school at very little income. His medication adds up and sometimes we struggle. We try to stay positive and do our best. Sometimes it is difficult and as a result of prior stress, I spent 7 weeks hospitalized for a nervous breakdown, but with my husband's help , we both are getting over it and find comfort in each other and our two children."

"Total exhaustion physically, mentally, emotionally (also spiritual) and much deep depression because of all the problems caused by MS. Being the breadwinner and caregiver is beyond one person but you don't discover this till you become ill yourself and disabled because before illness of self you are doing too many things to think about yourself. It is like continual slavery but you don't think about it at the time. Many hours of work outside the home and inside the home and very little sleep for year after year. Four to five hours sleep per night because so many little things to do."

"Our marriage started to have problems when he first started having symptoms. I thought they were just normal problems every couple goes through at the time, since he hadn't been diagnosed yet. Looking back now, I believe MS caused our divorce. Then I went through a period dealing with guilt feelings. But thank God we have still maintained a friendship and I am still around if he needs me."

"My husband has always been loving, supportive and my best friend. We were high school sweethearts and have known each other for 28 years. It is sometimes disappointing when at a wedding we can't dance - but if we can dance even just one song. We cherish the time and are grateful that we can slow dance (through one song). We concentrate mostly on what we both can do together. So we go to movies and eat out or entertain and try to do activities that won't involve walking too long for a period of time. Our sex life has slowed down from above average. We also have had to be creative and adjust ways to please each other. We still are very much in love. We cherish and treasure each day spent together. Our lord plays an important part in our lives. We do a daily couple devotional - so we are growing both spiritually, physically and emotionally together! I believe our feelings and emotions are just starting to unfold - since diagnosis! Our daughter says MS is a constant stress even if we don't realize it and when something little comes along sometimes it is hard to cope or I overreact. I think she is right, but I'm not aware it is a constant stress."

"I feel robbed of the best years of our life together. The unpredictability of the progression of the disease makes it very stressful to live with."

"Friends and medical care was thanked for care and support. The spouse was expected to provide 24 hour care for the MS partner, family, work, etc. with no thanks or recognition."

"By my wife dealing with MS and myself a motor vehicle accident, our dealing with our difficulties has brought us closer together."

"My spouse feels life is supposed to be all about him. He has changed dramatically and you need support from family and I have none from his. It is very difficult to keep your sanity plus we have 2 children ages 8 and 11."

"MS is simply another hurdle in life. For some people the death of a family member can be just as traumatic and emotionally crippling. We have been able to accept her illness as such, albeit, it is easier for me to accept since I have never had to feel the helplessness she feels sometimes in a body that doesn't want to work correctly. I feel your survey didn't stress the pride and admiration I have for her. I've seen a maturity and courage come forth that make me proud to be by her side when she is sick, not ashamed or guilty as the survey would suggest. I feel that stating that I don't feel guilty or ashamed simply does not convey what I truly feel."

I was extremely moved by the written experiences of these people. For me it put the statistics of the study into perspective. I was impressed with the courage and positive approach displayed by the patients and their partners in coping and living with this unpredictable and devastating disease.

CHAPTER 5: SUMMARY, DISCUSSION AND FUTURE DIRECTIONS

The purpose of this research was to gain a better understanding of the perceptions of the impact of MS on marital life from the individual perspectives of the MS patients and their partners. The first objective of this investigation was to identify the statements that individuals who have MS and their partners perceived to be relevant to their experience. The second objective was to analyze the statements that emerged and use concept mapping to determine the themes underlying the identified experiences. Two separate lists, a patient list containing 97 statements, and a partner list containing 98 statements were identified and subsequently sorted by 14 psychologists/psychology students. The sorts were statistically analyzed using multidimensional scaling and hierarchical cluster analysis (concept mapping) to identify potential themes. As a result of this process, a concept map was generated for patients that consisted of 11 themes: positive impact on marital life, coping and adaptation, sexual issues, financial issues, role of spirituality, lifestyle changes, perceived losses, negative impact on marital life, insecurity about the future, emotional reactions, and anxiety and fears. The concept map developed separately for partners consisted of 9 themes: lifestyle changes, uncertainty about future, financial issues, emotional reactions, feeling burdened, sense of losing spouse, stresses, changes in approach to life, and positive impact.

The third objective was to determine how relevant each of the identified statements was to MS patients and their partners. Two incidence surveys were developed using the statements from Phase one and were distributed to a sample of patients and partners (n=170 couples). Group comparisons of the statement data were made by gender, age, marital status, years with partner, years since diagnosis, disease course, symptoms, education, employment, and self report of marital satisfaction.

Results indicated that there is considerable variation in the perceptions of patients on the impact of MS on marital life. In general, MS patients were more likely to endorse survey questions that were positive and adaptive. Six statements had means greater than 4.00 and a total of 32 statements had means greater than 3.00 (indicating that they perceived the statement applying to them a fair amount or a great deal).

The theme of coping and adaptation (cluster #2) contained the most patient-endorsed statements, with eight statements having means greater than 3.00. cluster #1 (Positive Impact on Marital Life) contained six of the top 32 statements while cluster #7 (Perceived losses) was ranked third with four of the top items. Cluster #10 (Emotional Reactions) and cluster #11 (Anxieties and Fears) each contained 3 items with means above 3.00. Three clusters contained two statements that were ranked in the top 32 items. These were cluster #3 (Sexual Issues), cluster #4 (Financial Issues) and cluster #6 (Lifestyle Changes).

A statistical analysis was conducted to determine if the perceived applicability of each patient survey item differed significantly based on gender, age, current marital status, years with current partner, years since diagnosis, disease course, symptoms, years of education, employment status and reported satisfaction with the current relationship. Several items were found to be endorsed significantly differently based on these demographic variables.

Considerable variation in partner responses also existed in the perceived impact of MS on marital life. It was evident that partners were focused on being supportive and helping their partners to cope with the disease. However, it was also apparent that partners experienced stress and feeling burdened in the process of coping with their spouses' MS. A total of 36 statements had means greater than 3.00 indicating that partners perceived these items to apply a fair amount or a great deal to their experience.

The findings indicated that cluster #9 (Positive Changes) was the most relevant cluster for partners, with 15 out of the 17 items in this cluster having means greater than 3.00. Feeling burdened (cluster #5) was ranked second in relevance by partners with seven out of the top-ranked 36 items. Next in perceived relevance was cluster #1 (Lifestyle Changes) which contained six statements with means above 3.00, and cluster #8 (changes in approach to life) which had three statements with means above 3.00. The least relevant partner clusters were clusters #4 (Emotional Reactions) and #7 (Stresses) which each contained two statements with means greater than 3.00, and cluster #3 (Financial Issues) which had only one item out of the top 36.

A statistical analysis utilizing t-tests was conducted to determine if the perceived significance/applicability for each partner survey item differed according to various demographic variables. Significant differences were found based on gender, age, years since diagnosis of partner, disease course of partner, MS symptoms of partner, employment status and reported level of satisfaction with the present relationship.

Respondents were also asked to rate the present level of satisfaction with their marriage. Approximately 57% of patients reported they were very satisfied with their marriage and another 20% said they were moderately satisfied. Eight percent of patients gave a neutral response. Nine percent of patients reported they were moderately dissatisfied and 5% said they were very dissatisfied.

Approximately 54% of partners indicated they were very satisfied with their marriage and 30% said they were moderately satisfied. Five percent of partners gave a neutral response. Five percent reported that they were moderately dissatisfied and 8% reported they were very dissatisfied with their marriage.

Divorced or separated respondents were asked to indicate the degree to which they perceived that MS had been a factor in their divorce or separation. Of the 21 patient respondents 62% said MS had contributed a fair amount or had been a major factor in their divorce/separation. Only seven of the partner respondents were divorced. Of these, the majority indicated that MS contributed not at all or only a little to the divorce/separation.

Discussion

Few studies have investigated the impact of MS on marital life and the studies that have appeared have addressed specific issues such as spousal social support and coping, spousal caregiving, and marital adjustment. Both the patient and partner concept maps describe some concepts that have received little attention in the literature regarding the impact of MS on marital life. However, some of the concepts support findings in the existing research literature.

Marital adjustment has frequently been found to improve as a result of illness (Lichtman, Taylor & Wood, 1987). This suggests that positive interactions can be facilitated by illness. Both the patient concept map and the partner concept map contained a theme about the "positive impact of MS on marital life".

Patients indicated that they felt closer because of MS and that the illness had enabled them to spend more time together as well as caused them to work on their communication. Patients said that as a result of MS there was more sharing of the running of the household and child care. MS was perceived as helping patients to appreciate their partner more.

Partners indicated that MS had made them closer in their relationship and enabled them to spend more time together. Partners said that due to MS they had come to understand each other better and were more aware of living a healthy lifestyle. MS was thought to have helped the couple to focus on priorities in life.

Wineman et al. (1993) discussed the necessity of coming to terms with the illness in order to manage the necessary modifications in daily life. The patient concept map contained a theme related to coping and adaptive to MS. This theme focused on trying to make the best of things, taking one day at a time and making decisions based on the possible long-term effects of MS. Patients also emphasized the importance of not dwelling on the MS and attempting to keep themselves and their families as normal as possible. A separate patient theme dealing with coping was the role of spirituality. The partner concept map contained a theme related to changes in approach to life based on MS. Partners emphasized learning to live more day by day, doing more things on their own and sharing the household responsibilities.

Along the lines of coping with the day to day adjustments required by the illness, both the patient and the partner maps contained a theme related to lifestyle changes. In each of the maps this theme related to changes in activities, social life, and also in roles and relating to each other.

Both the patient and partner maps had a theme relating to financial issues indicating the extra financial burden caused by MS. There was a separate patient theme dealing with sexual issues such as changes in the sexual relationship and adjustments that had to be made sexually.

Wineman et al. (1993) also examined how each spouse's perception of illness uncertainty in MS influences the emotional well-being of the couple. The partner concept map contained a theme related to uncertainty about the future. Partners indicated they felt insecure about the future, had experienced a shattering of dreams for the future and were frustrated by the uncertainty of not knowing what will be ahead. The patient map contained a theme related to insecurity about the future. However, patients were insecure about the future of the relationship. Statements in this theme included "I am careful with my partner because I need the security of the relationship" and "We might be together now only because I am financially dependent". Other statements were "I feel my partner stays under obligation" and "I worry that I'm hanging on to the relationship because of the caregiving".

Stuifbergen (1992) found that spouses were one of the major sources of emotional support to help patients cope with their thoughts and feelings about MS. The statement in the patient concept map theme of emotional reactions with the highest bridging index (1.00) was the statement "My partner worries about me". Patients reported feeling devalued because of MS, feeling guilty about having MS, feeling frustrated by the continual losses, feeling angry at the disease and having trouble keeping their spirits up. Another patient map theme revolved around anxieties and fears. These fears and anxieties focused on the marital partner. Patients reported feeling unequal to their partner, resentful that their partner had more control and feeling that they had let their partner down. Patients reported feeling emotionally alone, fearful of losing their family, and increasing anxiety of losing their partner through separation or death. Patients also worried about becoming a burden and becoming totally dependent on their partner.

The partner emotional reaction theme focused on negative emotions; for example "I'm constantly driven crazy by the unpredictability", "I feel depressed a lot of the time", and "I get angry and annoyed about having to live with MS". These emotional reactions mirror those obtained in the Corbin and Strauss 1988 study in which loneliness, depression, frustration, and mental exhaustion were found to be association with spousal caregiving.

Negative emotional reactions in both patients and partners are more likely in those that are divorced/separated, and in those that reported a neutral feeling or dissatisfaction with the marriage. McNett (1987) found that people's perception of support helped them to cope with living with an unpredictable, chronic disease. Perceived unsupportiveness was associated with an increase in negative emotional reactions. Several research studies suggest that perceived spousal social support is a crucial factor in coping with the demands of physical illness and disability (McIvor et al., 1984, Weinert, 1983, O'Brien, 1993a).

Strauss et al. (1984) noted that chronic illness requires the spouse to do the things that the ill person cannot do. The many physical, social, and emotional disabilities associated with MS can result in dependency on spouses. Decker and Young (1991) noted that dependency needs in the chronically ill can have an adverse effect on the spouse. Several researchers have addressed the issue of caretaker stress among spouses of MS patients (O'Brien, 1993; White et al., 1993; Gulick, 1995; Cockerill & Warren, 1990; DesRosier et al., 1992).

The partner concept map contained a theme related to feeling burdened that contained statements such as "I feel like I have to do everything", " I feel like everybody depends on me" and "I think of myself as a back-up to do whatever my partner cannot do". A separate partner theme related to the stresses experienced as a result of caregiving. Examples of statements in this theme are: "I feel MS has contributed to my own illness", "I am constantly concerned about my partner's health" and "It takes an incredible amount of emotional awareness and energy to cope".

A theme in the patient map specifically addressed the negative impact of MS on marital life as perceived by patients. This theme included general statements such as, "We have more conflict in our marriage due to MS", "The marriage relationship became less and less", and "MS has shown me that our marriage is not as secure as I thought it was". Also included in this theme were negative partner reactions such as "My partner withdrew from me", "My partner didn't cope well" and "Spouse doesn't understand what I'm going through". Carter and Carter (1994) found that devitalization of marriages can result when illness worsens over time and erodes the resilience of the coping system. In the present study a number of the statements in the negative impact on marriage theme were significantly more applicable to those with a diagnosis of 10 or more years.

Conclusions

The objectives of this study were to identify the areas of impact on marital life perceived by MS patients and their partners, and to determine if these areas reflected underlying themes or categories. Ninety-seven statements were identified by patients and 98 statements by partners. The development and interpretation of the two concept maps created from those statements indicated some themes previously cited in the literature as well as other concepts that were largely unrepresented.

The concepts defined by patients seemed to center on coping and adaption and the positive impact of MS on marital life. The central themes defined by partners included being supportive and helping their partners cope with their disease as well as feeling the stress and burden of this supportive role.

Results from the survey data suggests that there is considerable variation in the personal experience of the impact of MS on marital life for both patients and partners. Themes contained both positive and negative aspects which may provide a more comprehensive representation of the domain specific to the experience of MS on marital life. Significant differences based on demographics were found on several of the survey items suggesting the complications in discussing multiple sclerosis because of the variety of forms the disease assumes.

Limitations of the Study

The purpose of this study was exploratory in nature. The objectives were to, i) identify the issues, ii) to determine underlying themes and to identify those themes, iii) to determine the prevalence of these issues among couples in which one partner has MS. Interpretations must be conducted with the following limitations in mind. The study focused on the areas perceived by MS patients and their partners to impact on marital life. Volunteer participants in the initial statement gathering phase and the lack of random sampling created a potential selection bias. Thus, it does not purport to discuss the entire domain of the experience of MS on marital life.

Consistency in the manner that the surveys were completed was not under the researcher's control. For example, if the two partners filled out the survey together rather than independently the meaning of the results could be altered.

While the sample that responded to the survey approximated the MS population in terms of demographics, the generalizability of the findings must be carefully evaluated, and the application of these findings to other populations must be done with caution.

Future Research

Findings of this study have implications for future research. Additional studies are required to validate the results of this investigation and to explore their reliability with different groups of MS patients and their partners. A random sample of respondents is necessary in order to generalize the results.

This study confirmed the necessity to evaluate the patients' and their partners' perspectives on the impact of MS on marital life. The findings emphasized the importance of continuing in future research to incorporate the perspectives of those "living the experience" into measures of the impact of disease on family life.

A validation of the concept maps identified in the present study would be a worthwhile undertaking. Findings could be presented to health-care providers that work with this population. These individuals could be asked to comment on the concept maps and incidence data in relation to their professional experiences. It would be interesting to generate concept maps from patients and partners across the illness trajectory from just diagnosed to up to twenty or more years into the chronic illness. This would help to determine if changes occur in the perception of the impact of MS on marital life. Different maps could be produced for the different disease courses. Such research could provide key conceptual themes of similarities and differences in the experiences.

Another avenue for future research would be to extend this study to include the concerns of children in MS families. Little research has evaluated the effect of MS on children in the family.

With respect to the results of the survey, when generating the statements, priority was given to uncovering the uniqueness of the experience of MS patients and their partners. A logical next step would be to refine the statements into a psychometrically sound instrument that could be used to assess the marital life of MS patients. This might be helpful in identifying marriages at risk and to facilitate therapeutic intervention.

The writings that participants included on the backs of the surveys illustrate the powerful insights of those living the experience or "walking the walk". Further research of a more qualitative nature would further increase the knowledge of the experience of MS in marital relationships and families.

Practical Clinical Implications

The findings of this study have practical clinical implications. The care of the MS patient and partner is contingent upon not only physical but also psychological and social processes.

As indicated in the previous section, survey questions could be refined into a psychometrically sound instrument. This instrument could be used in clinical settings, with specific feedback, to familiarize newly diagnosed MS patients and their partners with the themes and "lived experiences" of others. This would provide an opportunity to inform these couples, investigate their needs and encourage family involvement. Marital checklists can be developed for the various stages, disease courses and symptoms of MS. These could be utilized by health-care providers to act as organizing devices for discussion, reviews of progress, and to anticipate and usurp future problems. This could be a valuable way of identifying high risk caregivers who might benefit from counselling. The impact of MS can be as devastating for the well spouse as it is for the afflicted person. Both must sacrifice personal goals and pleasures if the marriage is to be maintained. A healthy marriage offers security and a sense of being loved and worthwhile. This is perhaps the most important context within which the psychological aspects of this chronic illness can be managed. Caring within the context of chronic illness must include psychological and social issues to ultimately achieve the goals of alleviating human suffering, minimizing discomfort and enhancing the quality of life for all of those involved.

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Appendix A

Consent Form - Phase I Interview Volunteers

Project: Multiple Sclerosis and Marital Life

Investigator: Lynda Grant, Ph.D. Candidate
Department of Educational Psychology
University of Alberta

You are invited to take part in a study of how MS patients and their spouses view their marital life. If you choose to participate, all of your answers will remain completely confidential and will be used for research purposes only.

Although chronic illness poses additional stresses in addition to the everyday problems that families must deal with, a supportive marital relationship can also be a valuable coping resource. We know surprisingly little about how MS affects marital life. A better understanding of strengths, as well as the problems that many couples face, will allow us to provide better counseling services to those who want professional help and support.

Consent to Participate

I, ______________________________ voluntarily consent to participate in a study with Lynda Grant, Ph.D. student in counseling psychology at the University of Alberta. The purpose of this study has been explained to me. I understand that any information I provide will be treated as confidential and will be used solely for research purposes. While findings may be published in scientific journals, there will be no identification of me personally in these papers. All information will be reported in group form and will remain strictly anonymous.

I hereby give permission to be interviewed and for the interview to be tape-recorded. I understand that, at the completion of this research, the tape will be erased. I understand that I am free to deny any answer to specific questions. I also understand I am free to withdraw my consent and terminate my participation at any time without penalty.

______________________________	______________________________
Participant	Researcher
______________________________	______________________________
Address	Date

Appendix B

Demographic Questionnaire

1. Male or female
2. Age
3. MS patient/spouse of MS patient
4. Months/years married
5. Years since diagnosis of MS
6. Age at onset of MS
7. Disease course(if known)
    a. chronic progressive
    b. remitting relapsing
       -# of attacks per year
    c. Benign
8. MS symptoms - please check those applicable
    a. physical symptoms
    b. emotional symptoms
    c. cognitive symptoms
    d. other
9. Level of education
    a. grade school
    b. some high school
    c. high school
    d. business/technical school
    e. some college
    f. college degree
    g. some grad/professional school
    h. graduate school
10. Employment Status
    a. outside home
    b. homebound employment
    c. homemaker
    d. student/trainee

Appendix C

Multiple Sclerosis and Marital Life

Statement Instructions

A study is being carried out through the University of Alberta which will attempt to develop a better understanding of the issues that arise for couples in which one partner has a diagnosis of Multiple Sclerosis. The information collected in this study will be used to design a questionnaire to be used in a follow-up study to further assess the nature, frequency and perceived importance of the relevant issues.

Your thoughts and ideas are important to us. It would be appreciated if you would take a few minutes to answer the following questions. Your participation is strictly voluntary and there is no need to identify yourself. Your answers will be completely confidential and only group results will be used.

If you choose to complete this questionnaire, it will require about 20 minutes of your time. Return the completed questionnaire within two weeks of receiving it.

This research project is due to be completed by fall of 1996. Upon request, participants will receive a summary of the results. If you would like a copy of the results, forward your request to the address on the return envelope. For this request please use an envelope separate from the completed questionnaire.

Thank you for your time and effort. If you have any questions please contact Lynda Grant at 459-2790.

Lynda Grant, Ph.D. Candidate
Department of Educational Psychology
University of Alberta

Dr. Peter Calder, Professor
Department of Educational Psychology
University of Alberta

Appendix D

Statements

We would like you to make one sentence statements about your perception of the ways that MS has affected your marital life.

Please produce as many statements as you can to answer the following question.

In what ways has MS affected your marital life?

1.

2.

3.

4.

5.

6.

7.

8.

9.

10.

11.

12.

13.

14.

15.

Please use additional pages if required

Appendix E

Cover Letter to Sorting Participants

To Research Participants:

A study is being carried out through the University of Alberta to develop a better understanding of the issues that arise when one marital partner has Multiple Sclerosis. It is hoped that the results of this study will assist newly diagnosed MS couples as well as assist counselors in providing more effective services to their MS clients. Your participation in this project would be greatly appreciated.

Phase one of this study involved in-depth interviews from couples in which one partner has a diagnosis of Multiple Sclerosis. The transcribed interviews were analyzed to extract a set of meaning units or statements. Phase two of the study involves sorting the statements into groups or themes.

If you are willing to help with this project, please take a few minutes to complete the enclosed task. Then place the materials in the return envelope. Please do not sign your name. Your answers are completely confidential. Return of the sorting cards will be viewed as consent to participate in the project.

Thank you for agreeing to take part in this study and for giving so generously of your time and effort. If you have any questions, please contact Lynda Grant at 459-2790.

Sincerely,

Lynda Grant, Ph.D. Candidate
Department of Educational Psychology
University of Alberta

Dr. Peter Calder, Professor
Department of Educational Psychology
University of Alberta

Enclosures

Appendix F

Multiple Sclerosis and the Marital Relationship

Sorting Instructions

Enclosed in the attached envelope is a set of cards. Each card lists a statement that MS couples perceive as an issue in their marital life that has been affected by one partner having MS.

Please sort these statements into groups which you feel contain a common theme. Sort similar statements into piles that make sense to you. You can sort the statements into as many groups as you wish. Statements can be separate if you don't think they fit into any group. The following example shows several statements which have been grouped together along with the theme or topic of the group.

Example:

Statements:
1. I am a good person
2. I always do my best
3. I do many things well

Theme: positive view of self.

After you have sorted the statements into groups

-staple each group together (or if too thick use an elastic band)

-place all the groups into the attached envelope

-please note that your name is not required

Cover Letter to Research Participants - Questionnaires

To Research Participants:

A study is being carried out through the University of Alberta to develop a better understanding of the issues that arise when one marital partner has Multiple Sclerosis. It is hoped that the results of this study will assist newly diagnosed MS couples as well as assist counselors in providing more effective services to their MS clients.

The participation of you and your spouse would be greatly appreciated.

Part one of this study involves interviews with several MS couples and the enclosed open ended questionnaire. Your thoughts and ideas are important to us. It would be appreciated if you would take a few minutes to answer the attached questions. Your participation is strictly voluntary and there is no need to identify yourself. Your answers will be completely confidential and only group results will be used. Two questionnaires are included so that each partner can respond independently. However, it is not necessary for both partners to respond. People in common-law relationships and divorced individuals are also invited to participate.

If you choose to complete this questionnaire, it will require about 20 minutes of your time. Please return the completed questionnaire within two weeks of receiving it. Return your completed questionnaire in the prestamped return envelope provided. Return of the questionnaire will be viewed as consent to participate in the research project.

The information collected in this study will be used to design a questionnaire to be used in a follow-up study to further assess the nature, frequency and perceived importance of the relevant issues. This questionnaire will be sent to you at a later date if you choose to participate.

Upon request, participants will receive a summary of the results. If you would like a copy of results, forward your request to the address on the return envelope. To maintain confidentiality, please use an envelope separate from the questionnaires.

Thank you for your time and effort. If you have any questions, please contact Lynda Grant at 459-2790.

Sincerely,

Lynda Grant, Ph.D. Candidate
Department of Educational Psychology
University of Alberta

Appendix H

Multiple Sclerosis and the Marital Relationship

Rating Instructions - Questionnaire

A study was recently carried out at the University of Alberta to develop a better understanding of the issues that arise when on marital partner has Multiple Sclerosis. Based on this initial study, the following questionnaire has been developed.

You are asked to give each statement a rating that indicates to what degree the statement reflects your experience. Circle the number that most closely matches the degree to which the statement applies to you.

1	2	3	4	5
not at all	a little bit	medium amount	a fair amount	a great deal

After you have completed the questionnaire

- -please complete both the demographic and this portion of the questionnaire
    - -place the completed questionnaire into the attached envelope.
- -please note that you name is <u>not</u> required
- -drop the envelope into the mail - no postage is required

Appendix I

Oath of Confidentiality

Project: **Multiple Sclerosis and Marital Life**

Investigator: **Lynda Grant, Ph.D. Candidate**
Department of Educational Psychology
University of Alberta

I, ______________________________, swear that I will not, without undue authorization, disclose or make known any matter or thing which comes to my knowledge by reasons of my involvement in service of this project.

____
signature

____
date

____
witness

Appendix J

Original Master List of Patient Statements

Participant #1 (M)

1. It made us closer together in the sense that I'm home a lot.
2. It allows for more conflict in some ways.
3. More sharing of the running of the household and raising of children
4. Because I can't curl or golf I find I'm home more.
5. I don't have the energy to do things so I'm happy to stay home and take it easy.
6. I always have to come right home because I need the rest.
7. I only work half time so I can get supper ready for the family.
8. When I was just lying around I think there was a bit of friction or resentment.
9. My partner likes to go on walks and I can't really walk because I'm too tired.
10. We don't do that much together.
11. I don't go shopping anymore.
12. We can't go out dancing.
13. When we go on holidays we tend to just rest and relax.
14. She's on edge all the time because of my bathroom problems.
15. She's worried that I'll embarrass her.
16. The uncertainty probably causes a lot of stress and anxiety in our lives.
17. There's problems in traveling in that I'm not as mobile and then we won't go on tours and walks.
18. I'm more conscious of trying to make the best of things now. and then make things enjoyable and do things now.
19. Over the years I've become more confident in that I should be okay.
20. Anything that required physical dexterity or stamina I had to quit a long time ago.
21. We've stayed in this house for 23 years because it would be a shame to move into say a two story and then find out a year from now I can't make the stairs.
22. We've tended to be a bit more cautious of our money.
23. My wife is more considerate and to the point of being too considerate, always worrying about me.
24. My partner enjoys resting, relaxing staying at home, she doesn't want to always be going out.
25. My partner is the same home-body I am, nothing like home at night, just a fireplace and reading a book.
26. We have to make a conscious effort to find some common things we can still share.
27. I've spent some very worried times and depressed times.
28. The sexual problems aren't an issue for my partner.
29. We enjoy closeness without a sexual relationship.

Participant #2 (F)

30. It was a major problem for my husband because he couldn't come to terms really with living with an invalid.
31. My partner was embarrassed by me if we were at a dance and I fell down for instance.
32. My partner wanted what he considered to be a perfect partner and didn't have that.
33. My partner was quite sports minded and I couldn't keep up.
34. We gave up skating because I lost my balance very early on.
35. We used to curl together but the balance effected that.
36. The largest thing that seems to have effected a great deal of my life is the decision of not having had children because of the MS.
37. I didn't know I was pregnant when diagnosed and because of the tests the doctor said I would have a terribly deformed, deficient child so I had an abortion.
38. I didn't want to be different and I didn't tell people I had MS.
39. Every little niggling thing was hard for my partner.

40. My partner had real difficulty with my memory loss and difficulty with language skills, confusing words, etc.
41. My partner was dismayed if I introduced somebody by the wrong name.
42. My partner was convinced that my memory loss was for my convenience and that I was just being difficult.
43. He was upset that I couldn't go skiing and couldn't go golfing.
44. I learned I had to be quite methodical, put things in the same place all the time or I wouldn't remember where they were.
45. My second partner has gone through a lot of the cognitive things with me and that's been the most difficult thing I think.
46. I get lost very easily, I'm always lost, so he carries a book with him to wait for me.
47. When I'm lost I'll ask people for directions but mostly it's very embarrassing.
48. I've tried to stay looking and seeming as normal as possible.
49. When something happens that I recognize as MS I'm not prepared to share it with my partner.
50. It's frustrating when people say that you look good for having had multiple sclerosis for all this time.
51. I've given up a lot. I've given up children. I've given up a husband.
52. My partner and I applied to adopt and were turned down because of my MS twice.
53. Because of my memory problems my mind works slow plodding and methodological whereas my partner is exactly the opposite.
54. Some of the symptoms of my MS are so problematic that there are times when I can't do something or don't want to do something because it will be too uncomfortable for me or just about impossible.
55. I want to be independent and I don't want to be a burden on anyone.
56. I want to take my share and do it but it can't be that way.
57. If I were ten years younger and healthier I would make a major change. I would walk away from this relationship for awhile anyway.
58. Our finances have been affected because I'm not able to work full-time.
59. When I think of a way out it wouldn't happen right now but I think of suicide not leaving home. Not leaving the family, just leaving period.
60. I actually have considered suicide maybe three or four times seriously in my life.
61. I feel awfully guilty about having MS. It affects everyone around me, affects my whole family.
62. My illness is so unpredictable that sometimes there are things I just can't do, things I would want to do if I didn't have MS.
63. For your marriage to stay intact you can't lean on MS as a reason to not do things.
64. Because it's unpredictable I don't know what's ahead but I know there's going to be adjustments and changes.
65. This house we purchased when we came to Edmonton, picked particularly because it's all on one level and the rooms are large enough that a wheelchair can turn around in one.
66. Although it's important not to dwell on your MS, when you're making major decisions I don't think you can ever forget it either.

Participant #3 (M)

67. In my first marriage, 13 months after my diagnosis we decided to divorce.
68. The potential for being a caretaker, my partner couldn't realize that.
69. I just go with it as it comes, what we're doing it changing on a daily basis.
70. It's exceedingly frustrating, you're continually losing something.
71. It's continual losses we have to adjust to and find new ways of doing things.
72. It's hard to go from lover to caretaker and determining where the dividing line is.
73. I worry about becoming totally reliant and expectant on her.
74. The bladder condition gets to be a 24 hour chore.
75. Living with MS is a learning process for both of us.
76. There's extreme highs and lows. I'm exceedingly emotional.
77. It's frustrating for my partner to see someone she loves going down. It hurts deeply to see that.

78. There are times I wish I could be on my own so my partner wouldn't have to be subjected to all this crap.
79. Having arguments and being as normal couples have arguments is tough because I can't handle the stress.
80. We can't let arguments go on for days. I go my own way and in five minutes come back.
81. Our finances come strictly from my disability pension and Canada pension which makes me glad to still be the provider.
82. Control is an issue. There are some things that you begrudgingly give up but you hang on to anything which you have any control.
83. Giving up the job was very difficult.
84. I had to give up a lot of my previous types of recreation.
85. I see that I have immediate requirements and I'm not going to deny myself in anticipation of my retirement.
86. My work was an environment that was difficult to leave. I felt needed in that environment.
87. One thing that's failing is our married sexual intimacy.
88. Sexuality has been a major loss for my partner.
89. It's a juggle to keep the marital relationship going and taking precedence over the caretaker relationship.
90. It's totally looking from the outside on everything, it's frustrating not to be able to do anything, like chores and repairs around the home.
91. There's a loss of control and you become resentful that your partner has their own mind on how to tackle a problem that's not even remotely close to yours.
92. Before MS it's easy to walk away from an argument.
93. When is your partner a lover or a caretaker and are you hanging on because of the caregiving.
94. You see yourself in need of a lot of care in the future and it scares you.
95. You're intelligent enough to know that you're never going to know what lies ahead, but your mind is active enough telling what you see in other folks.
96. Because of my perception of where I'm going to be I want better for my partner.
97. I can't visit my daughters anymore because I can't negotiate the distance or the steps.
98. Finance is a big, big issue

<u>Partner #4 (F)</u>

99. With MS you're asked to make the biggest amount of change when you have the fewest amount of resources to cope with change.
100. When everybody's in an upheaval two grieving people can't lean on each other.
101. People are certain things to each other. If your partner becomes disabled with MS what they were to each other is gone.
102. Maybe you can rebuild something else with a different set of priorities. Some people are willing to try and some people can't do it.
103. Prior to the MS we had a traditional relationship. My work was around my partner's
104. I had a lot of pain and tiredness which I ignored as best I could and when I mentioned it to my partner it was ignored.
105. In the family you don't complain, you tough it out, so I started to keep it to myself more.
106. I withdrew a great deal.
107. I went to all my tests on my own.
108. When I told my partner about the diagnosis he looked past me and said what color do you think we should pain the cupboards.
109. All I thought at the time is I think I'm really alone.
110. I needed my partner to say we'll find some way, we'll manage, it will be okay.
111. I just wanted to know I would get some help with something I needed.
112. One thing that got us through was we did not have a division of labor that was set, that was gender related.
113. I was his support, that's what he counted on me for.
114. We didn't talk about it. My husband never met the neurologist, never spoke to a doctor.

115. I went alone even during a severe attack with friends to the doctor who sent me to the neurologist the next day.
116. I realized it was my problem.
117. I was concerned about getting the kids taken care of.
118. My partner said I'll look after the kids and the house. Whatever you have to do just do it.
119. I still felt part of a family, at least I didn't have to worry about household things.
120. My partner didn't say a whole lot. didn't ask a whole lot.
121. My partner withdrew more and more. He stopped coming home in the evening.
122. I hardly ever left the house. I wasn't strong enough.
123. Homecare people assumed my husband would be home and I never told them that he wasn't.
124. I had been told in the hospital that people like me couldn't raise their children or look after them properly. I was afraid that I could lose my family so I kept my mouth shut.
125. I knew my partner wasn't coping. He drank a lot and didn't come home till late every night.
126. There was a lot of anger at the disease and that I had really messed up his whole life system. He couldn't say anything because he knew it wasn't my fault but I think there was a lot of anger unexpressed.
127. I didn't know I had any rights. I didn't want to be angry, upset because I thought what if he came home less. I needed a lot of things.
128. I felt more and more alone although I learned to manage the home a little better.
129. I learned that other people would do things if I asked. I thought this was odd because I thought help would come from my family.
130. Because they're emotionally involved family don't want to see that I'm different than I was or that the world has really changed and that I'll never be the same again.
131. I never stated my needs very much. I didn't know I had a right to. I knew what kind of upheaval I had caused.
132. I felt entirely responsible. I had none of my roles left. I wasn't a nurse. I wasn't functioning in my wife role. I didn't drive. I didn't cook. I had no identity.
133. How could I ask for anything when I had already created so much work around and so much upheaval.
134. I'd been told how grateful I should be that I even still had my family because so many people didn't.
135. I assumed that the impeccable behavior on my part is what's required.
136. I required a full-time housekeeper. At first I couldn't be up for more than 20 minutes three times a day.
137. My partner became involved in more socially acceptable desertion. to be away because he had to go to meetings. etc.
138. The full-time housekeeper was a financial burden.
139. I didn't know what to do about the relationship situation and I was afraid of making it worse so I did nothing.
140. I was very lonely.
141. I was barely functional and I felt very abandoned.
142. I found more and more support outside of the family but never said anything to anyone.
143. I kept trying to establish a relationship where he'd want to be there.
144. I placated and pussy-footed around.
145. If anything had happened I would not have gotten the custody of the kids in my condition. I did whatever I had to do to protect it.
146. I felt emotionally alone and our sexual relationship only occurred at 3 o'clock in the morning when he'd come home and had had a lot to drink.
147. Physically I was able to have a sexual relationship. The types of spasms, the types of problems weren't simple but it was not too difficult.
148. I tried to behave and live like a normal person. I thought that's what I had to do to keep my kids normal, to keep my family normal.
149. I backed off and lost a lot of trust in people.

150. I backed off emotionally a great deal. I relied on other people, it was like the marriage relationship got less and less.
151. I was not financially independent for one thing so I didn't leave.
152. I was afraid of what might happen to my children.
153. As I took over more and more financial responsibility I was more empowered with myself.
154. If I need a ride somewhere my partner is probably the last person I'd ask.
155. By not having support here and not having things done I found that I could find a way to do everything I had to do on my own.
156. I think if I'd had a real caregiver partner, I would not be as strong and capable as I am.
157. I was afraid to see a psychiatrist. I didn't know whether they'd consider me incapable and I didn't know what they would do about the kids.
158. Guilt is a huge huge issue. My own family prides physical strength and ability above most others.
159. My physical improvement was ignored and I felt like an imposition.
160. What I wanted and who I was didn't count.
161. There's been a lot of subtle control issues. I could only go somewhere if he agreed to take me.
162. We might be together now only because the MS kept that dependency.
163. I felt not as valuable, not as equal as another woman would be in this position so I backed off so as not to irritate him.
164. I was dependent entirely for financial things.
165. I wonder if women are more easily talked into an assisted suicide to remove themselves as a burden because they don't feel they're contributing in any way.

<u>Participant #5 (F)</u>

166. We had to move because I couldn't keep up with my physical work anymore for the farm.
167. It affected me more than it did him, but because it affected me so much it affected our relationship.
168. It took him a long time to comprehend what was happening for me.
169. He decided about the move. I wasn't ready yet, I needed time, but he decided that he worried too much about me.
170. I thought it was really unfair that I had to move when I thought I could still do it.
171. I used to make the decisions. I was independent and strong willed.
172. I didn't feel weaker but I didn't feel as much of an equal in the relationship.
173. The move caused me to lose my support system and I didn't have the energy to make new friends.
174. The move affected out social life a lot because all of a sudden we didn't have one.
175. I realized how dependent I had become for my social interactions, going places all that kind of stuff.
176. I covered up to the extent that he didn't think anything was wrong because I had seen other people with chronic illness almost destroy families because of the way that person dealt with them.
177. I took it upon myself that I had to protect him.
178. We still go camping but we can't go hiking and things like that anymore.
179. We used to go out to show homes for fun but we can't anymore.
180. We bought a bungalow, one floor plan.
181. We go arm in arm for walks around the neighborhood because I'm hanging on so I won't fall over.
182. My partner wants to retire and get an RV and travel but I have concerns for the length of time he's talking about. I don't know, I think I'll be too tired.
183. I'm scared I'm not going to be able to do the things he wants to do and then I don't know what he'll do.
184. I realized I don't have the energy to manage everybody's life.
185. If there's a hike I want to go on and I think I can do it he won't say, oh no I don't think you should do this. Although he worries he never puts reigns on and says don't do it.

186. He goes out of his way to stick with me and he's never impatient with me.
187. He's never belittled the fact that I can't do things.
188. It's important to let the person be all they can be. Like to encourage them to push the limits if they want but to be there if they can't.
189. He helps with the household things I can't do.
190. Our love life is affected because you're always tired and he's not.
191. Adjustments have to be made sexually but it was no big deal.
192. You have to be careful not to assume your partner knows how you feel physically and emotionally.
193. If I say too much of anything I feel like I'm complaining.
194. My husband likes to have company but he's fairly shy so I end up doing a lot of the ice breaking and I have to cook dinner and stuff and I just can't do this. it's just too much.
195. A person who has MS has to know where their limitations are and then somehow be able to find compromise that still serves the purpose and that you can live with.
196. Last year when we went to the Fringe we had to bring a wheelchair for me. I felt weird because I knew I could get up and walk around. I sort of felt like a fraud to some extent.
197. Spirituality has been quite profound for me. It's been something to hang on to as an anchor.
198. I found myself for a time walking carefully. I needed the security of the relationship and I didn't want to jeopardize it.
199. I feel like I've let him down. I didn't hold up my end of the bargain.
200. I think he protects me by not telling me how he feels.
201. I didn't have a clue what he was feeling.
202. We end up spending a lot of time apart because noise and stuff bothers me.
203. I need a quiet spot where I can go.
204. I'm more dependent on him. I can't drive at night because my vision's not very good. And if I'm tired my driving reactions aren't all that great either.
205. I resent the dependence. I'm not mad at him so much. just mad because it has to be that way.
206. It's important to maintain your independence.

<u>Participant #6 (F)</u>

207. For most of my kids young lives I didn't know what was wrong with me. Just suddenly I was absolutely out of control.
208. MS affects me emotionally dramatically. I thought I was losing my mind. it was crazy.
209. I'm really proud when noone knows I'm having an attack.
210. I couldn't stand the cologne my husband was wearing and it took me a long time before I was honest enough to say that to him. I used to go upstairs and open the window and stay there.
211. My husband takes over the essentials. he'll do the laundry and he'll do the grocery shopping.
212. MS stops me traveling to the extent that my partner wants to. Traveling is really hard for me. it's very tiring. So we don't holiday together.
213. In winter I don't go out unless I have to.
214. We never cook just to eat once.
215. We don't make plans for the future.
216. I started buying airline tickets with insurance.
217. I say no to outings because I really don't know what I'm going to feel like then.
218. We do things separately. He has a group of friends and he goes off and meets with them.
219. We don't have any sex life and we haven't for years.
220. With MS it's your personal responsibility to look after yourself. It's not anybody else's job.
221. The most valuable thing I learned is not to make assumptions. When you want to know what's up. ask them.
222. It's important to talk as openly about it with significant members of your family.
223. My kids must have felt like they were under attack. They dealt with someone who really had irrational emotional responses at times.

Participant #7(M)

224. As a family we've grown closer together because of MS.
225. My wife is a caregiver. She doesn't expect me to go out there and do things for her.
226. Sometimes I feel she pampers me too much.
227. There's a lot of things I can't do. Repairing things, doing carpentry work, which I loved, doing wood work.
228. A lot of things I liked to do and wanted to do and would love to continue doing I can't do anymore.
229. We used to walk an awful lot and I can't walk now.
230. I have to plan ahead a lot. I have to try an arrange to rent a scooter or something to take with me on trips.
231. It seemed to have brought the whole family together.
232. It's important to try not to grieve over it too long and try to maintain a positive attitude.
233. My wife doesn't criticize me.
234. We don't sleep together because my legs are jumping around a lot.
235. You sort of take life with more than one route to travel so that if something comes along that is not beneficial or is going to stop you from doing what you want to do, then you have an alternative.
236. I have anger quite often. I blow up like a rocket and my wife has trouble with that one.
237. My wife does all of the work in the house.
238. Take every day one at a time but be flexible in planning.
239. You try to control everything you're involved in but some things are uncontrollable, let's face it.
240. I try to live my life that I worry about the things I can control and not worry about the things I can't control.

Participant #8 (M)

241. I felt a hopelessness for the future. I turned myself over to God. I can't handle it, can't take it.
242. I was so tired all the time. I'd go to work, come home tired, go to work tired.
243. It was hard on the children. They couldn't be like ordinary children, like run around and play and laugh. They had to be quiet all the time while I was sleeping.
244. My wife and I, both of us, were walking on eggshells all the time because I was like a gun ready to go off.
245. I don't know if I feel that my wife is a wife or a caretaker.
246. I feel like she tolerates me, puts up with me.
247. Financially it's been really hard.
248. When we were first working we always had a nanny who would do everything.
249. We never really plan or talk about things.
250. I can't do a lot of things to help like going shopping and stuff like that.
251. We couldn't sit down and make plans for the future.
252. We couldn't take the kids out camping or do things with them like taking them to parades.
253. The biggest thing is frustration. If you can't do a thing you strike out and hurt the people you love.
254. MS is a trial and tribulation, just like now, like the situation, you have to live a very controlled lifestyle.
255. With the early retirement suddenly you've got a husband in the house 24 hours a day, which was hard for my wife.
256. My wife had to be the breadwinner, it was very hard for her.
257. You have to be very careful with finances. When you're used to having two incomes then all of a sudden you're down to one income.
258. It's difficult to have time to yourself.

Participant #9 (F)

259. Spend a lot of time at the doctor's office.
260. Spouse worries about chance of relapse

261. With young couples the person with MS feels they have to do everything while they still can which can cause many problems.
262. Spouse of patient is worried they can't put a lot of trust in someone who has to worry about a terminal illness.

Participant #10 (M)
263. Spend most of your time at home.
264. Trouble to keep spirits up.
265. Hard time to associate with company.
266. Planned trips are almost impossible.
267. Often arguments over activity.
268. Spouse gets impatient over dull life.
269. Need help in dressing, etc.

Participant #11 (M)
270. Focus on priorities, take a good look why we are doing something.
271. MS has enabled me to spend more time with my wife and two kids.
272. Frustrating watching your wife do all of the male jobs, i.e. cutting the lawn.
273. Forced us to work on our communication skills.
274. Unpredictable mood swings cause undue stress.
275. Changed life in the bedroom everywhere from sex to sleeping patterns.
276. Definitely makes me appreciate my wife a lot more.
277. Socially we aren't out binging every weekend. A lot more planning goes into an evening out.
278. You have to find new ways to help out at home.
279. Find new ways to show your appreciation for the things she does.
280. I take more interest in her hobbies and special activities. Before I wouldn't have had the time.
281. It has brought us closer and strengthened our marriage.

Participant #12 (F)
282. I have to be in bed early, no late nights.
283. It requires different positions when making love.
284. Because of my MS we have decided not to have children.
285. I might have MS but it doesn't have me.

Participant #13 (F)
286. Reduced amount and quality of our sex life.
287. Reduced the enjoyment of sex. It has almost become a chore.
288. Has reduced my feelings of desirability and attractiveness. Often spurn my husband's attentions because I no longer feel worthy of them.
289. Pretty much eliminated any real spontaneity in our lives.
290. Many of our long term goals are unattainable.
291. It is impossible to continue with most activities, hobbies we previously enjoyed together.
292. Having children, which we'd both like, is no longer a realistic option.
293. Two incomes became one income and expenses increased.
294. Household chores can no longer be split 50/50
295. Marriage no longer seems like an equal partnership.
296. Feelings of anger an frustration at my disability are often taken out on my spouse.
297. Negative feelings about my increasing dependency on my husband and my increased anxiety that I should lose him through separation or death cause tension.
298. Can no longer do "wifely duties" such as cooking or much cleaning, thereby questioning my worthiness as a wife.
299. The fact that I'm often tired sore and/or uncomfortable somtimes makes me grumpy and probably hard to get along with.

300. My husband must work all day then come home and work too. He's often tired and that makes him hard to get along with sometimes too
301. Sometimes I have trouble with my emotions making communication more difficult as well as causing more misunderstandings.

Participant #14 (F)
302. My husband has to assume more duties that I always did.
303. I constantly feel guilty re: the above, so I'm not extremely happy.
304. I feel very dependent. This makes me feel my husband stays under obligation.
305. Our friends don't invite us to join in as much being that I can't physically participate.
306. Our life seemed to revolve around sports before and my husband's life still does, but I'm not included.
307. I had to quit work and driving. I think our married life is different as I'm quite boring, having no outside contacts.
308. I'm very tired at most times and hurt a lot, therefore out sexual relations have diminished.

Participant #15 (F)
309. Marital life with MS is hell.
310. No confidence, no affection, spouse runs away from the problem.
311. Spouse will not admit to the problem, will not read up on the disease.
312. Spouse does not understand what I'm going through.
313. There's a loss of respect.
314. Doesn't want to be around me.
315. No support, physical or mental.
316. Spouse doesn't know if he loves me anymore.
317. A lot of anger.
318. Spouse was a very affectionate person prior to January '96 at diagnosis.
319. Lost my best friend, my husband.
320. Confusion about marriage, do I want to stay in it and work at it.

Participant #16 (F)
321. Has given me a greater appreciation for my spouse.
322. I realized what a patient and loving man I have married.
323. He has shown and proven to me that MS is not only my disease, it's ours.
324. It has brought us closer together.
325. I realize what a wonderful gift I have with my husband and children.
326. I've learned to share with him my day to day feelings so that he feels a part of this.
327. Have concern about our future and how it may affect my family.
328. I don't believe it's really altered our lifestyle at this point aside from the emotional aspect of it.

Participant #17 (F)
329. In the past six years spouse has had to help me to dress.
330. I have to be put on the toilet and have help to wash myself.
331. My sex life is limited as I don't move very much.
332. My writing is limited as MS has caused my fingers to not hold the pen very well.
333. I've been in a wheelchair full time since 1992 and I'm not able to do any housework anymore.
334. Unable to drive the car.
335. Not able to find transportation if we travel to other cities by airplane to get around.

Participant #18 (F)
336. My husband's love and support have further strengthened our bonds, yet we have had to work harder on communication.
337. I'm hesitant to complain about how I'm feeling.

338. I've tried to strike a balance between doing too much and not putting extra stress on my husband and overdoing it.
339. I don't verbalize about my symptoms and at times I get upset if my husband doesn't notice if I'm not feeling well.
340. My husband and I decided on a major life change. I was feeling pretty good so we accepted a job he was offered in Hawaii. We thought it might be now or never.
341. I go all out to clean the house despite not feeling well. Want to show him that I could cope okay. I felt hurt that he didn't appreciate what I had done.
342. I'm the one doing the financial end of things now. I feel the extra pressure and that increases symptoms. I take criticism more to heart.
343. When the children were younger I often felt too tired by night for sex and it took quite a while for the cycle to be broken.
344. My husband and I can no longer share our previous fun things, i.e. skiing, tennis, badminton, baseball, etc.
345. At times I became resentful when he takes 2 to 3 hours per day on the weekend and I can't share that time.
346. I don't expect him to stay home all the time but it would be nice to have my frustration acknowledged.
347. My husband at times tries to decrease stress on me by not telling me how things were at work and then it would be like a bombshell and I'd feel as if I had contributed to the problem.

Participant #19 (F)

348. We have sex less often.
349. It's put a great strain on us, especially during drug treatments.
350. Initially I thought the MS brought us closer, but now I feel as if he is withdrawing away from me and we are growing further apart.
351. It's been another big obstacle, the biggest of several that we've had to overcome and deal with, but I don't think we can tackle it like the others.
352. He says he understands me but he doesn't. He's not here for me often enough and I resent that.
353. I resent that he can always find time in his schedule for other people and things but not for me. I can not manage this family and household on my own.
354. It has shown me that our marriage it not as secure as I thought it was. Previous problems are just magnified now.
355. The word divorce has come up more in the last two years since diagnosis than it did in the previous 14 years.
356. I am surprised, very sad, and disappointed that my husband has not been supportive like I thought he would be. I feel I've lost my former best friend.
357. Our marital couples cause me stress which I believe has worsened my MS.

Participant #20 (F)

358. I have now become more dependent on others.
359.My independence now depends on circumstances.
360. I never look forward to facing the day.
361. Every move has to be preplanned to conserve energy.
362. My emotions sometimes should be secondary to those around me, e.g. family and friends.

Participant #21 (M)

363. My marital life ended when I was reliant on a wheelchair.
364. Family life slowly ended as my weakness and tiredness started to play it's role.
365. My presence in a wheelchair embarrassed, inconvenienced and cramped my wife's lifestyle.
366. Sex life and intimacy slowly tapered off to nothing.
367. My spouse assumed that since I was disabled that I could not make any business and financial decisions.
368. The other half became more demanding and controlling over me, my feelings, and finances.

369. I could not have the things that could make my life a little easier. for example a cordless phone.
370. Being married and then getting divorced has caused financial burdens.
371. Children's future education will have it's difficulties which will have to encountered later as money for this is being spent presently.
372. I found out my spouse's true colors when hardship was encountered.

Participant #22 (F)
373. Unable to hike. bicycle ride. ski. baseball. walk long distances with spouse due to leg weakness.
374. Chronic fatigue. change in sexual patterns and level of activity.
375. Unable to do heavy housework. painting the rooms. vacuuming. due to fatigue levels.
376. Unable to work, affecting our financial situation.
377. Unable to do activities throughout the entire day and evening.
378. Spouse participates with sports activities by self or with other "fit" people.

Participant #23 (F)
379. Uncomfortable to be around a lot of people at one time. so unable to socialize like we were used to.
380. Sometimes not interested in sex.
381. Mood swings.
382. Overall brought our entire family together more.
383. Spouse and myself communicate even more now.
384. Some household duties not done as often makes me feel incompetent even though I know I can't do it.
385. Since now I'm unemployed money at times is limited. Cannot do all the things we used to.
386. Overall our lives are more fulfilling. We take each day as it comes and do things as a team.
387. Positive attitudes help us to cope with anything to come.

Participant #24 (M)
388. We don't go out as often as we used to.
389. We don't entertain as often as we used to.
390. I don't feel as independent as I did before MS.
391. My partner cares for me more.
392. My partner makes sure I don't overtax myself.
393. My partner calls to remind me not to forget things.
394. My partner feeds me well. perhaps too well.
395. My partner understands my shortcomings and my sorrows.
396. We try to talk as much as possible but could talk more.
397. We try to go to bed at the same time.
398. We don't hug as much as we used to.
399. A slight hug and kiss and goodnight is all we do at bedtime.
400. We are not as intimate as we once were.
401. I must explain to my partner that good sex can be had without intercourse.

Participant #25 (F)
402. Need more patience and understanding.
403. Not as many activities.
404. Less sexual activity.
405. More sharing of household duties.
406. More dependent on spouse.
407. More specific communication.

Participant #26 (M)
408. Slowed down the pace of doing things.
409. Reduced the amount of cycling and walking done and distances.

410. Require extra time and patience to get ready for special outings or occasions.
411. Plan out the way things are done instead of doing things at random.
412. Found out the everything doesn't have to be done today. there is a tomorrow.

Participant #27 (M)
413. I'm home more often resting.
414. Fewer outside interests
415. Can't do many things together, walk. hike, skate.
416. Holidays are different. More time resting and relaxing rather than sightseeing.
417. Bathroom urgency and frequency limits some activity.
418. I'm less able to handle stress.
419. The physical part of our marriage is affected.
420. Diagnosis resulted in us not adopting a baby.
421. My wife is much more stressed living with the uncertainty. resentful. why her.

Participant #28 (M)
423. Hard to get things done.
424. Don't have money
425. No sex life.
426. Tired all the time.
427. Forget to do things.
428. Can't do a lot of things we want to do.

Participant #29 (F)
429. We no longer live as equal partners.
430. We do most things separately.
431. I cannot participate in the leisure activities that my partner prefers to do.
432. It's taken a heavy financial toll with child care and equipment.
433. I look outside of my marriage to friends for emotional support.
434. I learned that even though disabled I'm the strong person in the relationship.
435. There's a hesitancy when I ask for anything as I'm afraid of refusal.
436. I couldn't be angry with a partner that I depended on for things I can't do myself.
437. I became very lonely in the marriage.
438. I'm a much stronger person and less emotionally dependent than before the MS.
439. I feel like a single person in the marriage but without the privileges.
440. I've always felt guilty that I didn't handle things well enough to keep a strong marriage.

Participant #30 (F)
441. We spend more time together.
442. It has brought us closer.
443. I'm unsure. insecure about a lot of things.
444. My partner doesn't understand me and my fears.
445. It frustrates me that he feels like he has to fix everything wrong.
446. Made me realize how much he cares for me by sticking by me and wanting to protect me and keep me safe.
447. I feel more dependent on him.
448. He's my best friend.
449. Made us realize that in our lives together happiness is more important than money.
450. Sometimes he makes me feel incompetent (unconsciously of course).

Participant #31 (F)
451. I have become more dependent on my husband.
452. We no longer enjoy activities like long walks. hikes. shopping.
453. Scheduling sex is a problem because of fatigue.

454. We entertain much less and come home a lot earlier when out socially.
455. I sometimes feel like I'm not holding up my end of the relationship.
456. I'm more touchy and grouchy because of pain, fatigue and frustration, causing more tension in our relationship.
457. Our relationship is gentler because we don't live such busy lives any more. More time to talk, for quiet slow walks.

Participant #32 (F)
458. The variation of symptoms causes constant adjustment.
459. Psychological and cognitive difficulties are often very disruptive. Poor memory requires consistency and predictability for easier functioning. Partner's impulsiveness can conflict with my needs.
460. MS was the reason I did not have natural children.
461. Have had to stop teaching which has caused financial problems.
462. Lack of strength, lack of confidence in driving, and lack of independence was very hard to accept.
463. Friends, activities have changed dramatically.
464. Summer activities are curtailed often. Planning is hard.
465. Entertaining is limited to casual types.
466. Husband and I have frequent discussions to deal with changes.
467. Husband helps with housework, cooking, etc.
468. Difficulty doing gardening, some other hobbies. So much doesn't get done and some expectations are not met.
469. Sexual responses need to be talked about when there are physical changes in MS.

Participant #33 (M)
470. Sexually, have none.
471. Still emotionally and romantically involved.
472. Cannot contribute to home chores outside.
473. Still travel but curtailed.
474. Still able to support family with pension income.
475. Able to contribute to small chores inside.
476. Able to drive car with hand controls
477. Unable to walk.

Participant #34 (F)
478. I felt very lonely having this chronic illness. My husband kept forgetting I had this illness because I appeared to be normal.
479. When you look normal how would anyone know how you really feel inside.
480. I felt selfish in trying to preserve myself and my health.
481. I couldn't commit myself to helping in the community, school, and socially.
482. I kept my illness a secret for 18 years from co-workers, friends, and neighbors.
483. I feared losing my job.
484. I feared they would think even a normal cold or flu was due to my MS.
485. The secret of having MS took its toll on my marriage because of the stress and fatigue that resulted from trying to be normal.
486. I was an uncooperative sex partner most of the time because of the constant fatigue.
487. I feel this illness has lowered my self-esteem.
488. My balance became unsteady.
489. I gained 50 pounds after being on anti-depressants.
490. My husband was a poor communicator which contributed greatly to our marriage breakdown.
491. My fears that came with my MS landed on unempathic ears.
492. I felt devastated which made my disease progression worse.

493. We grew apart because I was unable to be physically active anymore and my husband liked to be.
494. I was unable to ride my bike or walk.
495. I felt very isolated because we had moved to the country.
496. I couldn't keep up with the big garden and yard.
497. I became depressed with the workload I used to enjoy.
498. My husband couldn't realize how frustrated I became.
499. When I had to go on long-term disability my income was cut by one third.
500. My spouse was angry that I wasn't keeping up 100% with my financial commitment.

Participant #35(M)
501. Cannot walk with my wife.
502. Functions and social outings impossible to attend.
503. Cannot drive to ease wife of responsibilities.
504. Cannot make my wife coffee or supper.
505. Cannot assist with the housework.
506. Cannot have a shower with my wife.
507. Cannot explore other sexual positions.
508. Possibility to have children is not there.
509. Find it hard to go out to buy my spouse a gift.
510. Cannot do outside work which is a burden on my spouse.
511. Cannot tuck daughter into bed while wife is asleep.
512. Need help with personal care.
513. Always asking spouse to get things for me.
514. If I'm uncomfortable I have to wake my spouse up to make me comfortable.
515. Lost independence and control for making decisions.
516. I get very tired and need to rest.
517. Sense of privacy is gone.
518. Require special adaptations to go places.
519. Fall more. Not as physical.

Participant #36 (M)
520. Earlier fatigue. more rest required.

Participant #37 (F)
521. We bumble along in a forced way. We make allowances for the frailties of each other. Time seems to be the affecting item. i.e. length of relationship.

Participant #38 (F)
522. In a wheelchair
523. Loss of use of left hand.
524. Eyesight not good.
525. Hard to get around.
526. Loss of interest in men.
527. Like to be on my own.

Participant #39 (F)
528. I'm divorced.

Participant #40 (M)
529. Can't do any shores. repairs. etc.
530. You use your mouth more.
531. Loss of control.
532. Resentful of caretaker.

533. Relying on partner for everything.
534. You get angry because you can't do it yourself.
535. A fine line between lover and caregiver.
536. Sexual problems.
537. It was too easy to walk away before.
538. Hard to know if you're hanging on to the marriage because your spouse is your caregiver.
539. Being aware of fear of being alone.
540. You see yourself as having a lot of need in the future.
541. The future scares you.
542. You know you don't know what is ahead.
543. When you see people worse off you see yourself.
544. Wanted many times to terminate the marriage because of perception of the future.
545. Difficulty visiting family.

Appendix K

Original Master List of Partner Statements

Participant #1 (M)

1. There were periods of frustration when I asked myself why me. even though I wasn't the one affected.
2. It was extremely difficult with three little kids.
3. I had to keep the household going, the job going, and making sure the kids were looked after.
4. You had to plan your whole day, your whole week ahead of time.
5. I had to do all the driving for the children.
6. Everybody depends on you.
7. When my spouse came home on weekends our routine was thrown off.
8. Homecare helped but I still had to do all the planning.
9. I had a sense that I had lost my spouse.
10. I didn't understand the disease.
11. It changed my outlook on a lot of things.
12. The uncertainty not knowing what will be ahead.
13. We had to put in wider doors in the house to accommodate the wheelchair.
14. We adapted our whole kitchen.
15. There were a lot of added expenses.
16. This wasn't part of our long term plan.
17. So many things had to be put on hold.
18. It was just easier not to do things because you don't know with certainty that you can do them.
19. It's difficult to have to take the power chair.
20. It's easier to say we'll just sit at home.
21. I say to myself this hasn't been fair to me.
22. The children were frustrated because their mom wasn't home.
23. One day my spouse was fine and the next day in the hospital and in a wheelchair.
24. The kids didn't like the attention that the wheelchair attracted.
25. There were a lot of things my spouse couldn't do any longer.
26. You just have to deal with things because that's the way it is.
27. It affected myself, my spouse and the children emotionally.
28. We could no longer spend weekends camping.
29. I miss some of the activities we used to do together.
30. I needed a support group to help understand my feelings.
31. I felt very angry.
32. The home wasn't the same anymore.
33. MS wasn't in the big master plan.
34. It was no longer the two of us raising the family.
35. I felt like I had to do everything
36. I took my spouse and it took every red cent that I worked for.
37. It seemed to affect everything, literally everything.
38. We used to go dancing a lot.
39. I met my spouse in a bowling league.
40. We had plans to go hiking together.
41. I have to go home right after work to make supper.
42. There are emotional scars between us that can never heal.
43. I had a tendency to close myself in.
44. You can shut yourself away from some things. You can shut yourself away from your partner.
45. A good relationship makes a world of difference.

Participant #2 (F)

46. It's made me much more aware of health and lifestyle.
47. We've made a conscious move to healthier diet and exercise.
48. MS has made us closer in our relationship.
49. Support is required for both of us from each other.
50. We understand each other better.
51. Fatigue plays a big role in our lives.
52. It's important to take time for ourselves independently.
53. My spouse tries to stay quite independent.
54. A positive attitude towards life makes it less stressful on the relationship.
55. Much of the household responsibilities are on my shoulders.
56. I felt I had too much on my plate.
57. The shock of diagnosis strained the relationship.
58. The aspect of selfishness is apparent.
59. We try to think of the other person more than ourselves.
60. MS hasn't seemed to affect our lives intimately.

Participant #3 (F)

61. A good thing is we are much closer.
62. My partner really needs me.
63. Sometimes my caregiving is not appreciated.
64. Sometimes my partner wants to go through a bad time alone.
65. I feel very negative when my partner doesn't want to accept my caring and giving.
66. It's tremendously important to maintain dignity for my partner.
67. It's important to have absolute respect for my partner.
68. We need each other very much.
69. We're more careful in expressing our feelings.
70. My partner can't do some things.
71. My partner needs help dressing.
72. I feel guilty because he can no longer leave if we argue.
73. We no longer fight the way we used to.
74. I fear I may lose myself in this
75. Caring for my partner has given me a purpose.
76. We no longer feel like equals.
77. There's now a tenderness instead of big hugs.
78. We look at life differently.
79. The pace of our life has slowed down.
80. We now do everything together.
81. It makes it difficult to plan for the future.
82. We find ways to adapt so we can still do some things we enjoy.
83. I love out quiet evenings together.
84. At times I feel very begrudging for the things I'm doing for my partner.
85. He's lost his sexual ability which has strained the relationship.
86. I feel hurt and resentful we no longer have a sexual relationship.
87. Caretaking has to be rewarded with sensitivity and appreciation.
88. MS is a sad thing and it makes you realize the value of life.
89. We're aware of the preciousness of what we have.
90. We try to be as comfortable while we face each hurdle.

Participant #4 (M)

91. Required surgery in order to make love in a special way.
92. My partner needs help with cooking and other physical things.
93. I do her therapy for her.
94. I help my partner with showers with pleasure.

95. I now do the grocery shopping for both of us
96. I feel that we both have MS.
97. We've learned about each other's strengths and weaknesses.
98. We love each other more.
99. I'd like to learn more about dealing with MS so I can help my partner more.

<u>Participant #5 (M)</u>

100. The period when it was not diagnosed was undoubtedly the worst.
101. The most impactful part of MS has been the emotional.
102. I'm constantly driven crazy by the unpredictability.
103. The person that I'd married no longer existed in many ways.
104. There were lots of discussions about separation and divorce.
105. It was very difficult to live with.
106. The emotional ups and downs caused frustration, anger and withdrawal
107. Coping with the unknown is very difficult.
108. It took an incredible amount of emotional awareness and energy to cope.
109. I was frustrated by my partner's mood swings.
110. It's difficult to cope with all the expectations placed on you.
111. There was a very painful period shortly after diagnosis.
112. I find I need space away from my partner.
113. We can no longer do a lot of the things we used to do.
114. I spent summer holidays with my kids leaving my partner at home.
115. My partner was quite unpredictable.
116. I feel I always need to evaluate how my wife is feeling before I talk to her.
117. We don't talk and make decisions any more.
118. I feel more responsibility to monitor what's going on with my wife.
119. It's important to let my partner do as much as possible.
120. I do grocery shopping.
121. I do the high energy stuff.
122. I think of myself as a back-up to do whatever she cannot do.
123. It's important to allow your partner dignity.
124. Simplistic communication skills in an average relationship become complex with a chronic illness.
125. The partner has to take on an additional burden.
126. You have to screen out what is illness related from what is personality related.
127. It's hard to live with somebody who's chronically depressed.
128. With MS it's worse because the bouts of depression or manic behavior come and go, so you're constantly monitoring.
129. You're constantly editing yourself.
130. It's very very tiring.
131. I often feel guilty because my partner is ill.
132. The person who is ill re quires the greatest care and sympathy.
133. With MS you cannot look at your partner and make the assumption he or she is fine.
134. You need to communication to your partner that their spouse is literally a lay man in an emotional minefield.
135. People in the caregiver role need to be better informed.
136. Things will probably change for the worse in the future.
137. It's very stressful dealing with a chronic illness.
138. The caretaker role is made more complex by the emotional ups and downs of the person you're caring for.
139. The whole sexual thing was so unpredictable.
140. We no longer have a sexual relationship.
141. There's a constantly shifting emotional response from my partner.
142. I think the non-MS person has to be constantly aware of their responsibility to reduce stress.

143. Evening social events are a thing of the past.
144. There are dimensions of the relationship that have been enhanced by MS.
145. Caring and trust are a big part of the relationship.
146. I have been able to put my own pain or frustration or fear or anxiety into perspective more.
147. My strong faith is a resource.

Participant #6(M)
148. Apprehension about our future with MS.
149. I find myself trying to do more to help with the housework.
150. I'm harder on our kids to behave better and not tire out my partner.
151. I feel guilty about working late or on weekends.
152. I try not to put a burden on my partner.

Participant #7 (F)
153. MS affects everything in a relationship.
154. It's really stressful.
155. MS contributed to my own illness.
156. I had to be the sole breadwinner of the family.
157. I had to take care of the children.
158. People didn't understand the illness.
159. I blame the illness. not the human being.
160. There has to be some humor in the relationship.
161. I sometimes say things that make my partner feel worse.
162. I couldn't be straight forward in my feelings.
163. I'm living my whole life inside my head.
164. I didn't share with other people what I was going through.
165. My partner became very abusive.
166. Seeing people in wheelchairs disturbed my partner.
167. I no longer had somebody to talk things over with.
168. I no longer had somebody to make decisions with.
169. My partner began spending a lot of money.
170. Everything a marriage is supposed to be was no longer there.
171. I stuck around because of my Christian values.
172. Our sexual life was greatly affected.
173. We didn't know what we could look forward to in the future.
174. I had to take over handling all the finances.
175. My partner no longer wanted to go anywhere.
176. It caused a lot of problems in the family.
177. I felt it was my duty to take care of things.
178. I spent my life looking after everybody else.

Participant #8 (M)
179. I'm unable to work due to my caretaking duties.
180. Unable to go on extended (over 4 or 5 days) holidays/vacations.
181. Unable to leave home for over 4 hours at a time by myself.
182. Endless emptying of catheter leg bags and toilet necessities.
183. Expensive to buy countless items. medical supplies.
184. Have to live near a fairly large city.
185. Have to live near appropriate doctors and hospitals.
186. There are endless minor chores.
187. Days are often long and boring.
188. A normal day is extended by nearly two and a half hours by washing. bathing. dressing in the morning and before bedtime.
189. Reduced companionship.

190. Spouse unable to participate in hobbies, gardening, etc.
191. Spouse's cognitive problems often lead to repetitive questions and poor communications.
192. Reduced greatly my free time to do many little things I would normally do.
193. Cuts back immensely the number of places we can visit.
194. Takes additional time to get ready to go anywhere.
195. Takes time to find suitable parking.
196. Forever arranging to keep appointments.
197. Constantly trying to maintain a smooth flow of daily routines and schedules.
198. Always cooking, cleaning and caretaking.

Participant #9 (M)

199. More reliance on spouse without MS.
200. More sharing of responsibilities.
201. Brought us closer together.
202. Admiration for strength and courage of spouse with MS.

Participant #10 (F)

203. It's been very tough. I like structure and things have to be very predictable, and MS is very unpredictable.
204. I had to learn to live more day by day.
205. When I got married I wanted to be looked after.
206. I felt I had to look after my partner.
207. I was constantly concerned about my partner's health.
208. The doctor suggested we not share the diagnosis with a lot of people.
209. I didn't tell my family so there was a lot of covering up.
210. We had applied to adopt a child and decided not to after diagnosis.
211. I didn't think I could cope alone if my partner got worse.
212. We grieve over the children we didn't have.
213. I felt depressed a lot of the time.
214. I don't think I'm as supportive as I should be.
215. I returned to work because I didn't know what the future would bring.
216. I felt I had to be stronger and more independent.
217. I ended up taking time off work because of stress.
218. I was always worried about my partner.
219. I wanted to protect my partner.
220. I kept the children away from my partner so that he/she wouldn't be disturbed.
221. I was exhausted a lot of the time.
222. I felt preoccupied with my partner's illness.
223. I was concerned I may have to push my partner around in a wheelchair.
224. I don't want to be a caregiver.
225. I fear someone being dependent on me.
226. I felt insecure about the future.
227. It helped me put things more in perspective.
228. There was a shattering of our dreams for the future.
229. We could no longer go skiing together or skating.
230. I feel envious of families that are not living with a chronic illness.
231. My partner's uncomfortable around other people because of his/her bathroom problems.
232. We're doing a lot of traveling now because we don't know what will happen in the future.
233. Every time we do something I think this may be the last time we'll ever be able to do it.
234. I wanted our lives to be the same as everybody else's.
235. I wanted our lives to stay the same.
236. I withdrew from people.
237. I felt I no longer had a lot in common with other people.
238. I tried not to appear upset when I told people about the MS.

239. The spousal support group pointed out how bad things could get.
240. I didn't feel our problems were bad enough to go to a counselor.
241. I felt I went through the motions of living but was not really living.
242. I resented having to go back to work.
243. I feared that my partner would no longer be able to work.
244. We had the expense of having to hire a housekeeper.
245. I had to do everything, the grocery shopping, the laundry, and housekeeping.
246. We had to rearrange everything financially.
247. The hardest thing for me is the insecurity.
248. We didn't tell the children.
249. I don't enjoy outings because I was petrified about if he has to go to the washroom.
250. I never shared with my daughter how burdened I felt.

Participant #11 (M)

251. I found out how selfish I had been.
252. More responsibility falls on the healthy spouse.
253. I now do all the household chores.
254. My feelings for my partner have grown stronger.
255. I'm now a part-time care attendant for my partner.
256. I help my partner with the catheter, bathing and minor medical.

Participant #12 (M)

257. It was hard making adjustments to a partner with MS.
258. I've had to slow down physically to my partner's level.
259. I've had to adjust my mental processes to my partner's level.
260. I have to be careful not to confuse my partner because of his/her memory problems.
261. I take care not to overload my partner with details.
262. I take care of most of the things like the housework and washing.
263. Sometimes there's friction because I do too much.
264. I have to read the signs and adjust accordingly.
265. Stress is a major player in our marriage.
266. Financially it's been difficult because my spouse no longer works.
267. I'm impressed with how my spouse has coped with the disease.
268. We would do a lot more things if she didn't have MS.
269. I'm worried about saying the wrong things.
270. My partner is very concerned about what other people think.
271. Short term memory is a concern because my partner tends to forget things.
272. I try to give my partner as much independence as possible.
273. One area of conflict is I try to do too much for my partner.
274. I get angry and annoyed about having to live with MS.
275. I've learned to live a slower paced lifestyle.
276. If we go somewhere we have to take the wheelchair.
277. My partner feels a stigma about using the wheelchair.
278. We worry about what will happen 5 years from now.
279. Ever once in a while it gets to me.
280. Sometimes what I'm doing isn't what my partner needs.
281. My partner's strength of character is amazing to me.
282. I do not fear being a caretaker in the future.
283. We have had to make some decisions we wouldn't have made without the MS.

Participant #13 (M)

284. Physical activities slowly diminishing.
285. Has affected me very little.
286. Change is slow so I'm growing into it with my partner.

287. If you're close to i t. you don't see the changes.
288. Take wheelchair on vacation just in case.
289. Purchased new house that was an open. thinking about the future.
290. Entertaining much less because she gets too tired.
291. I feel no hardships due to the changes in her physical condition.
292. I love my partner and the bond is very strong.
293. If she needs it I'll be there.

Participant #14 (F)
294. I've become more tolerant and understanding.
295. I've become more patient.
296. We've refocused on priorities in life like health. friends. and family.
297. We've changed our eating habits.
298. WE now use natural herbs.
299. We participate in Tai Chi classes.
300. Try to stay positive.
301. We're involved in the MS society.
302. We do as many fun things as possible.
303. I'm more supportive of my spouse.

Participant #15 (F)
304. It's made me more concerned. patient. and understanding of his/her problem.
305. Has limited activity.
306. Made us more aware of other people's problems.
307. Has made me become more patient.
308. Has made me try to be more positive.
309. Changed the way we live every day (not concerned about little things.
310. Keep a quite home for rest periods.
311. Find that people are not aware of MS people's capabilities.
312. When annoyed you often don't say what you would like to.
313. Have to take responsibility for doing everything.
314. Have to do many activities on your own.
315. NO longer travel.
316. Partner needs a lot of support.

Participant #16 (F)
317. Roles have changed.
318. Household duties have changed.
319. We're no longer sexually active.
320. We no longer dance.
321. For walks I have to push my partner in a wheelchair.
322. I do most of the driving.
323. I do most of the grocery shopping.
324. Being active in sports is hard because we both can't take part.
325. Had to learn to maneuver the wheelchair.
326. Had to understand when partner needs to rest.

Participant #17 (F)
327. Loss of physical sex.
328. Still have sharing of affection and emotional involvement.
329. Share same interests and tastes.
330. Traveling more difficult with wheelchair and bladder problems.
331. Partner unable to help with outside yardwork.
332. Still helps with inside household chores.

333. Partner has caring attitude on how my work day has gone.
334. My partner's still able to drive with hand controls.
335. Pension income helps with finances.
336. Difficult visiting friends and relatives because of accessibility by wheelchair.
337. Unable to do things or go places that ambulatory people can do.
338. Still have a full and busy life.
339. Try to dwell on what we have rather than what we don't have.
340. NO written guarantee when we are born that everything will run smoothly.

Participant #18 (M)
341. MS has affected our entertainment and enjoyment.
342. MS has affected our participation in sports.
343. MS has affected our sexual life.
344. MS has affected our social life.
345. MS has affected housework.
346. MS has affected household maintenance.

Participant #19 (F)
347. We no longer can do some activities together that we used to.
348. We spend more time together.
349. My partner is around so much I don't get much personal space.
350. I was tempted at first to just drive away.
351. It shattered that dreams I have about having children.
352. I tried to protect my partner too much.
353. Our life has a slower pace.
354. We appreciate little things more.
355. It's a more equal relationship than it would have been.
356. It has limited our social life.
357. We've had to plan financially more for the future.
358. I don't enjoy many activities because I'm worried about my partner.

Participant #20 (M)
359. We spend more time apart.
360. Time together is in sedentary activities.
361. During undiagnosed period much talk of separation and divorce.
362. Still a high stress relationship because of constant and unpredictable change.
363. I'm fully committed to the relationship.

Participant #21 (F)
364. Finances have been a constant pressure.
365. My partner is not the same person I married.
366. We no longer enjoy some activities.
367. Partner has great difficulty with orgasms.
368. No sexual relationship.
369. We spend less time together.
370. Cognitive problems make it difficult to discuss matters.
371. Embarrassed about my partner's behavior around other people.
372. Partner's problems with short-term memory cause problems in the relationship.
373. MS spouse doesn't like change.
374. Visiting friends is difficult.
375. I'm exhausted.
376. I feel MS has contributed to my own illness.
377. I feel I've lost my companion.

378. I feel like a full-time caretaker.
379. My partner is verbally abusive.
380. I've had to do everything in the relationship.

Participant #22 (M)
381. The physical and emotional needs of the affected spouse come first.
382. It's frustrating not being able to do the things we used to do.
383. We spend less time together.
384. Conversation seems to be centered on the needs of the person with MS.

Participant #23 (M)
385. I admire my partner more.
386. I trust our solidarity more.
387. I am far more protective of my partner.
388. I feel I have to be less selfish.
389. My attitude towards happiness rather than money has improved.
390. My partner's insecurity frustrates me.
391. I hate feeling helpless to cure my partner.

Participant #24 (F)
392. We are more sensitive toward each other.
393. MS has enriched our marriage.
394. It's slowed us down and given us time to smell the roses.
395. My caregiving has given me a sense of fulfillment and commitment to the marriage.
396. Added household responsibilities make me tired and resentful.
397. We both miss the regular sexual ways of loving.
398. We cry together for the way the marriage could have been.
399. I show my love by helping my partner.
400. My partner is much more emotionally sensitive to me.
401. MS has given us time for our families.

Participant #25 (M)
402. I've had to physically slow down to my partner's speed.
403. It's caused considerable stress.
404. I feel helpless with regard to my partner attempting to come to terms with the condition.
405. I have difficulty being all things my partner needs me to be.

Participant #26 (F)
406. Has made outings more challenging
407. Many or all responsibilities forced on the non-MS spouse.
408. We have to take extra time for outings or events than a normal couple.
409. We have lost many friends due to MS.
410. We associate with mainly handicapped people.
411. It's made me see a different view of people.
412. My attitude towards life is changed.
413. We focus on the little things in life that are important.
414. Caregiving creates a lot of stress.
415. There are financial hardships.
416. People see us as different.
417. People talk to me rather than my spouse.
418. We've had difficulties trying to have a child.
419. Have to deal with outsiders coming in to the home to do some personal care.
420. I find myself exhausted at the end of the day.
421. Have difficulty with other caretaker seeing my spouse naked.

422. We've lost most of our privacy in life.
423. Have had to work around the caregivers' schedule.
424. Hard to find intimacy.
425. Hard to do things together physically.
426. Hard to find time for myself.
427. Too tired to go out. Would rather stay home.
428. Constant fear of my partner deteriorating more.
429. Fear or partner hurting self while I'm not there.
430. Live life according to a routine.
431. Fear that the caretakers at not looking after my partner.
432. Sometimes my partner thinks that life revolves around him/her.
433. Cannot leave my partner alone to go on holiday.
434. I feel physically lonely sometimes.
435. I'm sad my partner cannot join me in activities.
436. I feel very isolated.

Participant #27 (M)

437. The person I love and married for life is no longer happy.
438. It's difficult to watch my partner's slow deterioration.
439. Totally altered. destroyed all plans for the future.
440. Made a decision not to have children.
441. Very high emotion stress in the home. Constant crying. bitterness. suicidal tendencies.
442. On the brink of financial ruin.
443. Dual income slashed to one.
444. Fear of financial foreclosure and collections.
445. Physical and mental fatigue.
446. Optimism for remission and cure and light at the end of the tunnel is fading along with my partner's health.
447. Trying to be a positive motivation to help my partner deal with symptoms gets harder.
448. Realization of how many friends you really have.
449. Added cost of wheelchair. remodeling home for accessibility. medication.
450. Lack of affection.
451. Lack of sex life.
452. Shared responsibilities are now inherited by one person.
453. Less support than for people with spinal cord injury.
454. Ill informed about what support is available to us.
455. Feel there'd be more assistance if my partner were single.
456. Require information to help us deal with life.

Appendix L

Edit #2 - Patient Statements

Participant #1 (M)

1. **a. We are closer because of MS.**
   b. We stay home a lot.
2. **We have for more conflict in our marriage due to MS.**
3. **a. More sharing of the running of the household.**
   b. More sharing of the raising of children
4. Because I can't curl or golf I find I'm home more. R1b
5. **a. I don't have the energy to do some things**
   b. I'm happy to stay home and take it easy. R1b
6. I always have to come right home because I need the rest. R5
7. a. I only work half time. O
   b. I can get supper ready for the family. O
8. When I was just lying around I think there was a bit of friction or resentment. R30
9. My partner likes to go on walks and I can't really walk because I'm too tired. R5
10. We don't do that much together. R9
11. I don't go shopping anymore. R3
12. We can't go out dancing. R291
13. **When we go on holidays we tend to just rest and relax.**
14. My partner's on edge all the time because of my bathroom problems. R15
15. **My partner is worried that I'll embarrass him/her.**
16. **The uncertainty of MS causes a lot of stress and anxiety in our lives.**
17. a. There's problems in traveling in that I'm not as mobile. R13
    b. We won't go on tours and walks. R13
18. **I'm more conscious of trying to make the best of things now**
19. I've become more confident that I should be okay. O
20. Anything that required physical dexterity or stamina I had to quit a long time ago. R5
21. We've stayed in this house because there's no stairs. R180
22. We've tended to be a bit more cautious of our money. R98
23. a. My partner is more considerate to the point of being too considerate. R205
    b. My partner is always worrying about me. R169b
24. a. My partner enjoys relaxing at home. R1
    b. My partner doesn't want to always be going out. R1
25. We both enjoy evenings at home. R1
26. **We make a conscious effort to find things we can still share.**
27. I've spent some very worried times and depressed times. O
28. The sexual problems aren't an issue for my partner. R29
29. **We enjoy closeness without a sexual relationship.**

Participant #2 (F)

30. **My partner couldn't come to terms with living with an invalid.**
31. My partner was embarrassed when I fell down. R15
32. My partner wanted what he considered to be a perfect partner and didn't have that. R15
33. My partner was quite sports minded and I couldn't keep up. R291
34. We gave up skating because I lost my balance very early on. R291
35. We used to curl together but the balance affected that. R291
36. **We decided not to have children because of the MS.**
37. I didn't know I was pregnant when diagnosed and because of the tests the doctor said I would have a terribly deformed. deficient child so I had an abortion. R36

38. a. I didn't want to be different R48
    b. **I didn't tell people I had MS.**
39. Every little niggling thing was hard for my partner. R30
40. a. My partner had real difficulty with my memory loss. R15
    b. My partner had difficulty with my language skills, confusing words, etc. R15
41. My partner was dismayed if I introduced somebody by the wrong name. R15
42. a. My partner was convinced that my memory loss was for my convenience. R312
    b. My partner felt I was just being difficult. R312
43. My partner was upset that I couldn't go skiing and couldn't go golfing. R291
44. I learned I had to be quite methodical otherwise I couldn't remember where they were. R45
45. **Thinking and memory problems have been the most difficult to deal with.**
46. I get lost very easily which my partner has to adapt to. R204a
47. When I'm lost I'll ask people for directions but mostly it's very embarrassing. O
48. **I've tried to stay looking and seeming as normal as possible.**
49. When something happens that I recognize as MS I'm not prepared to share it with my partner. R48
50. It's frustrating when people say that you look good for having had multiple sclerosis for all this time. R312
51. a. I've given up the idea of having children. R36
    b. I've given up a marital partner. O
52. My partner and I applied to adopt and were turned down because of my MS twice. R36
53. Because of my memory problems my mind works slow plodding and methodological whereas my partner is exactly the opposite. R45
54. Some of the symptoms of my MS are so problematic that there are times when I can't do something or don't want to do something because it will be too difficult R16
55. a. I want to be independent. R204
    b. **I don't want to be a burden on anyone.**
56. I want to do my share but it can't be that way. R150
57. If I were healthier I would walk away from this relationship for awhile anyway. R162
58. Our finances have been affected because I'm not able to work full-time. R98
59. **When I think of a way out I think of suicide.**
60. I've considered suicide seriously in my life. R59
61. **a. I feel guilty about having MS.**
    b. MS affects everyone around me. O
62. My illness is so unpredictable that sometimes there are things I just can't do. R64
63. For your marriage to stay intact you can't lean on MS as a reason to not do things. O
64. **a. Because MS is unpredictable I worry about the future.**
    b. There's going to be adjustments and changes required in the future. R64a
65. a. We purchased a house because it's all on one level. R180
    b. The rooms are large enough that a wheelchair can turn around in one. O
66. **a. It's important not to dwell on your MS**
    b. When you're making major decisions you can't forget MS. R230

Participant #3 (M)

67. After my diagnosis we decided to divorce. R310c
68. My partner couldn't cope with the potential of being a caretaker. R30
69. We're having to change on a daily basis. R238
70. **I'm frustrated to be continually losing something.**
71. We have to adjust to and find new ways of doing things. R75
72. It's hard to go from lover to caretaker and determining where the dividing line is. R89
73. **I worry about becoming totally dependent on my partner..**
74. The bladder condition gets to be a 24 hour chore. O
75. **Living with MS is a learning process for both of us.**
76. a. There's extreme highs and lows. R274

   b. I'm exceedingly emotional. R274
77. a. It's frustrating for my partner to see someone he/she loves going down. R96
   b. It hurts deeply to see my partner frustrated. R96
78. a. There are times I wish I could be on my own. R96
   b. I wish my partner wouldn't have to be subjected to my MS. R96
79. Having arguments is tough because I can't handle the stress. R80
80. We no longer argue the way we used to..
81. I'm glad that I can still contribute financially due to my disability pension. O
82. a. Control is an issue. R91
   b. You hang on to anything over which you have any control. R91
83. Giving up the job was very difficult. R98
84. I had to give up a lot of my previous types of recreation.
85. I take care of my immediate requirements rather than anticipate my retirement. R238
86. a. My work was difficult to leave. O
   b. I felt needed at work. O
87. One thing that's failing is our married sexual intimacy. R286
88. Lack of sexual relationship has been a major loss.
89. It's difficult to keep the marital relationship and caretaker relationship separate.
90. It's frustrating not to be able to do chores around the home. R3
91. I'm resentful that my partner has more control.
92. Before MS it was easy to walk away from an argument. R80
93. I worry that I'm hanging on to the relationship because of the caregiving.
94. a. You see yourself in need of a lot of care in the future. R93
   b. You're scared about the future. R64a
95. You never know what lies ahead. R64a
96. I want a better future for my partner.
97. I can't visit my daughters anymore because I can't negotiate the distance or the steps. R291
98. Finances are more of an issue because of MS.

Partner #4 (F)

99. With MS you're asked to make the biggest amount of change when you have the fewest amount of resources to cope with change. R64
100. When everybody's in an upheaval two grieving people can't lean on each other. R101
101. With MS what you were to each other is changed.
102. Some people are willing to rebuild a relationship with a different set of priorities. O
103. Prior to the MS we had a traditional relationship. O
104. a. I had a lot of pain and tiredness which I ignored as best I could. O
   b. When I mentioned my symptoms to my partner they were ignored. R356a
105. I started to keep things to myself more. R38b
106. I withdrew a great deal. R38b
107. I went to all my tests on my own. R312
108. When I told my partner about the diagnosis it was ignored. R356a
109. All I thought at the time is I think I'm really alone. R146a
110. I needed my partner to say we'll manage.
111. I just wanted to know I would get the help I needed. R110
112. We did not have a division of labor that was gender related. O
113. Prior to the MS my partner had counted on me for support. R101
114. a. We never talked about the MS
   b. My partner never met my doctors. R356a
115. I went to the doctor alone even during a severe attack. R356a
116. I consider MS to be my problem. O
117. I was concerned about getting the kids taken care of. R3b
118. a. My partner said I'll look after the kids and the house. O
   b. My partner left the medical intervention to me. R356a

119. a. I still felt part of a family. O
    b. I didn't have to worry about household things. R3a
120. a. My partner didn't say a whole lot. R114a
    b. My partner didn't ask a whole lot. R114a
121. **a My partner withdrew from me.**
    b. My partner stopped coming home in the evening. R121a
122. I wasn't strong enough to leave the house. R9
123. I never told people my partner didn't come home at night. R38b
124. **a. I was afraid that I could lose my family**
    b. I was afraid to say anything. R38b
125. **a. My partner didn't cope well.**
    b. My partner drank a lot. R125a
    c. My partner didn't come home until late every night. R121a
126. **a I have a lot of anger at the disease**
    b. The disease messed up my partner's whole life system. R125a
    c. There was a lot of unexpressed anger. R126a
127. **I didn't want to anger my partner because I needed a lot of help.**
128. a. I felt more and more alone. R140
    b. I learned to manage the home a little better. O
129. a. I learned that other people would do things if I asked. O
    b. I thought help would come from my family. O
130. My family couldn't see that my world had really changed. O
131. a. I didn't' know that I had a right to state my needs. R55
    b. I was aware of the kind of upheaval I had caused. R55
132. a. I felt entirely responsible. R55
    b. I felt that I had none of my roles left.
    c. I had lost my identity. R132b
133. I felt I had created too much work. R55
134. I'd been told how grateful I should be that I still had my family. R55
135. I assumed that impeccable behavior on my part is what's required. R48
136. a. I required a full-time housekeeper. R150
    b. I couldn't be up for more than 20 minutes three times a day. R150
137. My partner became involved in more things outside of the home. R121a
138. **MS causes financial burden.**
139. a. I didn't know what to do about the relationship situation. R127
    b. I was afraid of making the relationship worse so I did nothing. R127
140. I was very lonely. R146a
141. a. I was barely functional. O
    b. I felt very abandoned. R121
142. a. I found more and more support outside of the family. R150b
    b. I never said anything to anyone. R38b
143. I kept trying to establish a relationship where my partner would want to be home. R127
144. I placated and pussy-footed around my partner. R127
145. a. I was worried I would not have gotten custody of my kids in my condition. R124a
    b. I did whatever I had to do to protect my relationship with my children. R124a
146. **a. I feel emotionally alone**
    b. Our sexual relationship was strained
147. **Physically I was able to have a sexual relationship.**
148. a. I tried to behave and live like a normal person. R148b
    b. I tried to keep my kids and family normal.
149. I backed off and lost a lot of trust in people. R121
150. a. I backed off emotionally a great deal. R121
    b. I rely on other people
    c. The marriage relationship has become less and less.

151. I was not financially independent do I didn't leave the relationship. R162
152. I was afraid of what might happen to my children. R124a
153. I felt empowered as I took over more and more financial responsibility. O
154. If I need a ride somewhere my partner is probably the last person I'd ask. R356a
155. By not having my partner's support I found that I could find way to do everything I had to do on my own. R156
156. **If my partner had taken the caretaker role I wouldn't be as capable as I am.**
157. a. I was afraid to see a psychiatrist. O
    b. I was afraid that they'd consider me incapable of caring for my children. R124a
158. a. Guilt is a huge huge issue. R61
    b. My own family prides physical strength and ability above most others. O
159. a. My physical improvement was ignored. O
    b. I felt like an imposition. R55
160. What I wanted and who I was didn't count. R163a
161. a. There's been a lot of subtle control issues. R91
    b. I could only go somewhere if my partner agreed to take me. R150b
162. **We might be together now only because I am financially dependent.**
163. **a. I feel devalued because of the MS.**
    b. I feel unequal to my partner.
    c. I backed off so as not to irritate my partner. R127
164. I was dependent entirely for financial things. R162
165. I wonder if people consider suicide to remove themselves as a burden because they don't feel they're contributing in any way. R59

<u>Participant #5 (F)</u>

166. We had to move because I couldn't keep up with my physical work anymore for the farm. O
167. a. MS affected me more than my partner. R167b
    b. MS affected the relationship because it affected me so much.
168. It took my partner a long time to comprehend what was happening for me. R312
169. a. My partner decided we should move. O
    b. My partner worries about me.
170. a. I thought it was really unfair that we had to move. O
    b. I thought I could still manage the work. O
171. a. I used to make the decisions. R91
    b. I used to be independent. R150b
    c. I used to be strong willed. R91
172. I didn't' feel as much of an equal in the relationship. R163b
173. a. The move caused me to lose my support system. O
    b. I didn't have the energy to make new friends. O
174. MS affected our social life. R389
175. I realized how dependent I had become on my partner for my social interactions. R73
176. **a. I covered up to the extent that my partner didn't think anything was wrong**
    b. I was worried that chronic illness could destroy my family. R124a
177. I took it upon myself that I had to protect my partner. R96
178. a. We still go camping R291
    b. We can't go hiking anymore. R291
179. We used to go out to show homes for fun but we can't anymore. R291
180. **We bought a bungalow, one floor plan.**
181. We go arm in arm for walks around the neighborhood because I'm hanging on so I won't fall over. R291
182. My partner wants to retire and get an RV and travel but I have concerns about this because of the MS. R64
183. I'm scared I'm not going to be able to do the things my partner wants to do. R64
184. I realized I don't have the energy to manage everybody's life. R5

185. Although my partner worries about me, he/she encourages me to do what I want. R169b
186. My partner is supportive.
187. My partner never belittles the fact that I can't do things. R186
188. a. It's important to let the person be all they can be. O
    b. It's important to encourage them to push the limits if they want but to be there if they can't. O
189. My partner helps with the household things I can't do. R3a
190. Our love life is affected because you're always tired and your partner's not. R146b
191. Adjustments have to be made sexually.
192. You have to be careful not to assume your partner knows how you feel physically and emotionally. O
193. If I say too much of anything I feel like I'm complaining. R38b
194. My partner likes to have company but I just can't manage this anymore. R174
195. a. A person who has MS has to know where their limitations are. O
    b. A person who has MS has to be able to find compromise that still serves the purpose and that you can live with. R26
196. For some activities we have to bring a wheelchair for me. R291
197. a. Spirituality has been quite profound for me. R197b
    b. For me spirituality/religion is an anchor.
198. a. I am careful with my partner because I need the security of the relationship.
    b. I didn't want to jeopardize the relationship. R198a
199. a. I feel like I've let my partner down.
    b. I feel like I didn't hold up my end of the bargain. R199a
200. I think my partner protects me by not telling me how he/she feels.
201. I didn't have a clue what my partner was feeling. R200
202. We spend a lot of time apart.
203. I need a quiet spot where I can go. R78a
204. a. I'm more dependent on my partner.
    b. I can't drive at night because my vision's not very good. O
    c. If I'm tired my driving reactions aren't all that great either. O
205. a. I resent the dependence. R73
    b. I'm not mad at him so much, just mad at the situation. R126a
206. It's important to maintain your independence. R73

Participant #6 (F)
207. a. For most of my kids young lives I didn't know what was wrong with me. O
    b. Suddenly I was absolutely out of control. O
208. a. MS affects me emotionally. O
    b. I thought I was losing my mind. O
209. I'm really proud when noone knows I'm having an attack. R38
210. It took me a long time before I could be honest with my partner about things that bother me. R198a
211. My partner does the laundry and grocery shopping. R3a
212. a. MS stops me traveling to the extent that my partner wants to.
    b. We don't holiday together. R212a
213. In winter I don't go out unless I have to. R291
214. We never cook just to eat once. O
215. We don't make plans for the future.
216. I started buying airline tickets with insurance. R16
217. I say no to outings because I really don't know what I'm going to feel like then. R16
218. a. We do things separately. R202
    b. My partner has his/her own friends.
219. We don't have any sex life and we haven't for years. R29

220. With MS it's your personal responsibility to look after yourself and maintain your independence. O
221. a. The most valuable thing I learned is not to make assumptions. R273
   b. When you want to know what's up ask your partner. R273
222. It's important to talk openly about it with significant members of your family. R273
223. a. My kids must have felt like they were under attack. O
   b. My kids had to deal with someone who had irrational emotional responses at times. O

Participant #7(M)

224. As a family we've grown closer together because of MS. R1a
225. a. My partner is a caregiver. R89
   b. My partner doesn't expect me to go out there and do things for him/her. R89
226. Sometimes I feel my partner pampers me too much. R126
227. There's a lot of things I can't do. R291
228. A lot of things I liked to I can't do anymore. R291
229. We used to walk an awful lot and I can't walk now. R291
230. **a. I have to be flexible in planning ahead.**
   b. I have to try to arrange to rent a scooter or something to take with me on trips. R212a
231. It seemed to have brought the whole family together. R1a
232. a. It's important to try not to grieve over it too long. O
   b. It's important to try to maintain a positive attitude. O
233. My partner doesn't criticize me. R186
234. We don't sleep together because my legs are jumping around a lot. R190
235. You sort of take life with more than one route to travel so that you have an alternative. R230a
236. a. I am angry quite often. R208
   b. My partner has trouble when I blow up. O
237. My partner does all the work in the house. R3a
238. **a. We take every day one at a time**
   b. We're flexible in planning. R230a
239. Try to control what you can. O
240. I try to live my life that I worry about the things I can control and not worry about the things I can't control. O

Participant #8 (M)

241. a. I felt a hopelessness for the future. R74
   b. I turned myself over to God.
   c. I can't handle it, I can't take it. O
242. a. I was so tired all the time. R5
   b. I'd come home tired and go to work tired. R5
243. a. It was hard on the children. O
   b. They couldn't be like ordinary children running around playing and laughing. O
   c. The children have to be quite all the time while I'm sleeping. O
244. My partner and I felt like we were walking on eggshells all the time. O
245. I don't know if I feel that my partner is a lover or a caretaker. R89
246. I feel like my partner tolerates me. R304
247. Financially it's been really hard. R138
248. When we were first working we always had a nanny who would do everything. O
249. a. We never really plan things. R
   b. We never really talk about things. R114
250. I can't do a lot of things to help like going shopping and stuff like that. R294
251. We couldn't sit down and make plans for the future. R215
252. We couldn't take the kids out camping or do things with them like taking them to parades. R291
253. a. The biggest thing is frustration. R70

b. If you can't do a thing you strike out and hurt the people you love. R70

254. a. MS is a trial and tribulation. O

b. I have to live a very controlled lifestyle.

255. With early retirement suddenly your partner is in the house 24 hours a day. O

256. My partner had to be the sole breadwinner.

257. a. You have to be very careful with finances. R98

b. When you're used to having two incomes it's difficult when all of a sudden you're down to one. R98

258. It's difficult to have time to yourself.

Participant #9 (F)

259. I spend a lot of time at the doctor's office. O

260. My spouse worries about the chance of relapse. R169b

261. With young couples the person with MS feels they have to do everything while they still can which can cause many problems. R215

262. Spouse of patient is worried they can't put a lot of trust in someone who has to worry about a terminal illness. R169b

Participant #10 (M)

263. Spend most of your time at home. R16

264. I have trouble keeping my spirits up.

265. Hard time to associate with company. R174

266. Planned trips are almost impossible. R215

267. Often arguments over activity.

268. Spouse gets impatient over dull life.

269. Need help in dressing, etc. R204a

Participant #11 (M)

270. a. Made us focus on priorities.

b. Take a good look why we are doing something. R270a

271. MS has enabled me to spend more time with my partner.

272. Frustrating watching your partner do all of the household jobs. R70

273. Forced us to work on our communication skills.

274. My unpredictable mood swings cause undue stress.

275. Changed life in the bedroom everywhere from sex to sleeping patterns. R289

276. Has made me appreciate my partner more.

277. a. Socially we aren't out every weekend. R7b

b. A lot more planning goes into an evening out. R230a

278. You have to find new ways to help out at home. R18

279. Find new ways to show your appreciation for the things your partner does. R276

280. a. I take more interest in my partner's hobbies and special activities. R271

b. Before I wouldn't have had the time. R271

281. It has brought us closer and strengthened our marriage. R1a

Participant #12 (F)

282. I have to be in bed early, no late nights. R5

283. Requires different positions when making love.

284. Because of my MS we have decided not to have children. R36

285. I might have MS but it doesn't have me. O

Participant #13 (F)

286. Reduced amount and quality of our sex life.

287. a. Reduced the enjoyment of sex. R286

b. Sex has almost become a chore. R286

288. a. Has reduced my feelings of desirability and attractiveness.
   b. Often spurn my partner's attentions because I no longer feel worthy of them. R288a
289. Has eliminated spontaneity in our lives.
290. Many of our long term goals are unattainable.
291. It is impossible to continue with most activities, hobbies we previously enjoyed together.
292. Having children, which we'd both like, is no longer a realistic option. R36
293. Two incomes became one income and expenses increased. R98
294. Household chores can no longer be split 50/50. R3
295. Marriage no longer seems like an equal partnership. R163b
296. Feelings of anger and frustration at my disability are often taken out on my spouse. R126a
297. I have negative feelings about my increasing dependency on my partner. R73
   b. Increased anxiety that I should lose my partner through separation or death.
298. a. Can no longer do duties such as cooking or much cleaning. R3a
   b. I question my worthiness as a partner. R163a
299. The fact that I'm often tired sore and/or uncomfortable sometimes makes me grumpy and probably hard to get along with. R274
300. a. My partner works all day then comes home and works too.
   b. My partner is often tired and that makes him/her hard to get along with sometimes too. O
301. Sometimes I have trouble with my emotions making communication more difficult. R274

Participant #14 (F)

302. My partner has to assume more duties that I always did. R189
303. a. I constantly feel guilty. R61a
   b. I'm not extremely happy. R274
304. a. I feel very dependent. R204
   b. I feel my partner stays under obligation.
305. Our friends don't invite us to join in as much being that I can't physically participate. R291
306. Our life seemed to revolve around sports before and my partner's life still does, but I'm not included. R291
307. a. I had to quit work. O
   b. I had to quit driving. O
   c. I think our married life is different as I'm quite boring, having no outside contacts. O
308. I'm very tired at most times and hurt a lot, therefore our sexual relations have diminished. R286

Participant #15 (F)

309. Marital life with MS is hell. O
310. a. No confidence. O
   b. No affection. O
   c. Spouse runs away from the problem.
311. a. Spouse will not admit to the problem. R312
   b. Spouse will not read up on the disease. R310c
312. Spouse does not understand what I'm going through.
313. There's a loss of respect. R30
314. Doesn't want to be around me. R30
315. No support, physical or mental. R30
316. Spouse doesn't know if he/she loves me anymore. R304b
317. A lot of anger. R126
318. Spouse was a very affectionate person prior to diagnosis. R30
319. Lost my best friend, my partner. R304b
320. Confusion about marriage, do I want to stay in it and work at it. R304b

Participant #16 (F)

321. Has given me a greater appreciation for my spouse. R276
322. I realized what a patient and loving person I have married. R276

323. My partner has shown and proven to me that MS is not only my disease. it's ours. R186
324. It has brought us closer together. R1a
325. I realize what a wonderful gift I have with my partner and children. R276
326. I've learned to share with my partner my day to day feelings so that my partner feels a part of this. R273
327. a. Have concern about our future. R64
    b. Have concerns about how it may affect my family. R148
328. I don't believe it's really altered our lifestyle at this point aside from the emotional aspect of it. R

Participant #17 (F)

329. Spouse has had to help me to dress. O
330. a. I have to be put on the toilet O
    b. I need help to wash myself. O
331. My sex life is limited as I don't move very much. R286
332. My writing is limited as MS has caused my fingers to not hold the pen very well. O
333. a. I'm in a wheelchair full time. O
    b. I'm not able to do any housework anymore. R3a
334. Unable to drive the car. O
335. Not able to find transportation if we travel to other cities by airplane to get around. R212

Participant #18 (F

336. a. My partner's love and support have further strengthened our bonds. R1a
    b. We have had to work harder on communication. R273
337. I'm hesitant to complain about how I'm feeling. R127
338. I've tried to strike a balance between doing too much and not putting extra stress on my partner and overdoing it. R127
339. a. I don't verbalize about my symptoms. R249
    b. I get upset if my partner doesn't notice if I'm not feeling well. R312
340. My partner and I decided on a major life change because we thought it might be now or never. R238a
341. a. I go all out to clean the house despite not feeling well. O
    b. I want to show my partner that I can cope. I felt hurt that my partner didn't appreciate what I had done. R
342. a. I feel extra pressure because I'm doing the financial things now. O
    b. I take criticism more to heart. R288a
343. When the children were younger I often felt too tired by night for sex. R286
344. My partner and I can no longer share our previous fun things, i.e. skiing, tennis, badminton, baseball, etc. R291
345. At times I became resentful when my partner takes 2 to 3 hours per day on the weekend and I can't share that time. R310c
346. I don't expect my partner to stay home all the time but it would be nice to have my frustration acknowledged. R310c
347. My partner tries to decrease stress on me by not telling me how things were at work. R249

Participant #19 (F)

348. We have sex less often. R286
349. It's put a great strain on us, especially during drug treatments. O
350. a. Initially I thought the MS brought us closer, but now I feel as if my partner is withdrawing away from me. R121
    b. We are growing further apart. R121
351. MS has been another big obstacle. O
352. a. My partner says he/she understands me but doesn't. R312

b. My partner's not here for me often enough and I resent that. R310a

353. a. I resent that my partner can always find time for other people and things but not for me. R354

b. I cannot manage this family and household on my own. R204

354. a. MS has shown me that our marriage is not as secure as I thought it was.

b. Previous problems are just magnified now.

355. The word divorce has come up more since diagnosis than it did in previous years. R297

356. a. I am disappointed that my partner has not been as supportive as I thought he/she would be.

b. I feel I've lost my former best friend. R310c

357. Our marital troubles cause me stress which I believe has worsened my MS.

<u>Participant #20 (F)</u>

358. I have now become more dependent on others. R150
359. My independence now depends on circumstances. R150
360. I never look forward to facing the day. R
361. Every move has to be preplanned to conserve energy. R
362. My emotions sometimes should be secondary to those around me, e.g. family and friends. R148

<u>Participant #21 (M)</u>

363. My marital life ended when I was reliant on a wheelchair. R
364. Family life slowly ended as my weakness and tiredness started to play it's role. R
365. My presence in a wheelchair embarrassed, inconvenienced and cramped my partner's lifestyle. R15
366. Sex life and intimacy slowly tapered off to nothing. R190
367. My spouse assumed that since I was disabled that I could not make any business and financial decisions. R295
368. My partner became more demanding and controlling over me. R91
369. I could not have the things that could make my life a little easier, for example a cordless phone. O
370. Being married and then getting divorced has caused financial burdens. R257a
371. Children's future education will have it's difficulties which will have to encountered later as money for this is being spent presently. R257b
372. I found out my spouse's true colors when hardship was encountered. R30

<u>Participant #22 (F)</u>

373. Unable to hike, bicycle ride, ski, baseball, walk long distances with spouse due to leg weakness. R306

374. a. Chronic fatigue. R5

b. Change in sexual patterns. R286

c. Change in level of activity. R286

375. Unable to do heavy housework, painting the rooms, vacuuming, due to fatigue levels. R3a
376. Unable to work, affecting our financial situation. R257b
377. Unable to do activities throughout the entire day and evening. R291
378. Spouse participates with sports activities by self or with other "fit" people. R

Appendix M

Edit #2 - Partner Statements

Participant #1 (M)

1. There were periods of frustration when I asked myself why me, even though I wasn't the one affected. O
2. It was extremely difficult with three little kids. O
3. I had to keep the household going, the job going, and making sure the kids were looked after. R35
4. **We have to plan our days, our weeks ahead of time.**
5. **I have to do all the driving for the children.**
6. **I feel like everybody depends on me.**
7. When my spouse came home on weekends our routine was thrown off. O
8. Homecare helped but I still had to do all the planning. R84
9. **In a sense I have lost my spouse.**
10. I don't understand the disease. O
11. **MS changed my outlook on life.**
12. **I am frustrated by the uncertainty of not knowing what will be ahead.**
13. **We had to adapt the house to accommodate the wheelchair.**
14. We adapted our whole kitchen. R13
15. **There were a lot of added expenses.**
16. This wasn't part of our long term plan. R228
17. So many things had to be put on hold. R148
18. It's easier not to do things because you don't know with certainty that your partner can do them. O
19. It's difficult to have to take the power chair. O
20. It's easier to say we'll just sit at home. R29
21. I say to myself this hasn't been fair to me. O
22. The children were frustrated because one parent wasn't home. R100
23. One day my spouse was fine and the next day in the hospital and in a wheelchair. O
24. The kids didn't like the attention that the wheelchair attracted. O
25. There are a lot of things my spouse can't do any longer. R29
26. You just have to deal with things because that's the way it is. O
27. It affected myself, my spouse and the children emotionally. R101
28. We could no longer spend weekends camping. R29
29. **I miss some of the activities we used to do together.**
30. **I needed a support group to help understand my feelings.**
31. I felt very angry. R274
32. The home wasn't the same anymore. R310
33. MS wasn't in the big master plan. R228
34. **It was no longer the two of us raising the family.**
35. **I feel like I have to do everything**
36. It took my spouse and it took every red cent that I worked for. R
37. It seemed to affect everything, literally everything. O
38. We used to go dancing a lot. R113
39. I met my spouse in a bowling league. R113
40. We had plans to go hiking together. R113
41. I have to go home right after work to make supper. R
42. There are emotional scars between us that can never heal. O
43. I had a tendency to close myself in. R236
44. a. You can shut yourself away from some things. R236

b. You can shut yourself away from your partner. R236
45. A good relationship makes a world of difference. O

Participant #2 (F)
46. It's made me much more aware of having a healthier lifestyle.
47. We've made a conscious move to healthier diet and more exercise. R46k
48. MS has made us closer in our relationship.
49. Support is required for both of us from each other. R303
50. We understand each other better.
51. Fatigue plays a big role in our lives.
52. We take time for ourselves independently.
53. My spouse tries to stay quite independent. R52
54. We try to maintain a positive attitude towards life.
55. Much of the household responsibilities are on my shoulders.
56. a. I felt I had too much on my plate. R110
b. I had to be the sole breadwinner of the family. R266
57. The shock of diagnosis strained the relationship.
58. The aspect of selfishness is apparent. R293
59. We try to think of the other person more than ourselves. R132
60. MS hasn't seemed to affect our lives intimately. O

Participant #3 (F)
61. A good thing is we are much closer. R48
62. My partner really needs me.
63. Caregiving creates a lot of stress.
64. Sometimes my partner wants to go through a bad time alone. R272
65. I feel very negative when my partner doesn't want to accept my caring and giving. R63
66. It's tremendously important to maintain dignity for my partner. R123
67. It's important to have absolute respect for my partner. R123
68. We need each other very much. R50
69. We're more careful in expressing our feelings.
70. My partner can't do some things. R63
71. My partner needs help dressing. R63
72. I feel guilty because my partner can no longer leave if we argue. R73
73. We no longer fight the way we used to.
74. I fear I may lose myself in this. O
75. Caring for my partner has given me a sense of fulfillment.
76. We no longer feel like equals.
77. There's now a tenderness instead of big hugs. R172
78. We look at life differently. R11
79. The pace of our life has slowed down.
80. We now do everything together. R48
81. MS makes it difficult to plan for the future.
82. We find ways to adapt so we can still do some things we enjoy.
83. I love our quiet evenings at home. R54
84. At times I feel very begrudging for the things I'm doing for my partner.
85. My partner's lost his sexual ability which has strained the relationship. R86
86. I feel hurt and resentful we no longer have a sexual relationship.
87. Caretaking has to be rewarded with sensitivity and appreciation. R63
88. MS is a sad thing and it makes you realize the value of life. R11
89. We're aware of the preciousness of what we have.
90. We try to be as comfortable while we face each hurdle. R54

Participant #4 (M)
91. Partner required surgery in order to make love in a special way. R172
92. My partner needs help with cooking and other physical things. R55
93. I do therapy for my partner. R75
94. I help my partner with showers with pleasure. R75
95. I now do the grocery shopping for both of us. R55
96. I feel that we both have MS. O
97. We've learned about each other's strengths and weaknesses.
98. We love each other more. R48
99. I'd like to learn more about dealing with MS so I can help my partner more. O

Participant #5 (M)
100. The period before diagnosis was undoubtedly the worst. O
101. The most impactful part of MS has been the emotional.
102. I'm constantly driven crazy by the unpredictability.
103. The person that I'd married no longer exists in many ways.
104. There were lots of discussions about separation and divorce. O
105. It was very difficult to live with. R257
106. The emotional ups and downs caused frustration, anger and withdrawal. R101
107. Coping with the unknown is very difficult. R102
108. It takes an incredible amount of emotional awareness and energy to cope.
109. I was frustrated by my partner's mood swings. R106
110. It's difficult to cope with all the expectations placed on me.
111. There was a very painful period shortly after diagnosis. O
112. I find I need space away from my partner.
113. We can no longer do a lot of the things we used to do.
114. I spent summer holidays with my kids leaving my partner at home. R113
115. My partner was quite unpredictable. R101
116. I feel I always need to evaluate how my partner is feeling before I talk to him/her.
117. We don't make decisions together any more.
118. I feel more responsibility to monitor what's going on with my partner. R116
119. It's important to let my partner do as much as possible. R122
120. I go grocery shopping. R55
121. I do the high energy stuff. R55
122. I think of myself as a back-up to do whatever my partner cannot do.
123. I believe it's important to allow my partner dignity.
124. Simplistic communication skills in an average relationship become complex with a chronic illness. R126
125. The partner has to take on an additional burden. R110
126. I have to screen out what is illness related from what is personality related.
127. It's hard to live with somebody who's chronically depressed. R137
128. With MS it's worse because the bouts of depression or manic behavior come and go, so you're constantly monitoring. R106
129. You're constantly editing yourself. R116
130. It's very very tiring. R110
131. I often feel guilty because my partner is ill.
132. The person who is ill requires the greatest care and sympathy. R123
133. With MS I cannot look at my partner and assume he or she is fine.
134. You need to communicate to your partner that their spouse is literally a lay man in an emotional minefield. R126
135. People in the caregiver role need to be better informed. O
136. Things will probably change for the worse in the future. R148
137. It's very stressful dealing with a chronic illness.

138. The caretaker role is made more complex by the emotional ups and downs of the person you're caring for. R101
139. The whole sexual thing was so unpredictable. R172
140. We no longer have a sexual relationship.
141. There's a constantly shifting emotional response from my partner. R101
142. I think the non-MS person has to be constantly aware of their responsibility to reduce stress. R110
143. Evening social events are a thing of the past.
144. There are dimensions of the relationship that have been enhanced by MS. R48
145. Caring and trust are a big part of the relationship. R50
146. I have been able to put my own fear into perspective more.
147. My strong faith is a resource.

Participant #6(M)
148. Apprehension about our future with MS. R81
149. I find myself trying to do more to help with the housework. R122
150. I'm harder on our kids to behave better and not tire out my partner. O
151. I feel guilty about working late or on weekends. R131
152. I try not to burden my partner.

Participant #7 (F)
153. MS affects everything in a relationship. O
154. It's really stressful. R
155. MS contributed to my own illness. R
156. I had to be the sole breadwinner of the family. R
157. I had to take care of the children. R34
158. People didn't understand the illness. O
159. I blame the illness, not the human being. R126
160. There has to be some humor in the relationship. O
161. I sometimes say things that make my partner feel worse. R116
162. I can't be straight forward in my feelings.
163. I'm living my whole life inside my head. O
164. I don't share with other people what I'm going through.
165. My partner became very abusive. R106
166. Seeing people in wheelchairs disturbed my partner. O
167. I no longer have somebody to talk things over with.
168. I no longer have somebody to make decisions with. R117
169. My partner began spending a lot of money. O
170. Everything a marriage is supposed to be was no longer there. R103
171. I stuck around because of my Christian values. O
172. Our sexual life was greatly affected.
173. We didn't know what we could look forward to in the future. R81
174. I had to take over handling all the finances.
175. My partner no longer wanted to go anywhere. R113
176. It caused a lot of problems in the family. O
177. I feel it is my duty to take care of things.
178. I spent my life looking after everybody else. O

Participant #8 (M)
179. I'm unable to work due to my caretaking duties. R63
180. Unable to go on extended (over 4 or 5 days) holidays/vacations. R63
181. Unable to leave home for over 4 hours at a time by myself. R63
182. Endless emptying of catheter leg bags and toilet necessities. R63
183. Expensive to buy countless items, medical supplies. R15

184. We have to live near a fairly large city. R185
185. We have to live near appropriate doctors and hospitals.
186. There are endless minor chores. R110
187. Days are often long and boring.
188. A normal day is extended by nearly two and a half hours by washing, bathing, dressing in the morning and before bedtime. R63
189. Reduced companionship.
190. Spouse unable to participate in hobbies, gardening, etc. R113
191. Spouse's thinking/memory problems cause poor communications.
192. Reduced greatly my free time to do many little things.
193. Cuts back immensely the number of places we can visit. R113
194. Takes additional time to get ready to go anywhere. R63
195. Takes time to find suitable parking. O
196. Forever arranging to keep appointments. O
197. Constantly trying to maintain a smooth flow of daily routines and schedules. R110
198. Always cooking, cleaning and caretaking. R6

Participant #9 (M)
199. More reliance on spouse without MS. R110
200. More sharing of responsibilities.
201. Brought us closer together. R48
202. Admiration for strength and courage of spouse with MS. R267

Participant #10 (F)
203. a. It's been very tough. R110
b. I like structure and things have to be very predictable, and MS is very unpredictable. R102
204. I had to learn to live more day by day.
205. When I got married I wanted to be looked after. R103
206. I felt I had to look after my partner. R177
207. I am constantly concerned about my partner's health.
208. The doctor suggested we not share the diagnosis with a lot of people. R209
209. I didn't tell people so there was a lot of covering up.
210. We had applied to adopt a child and decided not to after diagnosis. R351
211. I didn't think I could cope alone if my partner got worse. R108
212. We grieve over the children we didn't have. R351
213. I feel depressed a lot of the time.
214. I don't think I'm as supportive as I should be. R303
215. I returned to work because I didn't know what the future would bring. R
216. I feel I have to be stronger and more independent.
217. I ended up taking time off work because of stress. R362
218. I was always worried about my partner. R207
219. I wanted to protect my partner. R387
220. I kept the children away from my partner so that he/she wouldn't be disturbed. O
221. I was exhausted a lot of the time. R110
222. I felt preoccupied with my partner's illness. R207
223. I was concerned I may have to push my partner around in a wheelchair. O
224. I don't want to be a caregiver. R84
225. I fear my partner being totally dependent on me.
226. I feel insecure about the future.
227. It helped me put things more in perspective. R11
228. There was a shattering of our dreams for the future.
229. We could no longer go skiing together or skating. R342
230. I feel envious of families that are not living with a chronic illness. R228

231. My partner's uncomfortable around other people because of his/her bathroom problems. R
232. We're doing a lot of traveling now because we don't know what will happen in the future. R226
233. Every time we do something I think this may be the last time we'll ever be able to do it. R226
234. I wanted our lives to be the same as everybody else's. R228
235. I wanted our lives to stay the same. R228
236. I withdrew from people.
237. I felt I no longer had a lot in common with other people. R228
238. I tried not to appear upset when I told people about the MS. R209
239. The spousal support group pointed out how bad things could be. O
240. I didn't feel our problems were bad enough to go to a counselor. O
241. I felt I went through the motions of living but was not really living. O
242. I resented having to go back to work. R110
243. I feared that my partner would no longer be able to work.
244. We had the expense of having to hire a housekeeper. R15
245. I had to do everything, the grocery shopping, the laundry, and housekeeping. R253
246. We had to rearrange everything financially. R357
247. The hardest thing for me is the insecurity. R226
248. We didn't tell the children. R209
249. I don't enjoy outings because I was petrified about if my partner has to go to the washroom. R113
250. I never shared with my daughter how burdened I felt. R209

Participant #11 (M)
251. I found out how selfish I had been. R392
252. More responsibility falls on the healthy spouse. R110
253. I now do all the household chores. R55
254. My feelings for my partner have grown stronger. R48
255. I'm now a part-time care attendant for my partner. R63
256. I help my partner with the catheter, bathing and minor medical. R63

Participant #12 (M)
257. It was hard making adjustments to a partner with MS. R57
258. I've had to slow down physically to my partner's level. R79
259. I've had to adjust my mental processes to my partner's level. O
260. I have to be careful not to confuse my partner because of his/her memory problems. R116
261. I take care not to overload my partner with details. R116
262. I take care of most of the things like the housework and washing. R55
263. Sometimes there's friction because I do too much. R273
264. I have to read the signs and adjust accordingly. R116
265. Stress is a major player in our family. R137
266. Financially it's been difficult.
267. I'm impressed with how my spouse has coped with the disease.
268. We would do a lot more things if my partner didn't have MS. R113
269. I'm worried about saying the wrong things. R124
270. My partner is very concerned about what other people think. O
271. Short term memory is a concern because my partner tends to forget things. R116
272. I try to give my partner as much independence as possible. R273
273. One area of conflict is I try to do too much for my partner.
274. I get angry and annoyed about having to live with MS.
275. I've learned to live a slower paced lifestyle. R79
276. If we go somewhere we have to take the wheelchair. O
277. My partner feels a stigma about using the wheelchair. O

278. We worry about what will happen 5 years from now. R81
279. Every once in a while it gets to me. R102
280. Sometimes what I'm doing isn't what my partner needs. R273
281. My partner's strength of character is amazing to me. R267
282. I do not fear being a caretaker in the future. R225
283. We have had to make some decisions we wouldn't have made without the MS.

Participant #13 (M)
284. Physical activities slowly diminishing. R113
285. Has affected me very little. O
286. Change is slow so I'm growing into it with my partner. O
287. If you're close to it, you don't see the changes. O
288. Take wheelchair on vacation just in case. O
289. Purchased new house that was an open floor plan.
290. Entertaining much less because my partner gets too tired.
291. I feel no hardships due to the changes in my partner's physical condition. R
292. I love my partner and the bond is very strong. R48
293. If my partner needs it I'll be there. R62

Participant #14 (F)
294. I've become more tolerant and understanding. R50
295. I've become more patient. R307
296. We've refocused on priorities in life like health, friends, and family.
297. We've changed our eating habits. R296
298. We now use natural herbs. R296
299. We participate in Tai Chi classes. R296
300. Try to stay positive. R54
301. We're involved in the MS society. O
302. We do as many fun things as possible. R54
303. I'm more supportive of my spouse.

Participant #15 (F)
304. It's made me more concerned, patient, and understanding of his/her problems. R50
305. Has limited activity. R113
306. Made us more aware of other people's problems.
307. Has made me become more patient. R303
308. Has made me try to be more positive. R54
309. Changed the way we live every day (not concerned about little things. R204
310. Keep a quite home for rest periods.
311. Find that people are not aware of MS people's capabilities. O
312. When annoyed you often don't say what you would like to. R
313. Have to take responsibility for doing everything. R110
314. I have to do many activities on my own.
315. No longer travel. R330
316. Partner needs a lot of support. R303

Participant #16 (F)
317. Roles have changed.
318. Household duties have changed. R55
319. We're no longer sexually active. R140
320. We no longer dance. R113
321. For walks I have to push my partner in a wheelchair. O
322. I do most of the driving. O
323. I do most of the grocery shopping. R

324. Being active in sports is hard because we both can't take part. R242
325. Had to learn to maneuver the wheelchair. O
326. Had to understand when partner needs to rest. R294

Participant #17 (F)
327. Loss of physical sex. R140
328. Still have sharing of affection and emotional involvement. R392
329. Share same interests and tastes. O
330. Traveling is more difficult.
331. Partner unable to help with outside yardwork. R55
332. Still helps with inside household chores. R55
333. Partner has caring attitude on how my work day has gone. R55
334. My partner's still able to drive with hand controls. R55
335. Pension income helps with finances. R266
336. Difficult visiting friends and relatives because of accessibility by wheelchair. R
337. Unable to do things or go places that ambulatory people can do. R
338. Still have a full and busy life. R300
339. Try to dwell on what we have rather than what we don't have. R
340. No written guarantee when we are born that everything will run smoothly. R148

Participant #18 (M)
341. MS has affected our entertainment and enjoyment. R290
342. MS has affected our participation in sports. R290
343. MS has affected our sexual life. R172
344. MS has affected our social life. R290
345. MS has affected housework. R318
346. MS has affected household maintenance. R318

Participant #19 (F)
347. We no longer can do some activities together that we used to. R113
348. We spend more time together.
349. My partner is around so much I don't get much personal space. R112
350. I was tempted at first to just drive away. R100
351. It shattered our dreams about having children.
352. I tried to protect my partner too much. R124
353. Our life has a slower pace. R79
354. We appreciate little things more. R11
355. It's a more equal relationship than it would have been. R317
356. It has limited our social life. R290
357. We've had to plan financially more for the future.
358. I don't enjoy many activities because I'm worried about my partner. R207

Participant #20 (M)
359. We spend more time apart. R348
360. Time together is in sedentary activities.
361. During undiagnosed period much talk of separation and divorce. R100
362. Stressful relationship because of constant and unpredictable change.
363. I'm fully committed to the relationship. O

Participant #21 (F)
364. Finances have been a constant pressure. R
365. My partner is not the same person I married. R103
366. We no longer enjoy some activities. R113

367. Partner has great difficulty with orgasms. R172
368. No sexual relationship. R140
369. We spend less time together. R348
370. Cognitive problems make it difficult to discuss matters. R168
371. Embarrassed about my partner's behavior around other people.
372. Partner's problems with short-term memory can cause problems in the relationship. R191
373. MS spouse doesn't like change. O
374. Visiting friends is difficult. R290
375. I'm exhausted. R110
376. I feel MS has contributed to my own illness.
377. I feel I've lost my companion. R9
378. I feel like a full-time caretaker. R
379. My partner is verbally abusive. R106
380. I've had to do everything in the relationship. R110

<u>Participant #22 (M)</u>

381. The physical and emotional needs of the ill spouse come first.
382. It's frustrating not being able to do the things we used to do. R29
383. We spend less time together. R369
384. Conversation seems to be centered on the needs of the person with MS.

<u>Participant #23 (M)</u>

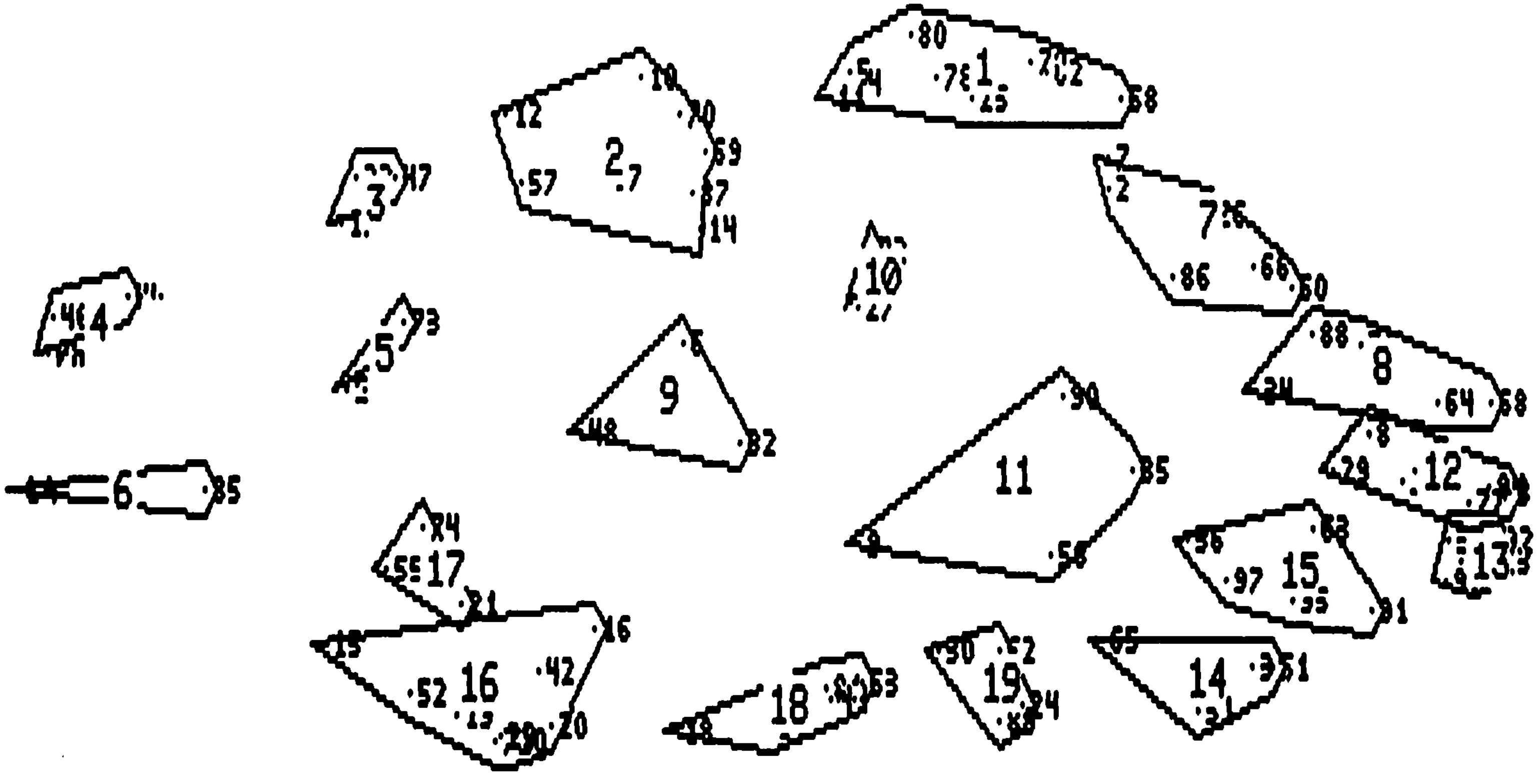
385. I admire my partner more. R267
386. I trust our solidarity more. R48
387. I am far more protective of my partner. R303
388. I feel I have to be less selfish. R303
389. My attitude towards happiness rather than money has improved. R296
390. My partner's insecurity frustrates me. R226
391. I hate feeling helpless to cure my partner. R226

<u>Participant #24 (F)</u>

392. We are more sensitive toward each other. R50
393. MS has enriched our marriage. R48
394. It's slowed us down and given us time to smell the roses. R79
395. My caregiving has given me a sense of fulfillment and commitment to the marriage. R75
396. Added household responsibilities make me tired and resentful. R35
397. We both miss the regular sexual ways of loving. R86
398. We cry together for the way the marriage could have been. R228
399. I show my love by helping my partner. R122
400. My partner is much more emotionally sensitive to me. R50
401. MS has given us time for our families. R348

<u>Participant #25 (M)</u>

402. I've had to physically slow down to my partner's speed. R79
403. It's caused considerable stress. R362
404. I feel helpless with regard to my partner attempting to come to terms with the condition. R226
405. I have difficulty being all things my partner needs me to be. R110



APPENDIX N: 19-Solution Map of 97 Patient Statements

Appendix P

Cluster Map and Bridging Indexes for the 19-Solution Cluster Map of MS Patients

Statements	**Bridging Index**
Cluster #1	
1. We are closer because of MS	0.04
4. More sharing of the running of the household.	0.05
78. Made us focus on priorities.	0.05
80. Forced us to work on our communication skills.	0.05
5. More sharing of the raising of children.	0.06
79. MS has enabled me to spend more time with my partner.	0.07
82. Has made me appreciate my partner more.	0.12
25. Living with MS is a learning process for both of us.	0.13
11. We make a conscious effort to find things we can still share.	0.14
58. My partner is supportive.	0.37
Cluster average	0.11
Cluster #2	
70. We take every day one at a time.	0.15
69. I have to be flexible in planning ahead.	0.16
87. Many of our long terms goals are unattainable.	0.17
14. We decided not to have children because of MS.	0.21
67. We don't make plans for the future.	0.21
10. I'm more conscious of trying to make the best of things now.	0.22
57. We bought a bungalow, one floor plan.	0.31
12. We enjoy closeness without a sexual relationship.	0.38
Cluster average	0.23
Cluster #3	
22. It's important not to dwell on your MS.	0.40
17. I've tried to stay looking and seeming as normal as possible.	0.44
47. I tried to keep my kids and family normal.	0.44
Cluster average	0.43
Cluster #4	
46. Physically I was able to have a sexual relationship.	0.00
28. Lack of a sexual relationship has been a major loss.	0.04
45. Our sexual relationship was strained.	0.04
84. Reduced amount and quality of our sex life.	0.04
59. Adjustments have to be made sexually.	0.17
83. Requires different positions when making love.	0.17
Cluster average	0.07

Cluster #5

33. Finances are more of an issue because of MS.	0.39
43. MS causes financial burden.	0.39
73. My partner had to be the sole breadwinner.	0.45
Cluster average	0.41

Cluster #6

60. For me spirituality/religion is an anchor.	0.41
71. I turned myself over to God.	0.41
85. Has reduced my feelings of desirability and attractiveness.	0.46
Cluster average	0.43

Cluster #7

2. We stay home a lot.	0.20
7. When we go on holidays we tend to just rest and relax.	0.21
86. Has eliminated spontaneity in our lives.	0.26
66. MS stops me traveling to the extent that my partner wants to.	0.28
26. We no longer argue the way we used to.	0.43
50. If my partner had taken the caretaker role I wouldn't be as capable as I am.	0.46
Cluster average	0.31

Cluster #8

64. We spend a lot of time apart.	0.22
76. Often arguments over activity.	0.28
68. My partner has his/her own friends.	0.29
88. It is impossible to continue with most activities, hobbies we previously enjoyed together.	0.30
34. With MS what you were to each other is changed.	0.33
Cluster average	0.28

Cluster #9

6. I don't have the energy to do some things.	0.42
32. I want a better future for my partner.	0.47
48. I rely on other people.	0.56
Cluster average	0.48

Cluster #10

72. I have to live a very controlled lifestyle.	0.28
27. I had to give up a lot of my previous types of recreation.	0.31
Cluster average	0.30

Cluster #11

35. I needed my partner to say we'll manage.	0.32

56. I covered up to the extent that my partner didn't think anything was wrong.	0.34
9. The uncertainty of MS causes a lot of stress and anxiety in our lives.	0.36
90. My partner works all day then comes home and works too.	0.40
Cluster average	0.35

Cluster #12

77. Spouse gets impatient over dull life.	0.10
3. We have more conflict in our marriage due to MS.	0.14
94. MS has shown me that our marriage is not as secure as I thought it was.	0.14
49. The marriage relationship has become less and less.	0.18
54. MS affected the relationship because it affected me so much.	0.18
8. My partner is worried that I'll embarrass him/her.	0.20
29. It's difficult to keep the marital relationship and caretaker relationship separate.	0.23
Cluster average	0.17

Cluster #13

93. Spouse does not understand what I'm going through.	0.04
13. My partner couldn't come to terms with living with an invalid.	0.06
92. Spouse runs away from the problem.	0.06
96. I am disappointed that my partner has not been as supportive as I thought he/she would be.	0.06
37. My partner withdrew from me.	0.09
39. My partner didn't cope well.	0.12
Cluster average	0.07

Cluster #14

31. I worry that I'm hanging on to the relationship because of the caregiving.	0.13
61. I am careful with my partner because I need the security of the relationship.	0.13
41. I didn't want to anger my partner because I needed a lot of help.	0.18
65. I'm more dependent on my partner.	0.21
51. We might be together now only because I an financially dependent.	0.26
Cluster average	0.18

Cluster #15

91. I feel my partner stays under obligation.	0.11
95. Previous problems are just magnified now.	0.19
97. Our marital troubles cause me stress which I believe has worsened my MS.	0.23

63. I think my partner protects me by not telling me how he/she feels.	0.23
36. We never talked about the MS.	0.24
Cluster average	0.20

Cluster #16

40. I have a lot of anger at the disease.	0.04
23. I'm frustrated to be continually losing something.	0.05
75. I have trouble keeping my spirits up.	0.07
20. I feel guilty about having MS.	0.11
19. When I think of a way out I think of suicide.	0.12
52. I feel devalued because of the MS.	0.15
42. I felt that I had none of my roles left.	0.24
16. Thinking and memory problems have been the most difficult to deal with.	0.32
15. I didn't tell people I had MS.	0.54
Cluster average	0.18

Cluster #17

21. Because MS is unpredictable I worry about the future.	0.41
74. It's difficult to have time to myself.	0.48
55. My partner worries about me.	1.00
Cluster average	0.63

Cluster #18

38. I was afraid that I could lose my family.	0.24
18. I don't want to be a burden on anyone.	0.26
53. I feel unequal to my partner.	0.28
81. My unpredictable mood swings cause undue stress.	0.30
44. I feel emotionally alone.	0.33
Cluster average	0.28

Cluster #19

24. I worry about becoming totally dependent on my partner.	0.22
89. Increased anxiety that I should lose my partner through separation or death.	0.24
30. I'm resentful that my partner has more control.	0.25
62. I feel like I've let my partner down.	0.25
Cluster average	0.24

Appendix O

Cluster Map and Bridging Indexes for the 19 Solution Concept Map of Partners of Multiple Sclerosis Patients

	Bridging Index
Cluster #1	
94. It shattered our dreams about having children.	0.42
8. We had to adapt the house to accommodate the wheelchair.	0.45
30. MS makes it difficult to plan for the future.	0.46
84. Purchased new house that was an open floor plan.	0.46
63. We have to live near appropriate doctors and hospitals.	0.47
1. We have to plan our days, our weeks ahead of time.	0.50
Cluster average	0.45
Cluster #2	
92. Traveling more difficult.	0.48
89. Keep a quiet home for rest periods.	0.55
29. The pace of our life has slowed down.	0.59
96. Time together is in sedentary activities.	0.60
83. We have had to make some decisions we wouldn't have made without the MS.	0.75
Cluster average	0.60
Cluster #3	
85. Entertaining much less because my partner gets too tired.	0.52
53. Evening social events are a thing of the past.	0.55
43. We can no longer do a lot of the things we used to do.	0.61
11. I miss some of the activities we used to do together.	0.66
18. Fatigue plays a big role in our lives.	0.83
Cluster average	0.63
Cluster #4	
95. We've had to plan financially more for the future.	0.36
9. There were a lot of added expenses.	0.37
79. Financially it's been difficult.	0.37
76. There was a shattering of our dreams for the future.	0.54
75. I feel insecure about the future.	0.60
7. I'm frustrated by the uncertainty of not knowing what will be ahead.	0.70
Cluster average	0.49

Appendix O

Cluster Map and Bridging Indexes for the 19 Solution Concept Map of Partners of Multiple Sclerosis Patients

	Bridging Index
Cluster #1	
94. It shattered our dreams about having children.	0.42
8. We had to adapt the house to accommodate the wheelchair.	0.45
30. MS makes it difficult to plan for the future.	0.46
84. Purchased new house that was an open floor plan.	0.46
63. We have to live near appropriate doctors and hospitals.	0.47
1. We have to plan our days, our weeks ahead of time.	0.50
Cluster average	0.45
Cluster #2	
92. Traveling more difficult.	0.48
89. Keep a quiet home for rest periods.	0.55
29. The pace of our life has slowed down.	0.59
96. Time together is in sedentary activities.	0.60
83. We have had to make some decisions we wouldn't have made without the MS.	0.75
Cluster average	0.60
Cluster #3	
85. Entertaining much less because my partner gets too tired.	0.52
53. Evening social events are a thing of the past.	0.55
43. We can no longer do a lot of the things we used to do.	0.61
11. I miss some of the activities we used to do together.	0.66
18. Fatigue plays a big role in our lives.	0.83
Cluster average	0.63
Cluster #4	
95. We've had to plan financially more for the future.	0.36
9. There were a lot of added expenses.	0.37
79. Financially it's been difficult.	0.37
76. There was a shattering of our dreams for the future.	0.54
75. I feel insecure about the future.	0.60
7. I'm frustrated by the uncertainty of not knowing what will be ahead.	0.70
Cluster average	0.49

Cluster #5

24. Caregiving creates a lot of stress.	0.55
66. Spouse's thinking and memory problems cause poor communications.	0.62
74. I fear my partner being totally dependent on me.	0.62
22. The shock of diagnosis strained the relationship.	0.65
97. Stressful relationship because of constant and unpredictable change.	0.74
Cluster average	0.64

Cluster #6

72. I feel depressed a lot of the time.	0.44
82. I get angry and annoyed about having to live with MS.	0.45
49. I often feel guilty because my partner is ill.	0.46
51. It's very stressful dealing with a chronic illness.	0.48
37. The most impactful part of MS has been the emotional.	0.49
98. Embarrassed about my partner's behavior around other people.	0.54
38. I'm constantly driven crazy by the unpredictability.	0.65
Cluster average	0.50

Cluster #7

77. I withdrew from people.	0.76
58. I don't share with people what I'm going through.	0.76
33. I feel hurt and resentful we longer have a sexual relationship.	0.82
71. I didn't tell people so there was a lot of covering up.	0.92
Cluster average	0.82

Cluster #8

78. I feared that my partner would no longer be able to work.	0.93
52. We no longer have a sexual relationship.	0.96
60. Our sexual life was greatly affected.	0.96
Cluster average	0.95

Cluster #9

2. I have to do all the driving for the children.	0.40
73. I feel I have to be stronger and more independent.	0.48
13. It was no longer the two of us raising the family.	0.65
23. My partner really needs me.	0.65
91. Roles have changed.	0.72
25. We're more careful in expressing our feelings.	1.00
Cluster average	0.65

Cluster #10

3. I feel like everybody depends on me.	0.30

14. I feel like I have to do everything.	0.30
62. I feel it is my duty to take care of things.	0.30
21. Much of the household responsibilities are on my shoulders.	0.31
46. I think of myself as a back-up to do whatever my partner cannot do.	0.42
56. I try not to burden my partner.	0.43
61. I had to take over handling all the finances.	0.56
Cluster average	0.37
Cluster #11	
39. The person that I'd married no longer existed in many ways.	0.38
59. I no longer have somebody to talk things over with.	0.38
44. I feel I always need to evaluate how my partner is feeling before I talk to him/her.	0.40
36. Conversation seems to be centered on the needs of the person with MS.	0.41
4. In a sense I have lost my spouse.	0.42
28. We no longer feel like equals.	0.46
50. With MS I cannot look at my partner and assume he or she is fine.	0.46
57. I can't be straight forward in my feelings.	0.46
65. Reduced companionship.	0.46
Cluster average	0.43
Cluster #12	
45. We don't make decisions together any more.	0.44
48. I have to screen out what is illness related from what is personality related.	0.48
81. One area of conflict is I try to do too much for my partner.	0.52
Cluster average	0.48
Cluster #13	
70. I am constantly concerned about my partner's health.	0.44
32. At times I feel very begrudging for the things I'm doing for my partner.	0.46
41. It's difficult to cope with all the expectations placed on me.	0.48
67. Reduced greatly my free time to do many little things.	0.54
64. Days are often long and boring.	0.56
5. I feel MS has contributed to my own illness.	0.57
Cluster average	0.51
Cluster #14	
40. It takes an incredible amount of emotional awareness and energy to cope.	0.50
10. The physical and emotional needs of the ill spouse come first.	0.60

Cluster average	0.55
Cluster #15	
69. I had to learn to live more day by day.	0.79
6. MS changed my outlook on life.	0.80
Cluster average	0.79
Cluster #16	
90. I have to do many activities on my own.	0.68
12. I needed a support group to help understand my feelings.	0.79
42. I find I need space away from my partner.	0.83
Cluster average	0.77
Cluster #17	
68. More sharing of responsibilities.	0.65
54. I have been able to put my own fear into perspective more.	0.74
26. We no longer fight the way we used to.	0.79
Cluster average	0.73
Cluster #18	
34. We're aware of the preciousness of what we have.	0.08
88. Made us more aware of other people's problems.	0.19
15. It's made us much more aware of having a healthier lifestyle.	0.23
86. We've refocused on priorities in life like health, friends, and family.	0.23
80. I'm impressed with how my spouse has coped with the disease.	0.35
55. My strong faith is a resource.	0.36
47. I believe it's important to allow my partner dignity.	0.84
Cluster average	0.33
Cluster #19	
93. We spend more time together.	0.00
17. We understand each other better.	0.00
16. MS has made us closer in our relationship.	0.00
35. We've learned about each other's strengths and weaknesses.	0.06
87. I'm more supportive of my spouse.	0.13
31. We find ways to adapt so we can still do some things we enjoy.	0.18
19. We take time for ourselves independently.	0.19
20. We try to maintain a positive attitude towards life.	0.21
27. Caring for my partner has given me a sense of fulfillment.	0.27
Cluster average	0.11

Appendix P

Patient Incidence Survey

Survey for the Individual with MS

Multiple Sclerosis and Marital Life
Part A - Demographic Survey

1. _____ Male
   _____ Female

2. Age _____

3. What is your current marital status
   1. _____ married
   2. _____ separated/divorced
   3. _____ other, please specify ____________________

4. # of years living with present partner _____

5. Years since diagnosis of MS _____

6. Disease course (if known)
   1. _____ Chronic progressive
   2. _____ Remitting relapsing ... # of attacks per year _____
   3. _____ Benign

7. MS symptoms - please check those applicable
   1. _____ physical symptoms
   2. _____ emotional symptoms
   3. _____ thinking/memory/cognitive symptoms
   4. _____ other ... please describe ______________________

8. Number of years of formal education completed _____

9. Are you employed outside the home? _____ yes _____ no
   Average number of hours at work per week _____

10. Please rate your level of satisfaction with your marriage

very dissatisfied	moderately dissatisfied	neutral	moderately satisfied	very satisfied

11. If divorced or separated please indicate if you perceive MS to have been a factor contributing to the divorce or separation

1	2	3	4	5
not at all	little	fair amount	quite a bit	a major factor

Multiple Sclerosis and Marital Life
Part B - Survey

Directions:

Please give each of the following statements a rating that indicates to what degree the statement reflects your experience. Circle the number that most closely matches the degree to which the statement applies to you.

not at all	a little bit	a medium amount	a fair amount	a great deal
1	2	3	4	5

Statement	Degree to which it applies					
	not at all				a great deal	
1. We are closer because of MS	1	2	3	4	5	NA
2. We stay home a lot.	1	2	3	4	5	NA
3. We have more conflict in our marriage due to MS.	1	2	3	4	5	NA
4. More sharing of the running of the household.	1	2	3	4	5	NA
5. More sharing of the raising of children.	1	2	3	4	5	NA
6. I don't have the energy to do some things.	1	2	3	4	5	NA
7. When we go on holidays we tend to just rest and relax.	1	2	3	4	5	NA
8. My partner is worried that I'll embarrass him/her.	1	2	3	4	5	NA
9. The uncertainty of MS causes a lot of stress and anxiety in our lives.	1	2	3	4	5	NA
10. I'm more conscious of trying to make the best of things now.	1	2	3	4	5	NA
11. We make a conscious effort to find things we can still share.	1	2	3	4	5	NA
12. We enjoy closeness without a sexual relationship.	1	2	3	4	5	NA
13. My partner couldn't come to terms with living with an invalid.	1	2	3	4	5	NA
14. We decided not to have children because of MS.	1	2	3	4	5	NA
15. I didn't tell people I had MS.	1	2	3	4	5	NA
16. Thinking and memory problems have been the most difficult to deal with.	1	2	3	4	5	NA
17. I've tried to stay looking and seeming as normal as possible.	1	2	3	4	5	NA
18. I don't want to be a burden on anyone.	1	2	3	4	5	NA
19. When I think of a way out I think of suicide.	1	2	3	4	5	NA

Statement	Degree to which it applies					
	not at all				a great deal	
20. I feel guilty about having MS.	1	2	3	4	5	NA
21. Because MS is unpredictable I worry about the future.	1	2	3	4	5	NA
22. It's important not to dwell on your MS.	1	2	3	4	5	NA
23. I'm frustrated to be continually losing something.	1	2	3	4	5	NA
24. I worry about becoming totally dependent on my partner.	1	2	3	4	5	NA
25. Living with MS is a learning process for both of us.	1	2	3	4	5	NA
26. We no longer argue the way we used to.	1	2	3	4	5	NA
27. I had to give up a lot of my previous types of recreation.	1	2	3	4	5	NA
28. Lack of a sexual relationship has been a major loss.	1	2	3	4	5	NA
29. It's difficult to keep the marital relationship and caretaker relationship separate.	1	2	3	4	5	NA
30. I'm resentful that my partner has more control.	1	2	3	4	5	NA
31. I worry that I'm hanging on to the relationship because of the caregiving.	1	2	3	4	5	NA
32. I want a better future for my partner.	1	2	3	4	5	NA
33. Finances are more of an issue because of MS.	1	2	3	4	5	NA
34. With MS what you were to each other is changed.	1	2	3	4	5	NA
35. I needed my partner to say we'll manage.	1	2	3	4	5	NA
36. We never talked about the MS.	1	2	3	4	5	NA
37. My partner withdrew from me.	1	2	3	4	5	NA
38. I was afraid that I could lose my family.	1	2	3	4	5	NA
39. My partner didn't cope well.	1	2	3	4	5	NA
40. I have a lot of anger at the disease.	1	2	3	4	5	NA
41. I didn't want to anger my partner because I needed a lot of help.	1	2	3	4	5	NA
42. I felt that I had none of my roles left.	1	2	3	4	5	NA
43. MS causes financial burden.	1	2	3	4	5	NA
44. I feel emotionally alone.	1	2	3	4	5	NA
45. Our sexual relationship was strained.	1	2	3	4	5	NA
46. Physically I was able to have a sexual relationship.	1	2	3	4	5	NA
47. I tried to keep my kids and family normal.	1	2	3	4	5	NA
48. I rely on other people.	1	2	3	4	5	NA
49. The marriage relationship has become less and less.	1	2	3	4	5	NA

Statement	**Degree to which it applies**					
	not at all				**a great deal**	
50. If my partner had taken the caretaker role I wouldn't be as capable as I am.	1	2	3	4	5	NA
51. We might be together now only because I an financially dependent.	1	2	3	4	5	NA
52. I feel devalued because of the MS.	1	2	3	4	5	NA
53. I feel unequal to my partner.	1	2	3	4	5	NA
54. MS affected the relationship because it affected me so much.	1	2	3	4	5	NA
55. My partner worries about me.	1	2	3	4	5	NA
56. I covered up to the extent that my partner didn't think anything was wrong.	1	2	3	4	5	NA
57. We bought a bungalow, one floor plan.	1	2	3	4	5	NA
58. My partner is supportive.	1	2	3	4	5	NA
59. Adjustments have to be made sexually.	1	2	3	4	5	NA
60. For me spirituality/religion is an anchor.	1	2	3	4	5	NA
61. I am careful with my partner because I need the security of the relationship.	1	2	3	4	5	NA
62. I feel like I've let my partner down.	1	2	3	4	5	NA
63. I think my partner protects me by not telling me how he/she feels.	1	2	3	4	5	NA
64. We spend a lot of time apart.	1	2	3	4	5	NA
65. I'm more dependent on my partner.	1	2	3	4	5	NA
66. MS stops me traveling to the extent that my partner wants to.	1	2	3	4	5	NA
67. We don't make plans for the future.	1	2	3	4	5	NA
68. My partner has his/her own friends.	1	2	3	4	5	NA
69. I have to be flexible in planning ahead.	1	2	3	4	5	NA
70. We take every day one at a time.	1	2	3	4	5	NA
71. I turned myself over to God.	1	2	3	4	5	NA
72. I have to live a very controlled lifestyle.	1	2	3	4	5	NA
73. My partner had to be the sole breadwinner.	1	2	3	4	5	NA
74. It's difficult to have time to myself.	1	2	3	4	5	NA
75. I have trouble keeping my spirits up.	1	2	3	4	5	NA
76. Often arguments over activity.	1	2	3	4	5	NA
77. Spouse gets impatient over dull life.	1	2	3	4	5	NA
78. Made us focus on priorities.	1	2	3	4	5	NA
79. MS has enabled me to spend more time with my partner.	1	2	3	4	5	NA
80. Forced us to work on our communication skills.	1	2	3	4	5	NA
81. My unpredictable mood swings cause undue stress.	1	2	3	4	5	NA
82. Has made me appreciate my partner more.	1	2	3	4	5	NA
83. Requires different positions when making love.	1	2	3	4	5	NA

Statement	Degree to which it applies					
	not at all				a great deal	
84. Reduced amount and quality of our sex life.	1	2	3	4	5	NA
85. Has reduced my feelings of desirability and attractiveness.	1	2	3	4	5	NA
86. Has eliminated spontaneity in our lives.	1	2	3	4	5	NA
87. Many of our long terms goals are unattainable.	1	2	3	4	5	NA
88. It is impossible to continue with most activities, hobbies we previously enjoyed together.	1	2	3	4	5	NA
89. Increased anxiety that I should lose my partner through separation or death.	1	2	3	4	5	NA
90. My partner works all day then comes home and works too.	1	2	3	4	5	NA
91. I feel my partner stays under obligation.	1	2	3	4	5	NA
92. Spouse runs away from the problem.	1	2	3	4	5	NA
93. Spouse does not understand what I'm going through.	1	2	3	4	5	NA
94. MS has shown me that our marriage is not as secure as I thought it was.	1	2	3	4	5	NA
95. Previous problems are just magnified now.	1	2	3	4	5	NA
96. I am disappointed that my partner has not been as supportive as I thought he/she would be.	1	2	3	4	5	NA
97. Our marital troubles cause me stress which I believe has worsened my MS.	1	2	3	4	5	NA

Please list any areas of your marital experience with MS not included in the questionnaire above:

Thank you for agreeing to take part in this study and for giving so generously of your time and effort. If you have any questions, please contact Lynda Grant at 403-459-2790

Appendix Q

Partner Incidence Survey

Partner Survey (for the partner without MS)

Multiple Sclerosis and Marital Life
Part A - Demographic Survey

1. _____ Male
   _____ Female

2. Age _____

3. What is your current marital status
   1. _____ married
   2. _____ separated/divorced
   3. _____ other, please specify ____________________

4. # of years living with present partner _____

5. Years since diagnosis of MS (of spouse) _____

6. Disease course of spouse (if known)
   1. _____ Chronic progressive
   2. _____ Remitting relapsing ... # of attacks per year _____
   3. _____ Benign

7. MS symptoms of spouse - please check those applicable
   1. _____ physical symptoms
   2. _____ emotional symptoms
   3. _____ thinking/memory/cognitive symptoms
   4. _____ other ... please describe _______________________

8. Number of years of formal education completed _____

9. Are you employed outside the home? _____ yes _____ no
   Average number of hours at work per week _____

10. Please rate your level of satisfaction with your marriage

very dissatisfied	moderately dissatisfied	neutral	moderately satisfied	very satisfied

11. If divorced or separated please indicate if you perceive MS to have been a factor contributing to the divorce or separation

1	2	3	4	5
not at all	little	fair amount	quite a bit	a major factor

Multiple Sclerosis and Marital Life
Part B - Survey

Directions:

Please give each of the following statements a rating that indicates to what degree the statement reflects your experience. Circle the number that most closely matches the degree to which the statement applies to you.

not at all	a little bit	a medium amount	a fair amount	a great deal
1	2	3	4	5

Statement	Degree to which it applies					
	not at all				a great deal	
1. We have to plan our days, our weeks ahead of time.	1	2	3	4	5	NA
2. I have to do all the driving for the children.	1	2	3	4	5	NA
3. I feel like everybody depends on me.	1	2	3	4	5	NA
4. In a sense I have lost my spouse.	1	2	3	4	5	NA
5. I feel MS has contributed to my own illness.	1	2	3	4	5	NA
6. MS changed my outlook on life.	1	2	3	4	5	NA
7. I'm frustrated by the uncertainty of not knowing what will be ahead.	1	2	3	4	5	NA
8. We had to adapt the house to accommodate the wheelchair.	1	2	3	4	5	NA
9. There were a lot of added expenses.	1	2	3	4	5	NA
10. The physical and emotional needs of the ill spouse come first.	1	2	3	4	5	NA
11. I miss some of the activities we used to do together.	1	2	3	4	5	NA
12. I needed a support group to help understand my feelings.	1	2	3	4	5	NA
13. It was no longer the two of us raising the family.	1	2	3	4	5	NA
14. I feel like I have to do everything.	1	2	3	4	5	NA
15. It's made us much more aware of having a healthier lifestyle.	1	2	3	4	5	NA
16. MS has made us closer in our relationship.	1	2	3	4	5	NA
17. We understand each other better.	1	2	3	4	5	NA
18. Fatigue plays a big role in our lives.	1	2	3	4	5	NA
19. We take time for ourselves independently.	1	2	3	4	5	NA

Statement	Degree to which it applies					
	not at all				a great deal	
20. We try to maintain a positive attitude towards life.	1	2	3	4	5	NA
21. Much of the household responsibilities are on my shoulders.	1	2	3	4	5	NA
22. The shock of diagnosis strained the relationship.	1	2	3	4	5	NA
23. My partner really needs me.	1	2	3	4	5	NA
24. Caregiving creates a lot of stress.	1	2	3	4	5	NA
25. We're more careful in expressing our feelings.	1	2	3	4	5	NA
26. We no longer fight the way we used to.	1	2	3	4	5	NA
27. Caring for my partner has given me a sense of fulfillment.	1	2	3	4	5	NA
28. We no longer feel like equals.	1	2	3	4	5	NA
29. The pace of our life has slowed down.	1	2	3	4	5	NA
30. MS makes it difficult to plan for the future.	1	2	3	4	5	NA
31. We find ways to adapt so we can still do some things we enjoy.	1	2	3	4	5	NA
32. At times I feel very begrudging for the things I'm doing for my partner.	1	2	3	4	5	NA
33. I feel hurt and resentful we longer have a sexual relationship.	1	2	3	4	5	NA
34. We're aware of the preciousness of what we have.	1	2	3	4	5	NA
35. We've learned about each other's strengths and weaknesses.	1	2	3	4	5	NA
36. Conversation seems to be centered on the needs of the person with MS.	1	2	3	4	5	NA
37. The most impactful part of MS has been the emotional.	1	2	3	4	5	NA
38. I'm constantly driven crazy by the unpredictability.	1	2	3	4	5	NA
39. The person that I'd married no longer existed in many ways.	1	2	3	4	5	NA
40. It takes an incredible amount of emotional awareness and energy to cope.	1	2	3	4	5	NA
41. It's difficult to cope with all the expectations placed on me.	1	2	3	4	5	NA
42. I find I need space away from my partner.	1	2	3	4	5	NA
43. We can no longer do a lot of the things we used to do.	1	2	3	4	5	NA

Statement	Degree to which it applies					
	not at all				a great deal	
44. I feel I always need to evaluate how my partner is feeling before I talk to him/her.	1	2	3	4	5	NA
45. We don't make decisions together any more.	1	2	3	4	5	NA
46. I think of myself as a back-up to do whatever my partner cannot do.	1	2	3	4	5	NA
47. I believe it's important to allow my partner dignity.	1	2	3	4	5	NA
48. I have to screen out what is illness related from what is personality related.	1	2	3	4	5	NA
49. I often feel guilty because my partner is ill.	1	2	3	4	5	NA
50. With MS I cannot look at my partner and assume he or she is fine.	1	2	3	4	5	NA
51. It's very stressful dealing with a chronic illness.	1	2	3	4	5	NA
52. We no longer have a sexual relationship.	1	2	3	4	5	NA
53. Evening social events are a thing of the past.	1	2	3	4	5	NA
54. I have been able to put my own fear into perspective more.	1	2	3	4	5	NA
55. My strong faith is a resource.	1	2	3	4	5	NA
56. I try not to burden my partner.	1	2	3	4	5	NA
57. I can't be straight forward in my feelings.	1	2	3	4	5	NA
58. I don't share with people what I'm going through.	1	2	3	4	5	NA
59. I no longer have somebody to talk things over with.	1	2	3	4	5	NA
60. Our sexual life was greatly affected.	1	2	3	4	5	NA
61. I had to take over handling all the finances.	1	2	3	4	5	NA
62. I feel it is my duty to take care of things.	1	2	3	4	5	NA
63. We have to live near appropriate doctors and hospitals.	1	2	3	4	5	NA
64. Days are often long and boring.	1	2	3	4	5	NA
65. Reduced companionship.	1	2	3	4	5	NA
66. Spouse's thinking and memory problems cause poor communications.	1	2	3	4	5	NA
67. Reduced greatly my free time to do many little things.	1	2	3	4	5	NA
68. More sharing of responsibilities.	1	2	3	4	5	NA

Statement	Degree to which it applies					
	not at all				a great deal	
69. I had to learn to live more day by day.	1	2	3	4	5	NA
70. I am constantly concerned about my partner's health.	1	2	3	4	5	NA
71. I didn't tell people so there was a lot of covering up.	1	2	3	4	5	NA
72. I feel depressed a lot of the time.	1	2	3	4	5	NA
73. I feel I have to be stronger and more independent.	1	2	3	4	5	NA
74. I fear my partner being totally dependent on me.	1	2	3	4	5	NA
75. I feel insecure about the future.	1	2	3	4	5	NA
76. There was a shattering of our dreams for the future.	1	2	3	4	5	NA
77. I withdrew from people.	1	2	3	4	5	NA
78. I feared that my partner would no longer be able to work.	1	2	3	4	5	NA
79. Financially it's been difficult.	1	2	3	4	5	NA
80. I'm impressed with how my spouse has coped with the disease.	1	2	3	4	5	NA
81. One area of conflict is I try to do too much for my partner.	1	2	3	4	5	NA
82. I get angry and annoyed about having to live with MS.	1	2	3	4	5	NA
83. We have had to make some decisions we wouldn't have made without the MS.	1	2	3	4	5	NA
84. Purchased new house that was an open floor plan.	1	2	3	4	5	NA
85. Entertaining much less because my partner gets too tired.	1	2	3	4	5	NA
86. We've refocused on priorities in life like health, friends, and family.	1	2	3	4	5	NA
87. I'm more supportive of my spouse.	1	2	3	4	5	NA
88. Made us more aware of other people's problems.	1	2	3	4	5	NA
89. Keep a quiet home for rest periods.	1	2	3	4	5	NA
90. I have to do many activities on my own.	1	2	3	4	5	NA
91. Roles have changed.	1	2	3	4	5	NA
92. Traveling more difficult.	1	2	3	4	5	NA
93. We spend more time together.	1	2	3	4	5	NA
94. It shattered our dreams about having children.	1	2	3	4	5	NA
95. We've had to plan financially more for the future.	1	2	3	4	5	NA

96. Time together is in sedentary activities.	1	2	3	4	5	NA
97. Stressful relationship because of constant and unpredictable change.	1	2	3	4	5	NA
98. Embarrassed about my partner's behavior around other people.	1	2	3	4	5	NA

Please list any of your marital experiences with MS not included in the questionnaire above:

Thank you for agreeing to take part in this study and for giving so generously of your time and effort. If you have any questions, please contact Lynda Grant at 403-459-2790.

Appendix R: Frequencies, Percentages, Means and Standard Deviations for Patient Incidence Survey

	1		2		3		4		5			
STATEMENTS	f	%	f	%	f	%	f	%	f	%	Mean	SD
1. We are closer because of MS	18	25.7	11	15.7	14	20.0	14	20.0	13	18.6	2.90	1.47
2. We stay home a lot.	6	7.1	15	20.5	22	30.1	11	15.1	19	26.0	3.30	1.29
3. We have more conflict in our marriage due to MS.	24	32.9	23	31.5	12	16.4	9	12.3	5	6.8	2.29	1.24
4. More sharing of the running of the household.	15	20.3	11	14.9	20	27.0	13	17.6	15	20.3	3.03	1.40
5. More sharing of the raising of children.	10	23.8	7	16.7	12	28.6	7	16.7	6	14.3	2.81	1.37
6. I don't have the energy to do some things.	2	2.6	6	7.9	21	27.6	19	25.0	28	36.8	3.86	1.09
7. When we go on holidays we tend to just rest and relax.	6	9.5	13	20.6	23	36.5	12	19.0	9	14.3	3.08	1.17
8. My partner is worried that I'll embarrass him/her.	47	63.5	7	9.5	10	13.5	6	8.1	4	5.4	1.82	1.25
9. The uncertainty of MS causes a lot of stress and anxiety in our lives.	11	14.9	19	25.7	18	24.3	18	24.3	8	10.8	2.91	1.24
10. I'm more conscious of trying to make the best of things now.	2	2.6	9	11.5	12	15.4	24	30.8	31	39.7	3.94	1.12
11. We make a conscious effort to find things we can still share.	8	11.1	13	18.1	17	23.6	16	22.2	18	25.0	3.32	1.33
12. We enjoy closeness without a sexual relationship.	13	22.0	5	8.5	10	16.9	17	28.8	14	23.7	3.24	1.48
13. My partner couldn't come to terms with living with an invalid.	33	53.2	10	16.1	6	9.7	5	8.1	8	12.9	2.11	1.46
14. We decided not to have children because of MS.	18	58.1	3	9.7	1	3.2	1	3.2	8	25.8	2.29	1.75
15. I didn't tell people I had MS.	36	48.6	8	10.8	13	17.6	9	12.2	8	10.8	2.26	1.44
16. Thinking and memory problems have been the most difficult to deal with.	15	21.7	16	23.2	11	15.9	12	17.4	15	21.7	2.94	1.47
17. I've tried to stay looking and seeming as normal as possible.	3	3.8	3	3.8	7	8.9	25	31.6	41	51.9	4.24	1.03

18. I don't want to be a burden on anyone.	3	3.8	1	1.3	7	8.8	16	20.0	53	66.3	4.44	0.98
19. When I think of a way out I think of suicide.	49	62.8	7	9.0	11	14.1	6	7.7	5	6.4	1.86	1.29
20. I feel guilty about having MS.	30	37.0	12	14.8	11	13.6	16	19.8	12	14.8	2.60	1.51
21. Because MS is unpredictable I worry about the future.	3	3.8	17	21.3	20	25.0	13	16.3	27	33.8	3.55	1.26
22. It's important not to dwell on your MS.	2	2.7	6	8.0	13	17.3	12	16.0	42	56.0	4.15	1.14
23. I'm frustrated to be continually losing something.	4	5.5	11	15.1	18	24.7	19	26.0	21	28.8	3.58	1.21
24. I worry about becoming totally dependent on my partner.	6	7.9	10	13.2	15	19.7	13	17.1	32	42.1	3.72	1.34
25. Living with MS is a learning process for both of us.	2	2.7	5	6.7	18	24.0	17	22.7	33	44.0	3.99	1.10
26. We no longer argue the way we used to.	16	25.0	12	18.8	21	32.8	8	12.5	7	10.8	2.66	1.29
27. I had to give up a lot of my previous types of recreation.	4	5.1	10	12.8	9	11.5	17	21.8	38	48.7	3.96	1.26
28. Lack of a sexual relationship has been a major loss.	20	30.3	12	18.2	5	7.6	17	25.8	12	18.2	2.83	1.55
29. It's difficult to keep the marital relationship and caretaker relationship separate.	22	36.1	14	23.0	10	16.4	9	14.8	6	9.8	2.39	1.37
30. I'm resentful that my partner has more control.	35	48.6	16	22.2	4	5.6	9	12.5	8	11.1	2.15	1.43
31. I worry that I'm hanging on to the relationship because of the caregiving.	44	65.7	11	16.4	6	9.0	3	4.5	3	4.5	1.66	1.11
32. I want a better future for my partner.	10	14.3	13	18.6	15	21.4	13	18.6	19	27.1	3.26	1.41
33. Finances are more of an issue because of MS.	19	25.0	15	19.7	8	10.5	15	19.7	19	25.0	3.00	1.56
34. With MS what you were to each other is changed.	27	37.0	14	19.2	11	15.1	10	13.7	11	15.1	2.51	1.48
35. I needed my partner to say we'll manage.	12	16.4	4	5.5	9	12.3	13	17.8	35	47.9	3.75	1.51

36. We never talked about the MS.	28	38.9	14	19.4	14	19.4	6	8.3	10	13.9	2.39	1.43
37. My partner withdrew from me.	40	56.3	12	16.9	7	9.9	5	7.0	7	9.9	1.97	1.36
38. I was afraid that I could lose my family.	36	51.4	10	14.3	11	15.7	4	5.7	9	12.9	2.14	1.44
39. My partner didn't cope well.	31	41.9	15	20.3	12	16.2	4	5.4	12	16.2	2.34	1.47
40. I have a lot of anger at the disease.	12	15.6	20	26.0	12	15.6	12	15.6	21	27.3	3.13	1.46
41. I didn't want to anger my partner because I needed a lot of help.	20	29.0	19	27.5	15	21.7	4	5.8	11	15.9	2.52	1.39
42. I felt that I had none of my roles left.	21	28.4	22	29.7	12	16.2	8	10.8	11	14.9	2.54	1.40
43. MS causes financial burden.	15	20.0	13	17.3	16	21.3	9	12.0	22	29.3	3.13	1.51
44. I feel emotionally alone.	20	25.6	13	16.7	15	19.2	14	17.9	16	20.5	2.91	1.49
45. Our sexual relationship was strained.	20	27.4	13	17.8	12	16.4	7	9.6	21	28.8	2.95	1.60
46. Physically I was able to have a sexual relationship.	12	15.4	8	10.3	18	23.1	15	19.2	25	32.1	3.42	1.43
47. I tried to keep my kids and family normal.	2	3.0	1	1.5	7	10.4	13	19.4	44	65.7	4.43	0.96
48. I rely on other people.	11	14.3	27	35.1	20	26.0	8	10.4	11	14.3	2.75	1.25
49. The marriage relationship has become less and less.	34	49.3	8	11.6	10	14.5	7	10.1	10	14.5	2.29	1.52
50. If my partner had taken the caretaker role I wouldn't be as capable as I am.	21	33.3	10	15.9	12	19.0	9	14.3	11	17.5	2.67	1.50
51. We might be together now only because I an financially dependent.	44	77.2	2	3.5	5	8.8	3	5.3	3	5.3	1.58	1.18
52. I feel devalued because of the MS.	21	26.6	18	22.8	13	16.5	9	11.4	18	22.8	2.81	1.52
53. I feel unequal to my partner.	26	37.1	13	18.6	14	20.0	8	11.4	9	12.9	2.44	1.42
54. MS affected the relationship because it affected me so much.	20	28.2	21	29.6	13	18.3	7	9.9	10	14.1	2.52	1.37
55. My partner worries about me.	10	13.3	11	14.7	13	17.3	22	29.3	19	25.3	3.39	1.36
56. I covered up to the extent that my partner didn't think anything was wrong.	33	47.8	11	15.9	8	11.6	11	15.9	6	8.7	2.22	1.41
57. We bought a bungalow, one floor plan.	16	33.3	1	2.1	1	2.1	1	2.1	29	60.4	3.54	1.89
58. My partner is supportive.	6	8.2	2	2.7	8	11.0	11	15.1	46	63.0	4.22	1.25

59. Adjustments have to be made sexually.	21	31.3	9	13.4	11	16.4	11	16.4	15	22.4	2.85	1.57
60. For me spirituality/religion is an anchor.	20	28.2	10	14.1	8	11.3	9	12.7	24	33.8	3.10	1.67
61. I am careful with my partner because I need the security of the relationship.	28	41.2	13	19.1	14	20.6	7	10.3	6	8.8	2.26	1.33
62. I feel like I've let my partner down.	23	31.5	17	23.3	13	17.8	7	9.6	13	17.8	2.59	1.47
63. I think my partner protects me by not telling me how he/she feels.	15	21.1	19	26.8	13	18.3	11	15.5	13	18.3	2.83	1.41
64. We spend a lot of time apart.	23	31.5	14	19.2	16	21.9	9	12.3	11	15.1	2.60	1.43
65. I'm more dependent on my partner.	16	21.6	13	17.6	21	28.4	13	17.6	11	14.9	2.86	1.35
66. MS stops me traveling to the extent that my partner wants to.	25	37.3	13	19.4	10	14.9	8	11.9	11	16.4	2.51	1.50
67. We don't make plans for the future.	26	37.7	12	17.4	13	18.8	10	14.5	8	11.6	2.45	1.42
68. My partner has his/her own friends.	20	28.6	13	18.6	11	15.7	16	22.9	10	14.3	2.76	1.45
69. I have to be flexible in planning ahead.	7	9.0	8	10.3	19	24.4	21	26.9	23	29.5	3.58	1.26
70. We take every day one at a time.	6	8.1	11	14.9	13	17.6	17	23.0	27	36.5	3.65	1.33
71. I turned myself over to God.	21	33.3	8	12.7	7	11.1	5	7.9	22	34.9	2.98	1.73
72. I have to live a very controlled lifestyle.	10	12.5	20	25.0	27	33.8	13	16.3	10	12.5	2.91	1.19
73. My partner had to be the sole breadwinner.	28	43.8	6	934	11	17.2	2	3.1	17	26.6	2.59	1.68
74. It's difficult to have time to myself.	43	55.8	6	7.8	12	15.6	8	10.4	8	10.4	2.12	1.44
75. I have trouble keeping my spirits up.	13	16.3	29	36.3	18	22.5	11	131.8	9	11.3	2.68	1.23
76. Often arguments over activity.	31	41.9	24	32.4	15	20.3	3	4.1	1	1.4	1.91	0.95
77. Spouse gets impatient over dull life.	35	47.3	16	21.6	9	12.2	8	10.8	6	8.1	2.11	1.33
78. Made us focus on priorities.	5	6.8	12	16.2	19	25.7	16	21.6	22	29.7	3.51	1.26
79. MS has enabled me to spend more time with my partner.	24	32.9	8	11.0	22	30.1	11	15.1	8	11.0	2.60	1.37
80. Forced us to work on our communication skills.	16	21.9	16	21.9	12	16.4	14	19.2	15	20.5	2.95	1.46
81. My unpredictable mood swings cause undue stress.	12	16.4	14	19.2	19	26.0	17	23.3	11	15.1	3.01	1.31

82. Has made me appreciate my partner more.	6	8,1	4	5,4	7	9,5	20	27,0	37	50,0	4,05	1,25
83. Requires different positions when making love.	23	37,0	10	16,1	12	19,4	10	16,1	7	11,3	2,48	1,42
84. Reduced amount and quality of our sex life.	24	33,3	8	11,1	7	9,7	10	13,9	23	31,9	3,00	1,70
85. Has reduced my feelings of desirability and attractiveness.	19	24,4	18	23,1	15	19,2	11	14,1	15	19,2	2,81	1,45
86. Has eliminated spontaneity in our lives.	16	21,9	20	27,4	13	17,8	11	15,1	13	17,8	2,79	1,41
87. Many of our long terms goals are unattainable.	18	25,0	23	31,9	10	13,9	11	15,3	10	13,9	2,61	1,38
88. It is impossible to continue with most activities, hobbies we previously enjoyed together.	17	23,6	18	25,0	15	20,8	13	18,1	9	12,5	2,71	1,35
89. Increased anxiety that I should lose my partner through separation or death.	23	32,4	18	25,4	7	9,9	13	18,3	10	14,1	2,56	1,46
90. My partner works all day then comes home and works too.	19	28,4	9	13,4	12	17,9	15	22,4	12	17,9	2,88	1,49
91. I feel my partner stays under obligation.	42	59,2	10	14,1	7	9,9	7	9,9	5	7,0	1,92	1,32
92. Spouse runs away from the problem.	43	61,4	9	12,9	8	11,4	4	5,7	6	8,6	1,87	1,32
93. Spouse does not understand what I'm going through.	16	22,9	18	25,7	15	21,4	13	18,6	8	11,4	2,70	1,32
94. MS has shown me that our marriage is not as secure as I thought it was.	43	62,3	4	5,8	7	10,1	5	7,2	10	14,5	2,06	1,53
95. Previous problems are just magnified now.	28	41,2	15	22,1	8	11,8	8	11,8	9	13,2	2,34	1,45
96. I am disappointed that my partner has not been as supportive as I thought he/she would be.	42	60,0	5	7,1	8	11,4	6	8,6	9	12,9	2,07	1,50
97. Our marital troubles cause me stress which I believe has worsened my MS.	37	52,1	9	12,7	5	7,0	7	9,9	13	18,3	2,30	1,61

Appendix S

Frequencies, Percentages, Means and Standard Deviations for Partner Incidence Survey

STATEMENTS	1		2		3		4		5			
	f	%	f	%	f	%	f	%	f	%	Mean	SD
1. We have to plan our days, our weeks ahead of time.	17	25.0	14	20.6	15	22.1	15	22.1	7	10.3	2.72	1.34
2. I have to do all the driving for the children.	17	45.9	5	13.5	7	18.9	1	2.7	7	18.9	2.35	1.55
3. I feel like everybody depends on me.	12	18.2	11	16.7	13	19.7	14	21.2	16	24.2	3.17	1.44
4. In a sense I have lost my spouse.	32	47.8	12	17.9	6	9.0	7	10.4	10	14.9	2.27	1.51
5. I feel MS has contributed to my own illness.	41	75.9	4	7.4	3	5.6	1	1.9	5	9.3	1.61	1.27
6. MS changed my outlook on life.	12	17.9	6	9.0	15	22.4	14	20.9	20	29.9	3.36	1.45
7. I'm frustrated by the uncertainty of not knowing what will be ahead.	14	19.7	20	28.2	8	11.8	16	23.5	10	14.7	2.82	1.39
8. We had to adapt the house to accommodate the wheelchair.	26	51.0	8	15.7	2	3.9	5	9.8	10	19.6	2.31	1.63
9. There were a lot of added expenses.	19	29.2	11	16.9	14	21.5	9	13.8	12	18.5	2.75	1.48
10. The physical and emotional needs of the ill spouse come first.	6	8.6	3	4.3	15	21.4	16	22.9	30	42.9	3.87	1.26
11. I miss some of the activities we used to do together.	12	17.6	12	17.6	14	20.6	11	16.2	19	27.9	3.19	1.47
12. I needed a support group to help understand my feelings.	41	62.1	6	9.1	9	13.6	4	6.1	6	9.1	1.91	1.36
13. It was no longer the two of us raising the family.	26	61.9	2	4.8	4	9.5	3	7.1	7	16.7	2.12	1.60
14. I feel like I have to do everything.	21	30.9	13	19.1	6	8.8	14	20.6	14	20.6	2.81	1.57
15. It's made us much more aware of having a healthier lifestyle.	8	11.6	16	23.2	16	23.2	9	13.0	20	29.0	3.25	1.40

16. MS has made us closer in our relationship.	16	22.9	14	20.0	8	11.4	16	22.9	16	22.9	3.03	1.51
17. We understand each other better.	16	23.5	8	11.8	12	17.6	17	25.0	15	22.1	3.10	1.49
18. Fatigue plays a big role in our lives.	1	1.4	9	13.0	9	13.0	19	27.5	31	44.9	4.01	1.12
19. We take time for ourselves independently.	13	19.4	15	22.4	16	23.9	11	16.4	12	17.9	2.91	1.38
20. We try to maintain a positive attitude towards life.	1	1.4	2	2.8	6	8.7	25	36.2	35	50.7	4.32	0.87
21. Much of the household responsibilities are on my shoulders.	11	16.2	12	17.6	13	19.1	12	17.6	20	29.4	3.26	1.46
22. The shock of diagnosis strained the relationship.	31	47.7	17	26.2	8	12.3	6	9.2	3	4.6	1.97	1.19
23. My partner really needs me.	3	4.3	10	14.5	9	13.0	14	20.3	33	47.8	3.93	1.26
24. Caregiving creates a lot of stress.	17	26.6	12	18.8	11	17.2	11	17.2	13	20.3	2.86	1.50
25. We're more careful in expressing our feelings.	23	33.8	8	11.8	21	30.9	6	8.8	10	14.7	2.59	1.42
26. We no longer fight the way we used to.	16	30.2	16	30.2	13	24.5	5	9.4	3	5.7	2.30	1.17
27. Caring for my partner has given me a sense of fulfillment.	13	20.6	16	25.4	17	27.0	11	17.5	6	9.5	2.70	1.25
28. We no longer feel like equals.	37	56.9	4	6.2	10	15.4	4	6.2	10	15.4	2.17	1.54
29. The pace of our life has slowed down.	9	13.0	18	26.1	11	15.9	10	14.5	21	30.4	3.23	1.46
30. MS makes it difficult to plan for the future.	17	25.4	11	16.4	14	20.9	8	11.9	17	25.4	2.96	1.53
31. We find ways to adapt so we can still do some things we enjoy.	4	5.8	9	13.0	13	18.8	23	33.3	20	29.0	3.67	1.20
32. At times I feel very begrudging for the things I'm doing for my partner.	31	45.6	17	25.0	6	8.8	11	16.2	3	4.4	2.09	1.27
33. I feel hurt and resentful we longer have a sexual relationship.	22	42.3	12	23.1	8	15.4	4	7.7	6	11.5	2.23	1.38

34. We're aware of the preciousness of what we have.	2	2.9	7	10.1	14	20.3	16	23.2	30	43.5	3.94	1.15
35. We've learned about each other's strengths and weaknesses.	1	1.4	9	13.0	11	15.9	27	39.1	21	30.4	3.84	1.05
36. Conversation seems to be centered on the needs of the person with MS.	26	37.7	9	13.0	13	18.8	7	10.1	14	20.3	2.62	1.56
37. The most impactful part of MS has been the emotional.	6	8.8	11	16.2	17	25.0	19	27.9	15	22.1	3.38	1.25
38. I'm constantly driven crazy by the unpredictability.	30	43.5	17	24.6	13	18.8	4	5.8	5	7.2	2.09	1.23
39. The person that I'd married no longer existed in many ways.	30	45.5	11	16.7	11	16.7	4	6.1	10	15.2	2.29	1.48
40. It takes an incredible amount of emotional awareness and energy to cope.	17	24.6	14	20.3	9	13.0	17	24.6	12	17.4	2.90	1.47
41. It's difficult to cope with all the expectations placed on me.	24	35.3	11	16.2	18	26.5	9	13.2	6	8.8	2.44	1.33
42. I find I need space away from my partner.	21	30.4	13	18.8	12	17.4	12	17.4	11	15.9	2.70	1.47
43. We can no longer do a lot of the things we used to do.	9	14.1	15	23.4	13	20.3	10	15.6	17	26.6	3.17	1.42
44. I feel I always need to evaluate how my partner is feeling before I talk to him/her.	25	36.8	11	16.2	13	19.1	9	13.2	10	14.7	2.53	1.47
45. We don't make decisions together any more.	39	56.5	16	23.2	7	10.1	3	4.3	4	5.8	1.80	1.16
46. I think of myself as a back-up to do whatever my partner cannot do.	14	20.3	9	13.0	9	13.0	14	20.3	23	33.3	3.33	1.55
47. I believe it's important to allow my partner dignity.	1	1.5	0	0.0	2	3.0	13	19.7	50	75.8	4.68	0.68

48. I have to screen out what is illness related from what is personality related.	19	28.8	9	13.6	14	21.2	13	19.7	11	16.7	2.82	1.47
49. I often feel guilty because my partner is ill.	34	50.0	9	13.2	10	14.7	8	11.8	7	10.3	2.19	1.43
50. With MS I cannot look at my partner and assume he or she is fine.	12	18.5	19	29.2	14	21.5	7	10.8	13	20.0	2.85	1.39
51. It's very stressful dealing with a chronic illness.	11	17.2	12	18.8	8	12.5	17	26.6	16	25.0	3.23	1.46
52. We no longer have a sexual relationship.	24	42.0	5	8.8	15	26.3	1	1.8	12	21.1	2.51	1.56
53. Evening social events are a thing of the past.	32	47.1	7	10.3	9	13.2	9	13.2	11	16.2	2.41	1.57
54. I have been able to put my own fear into perspective more.	7	10.9	17	26.6	17	26.6	13	20.3	10	15.6	3.03	1.25
55. My strong faith is a resource.	13	21.0	8	12.9	17	27.4	10	16.1	14	22.6	3.06	1.44
56. I try not to burden my partner.	7	10.4	8	11.9	15	22.4	18	26.9	19	28.4	3.51	1.31
57. I can't be straight forward in my feelings.	28	41.8	12	17.9	10	14.9	4	6.0	13	19.4	2.43	1.55
58. I don't share with people what I'm going through.	16	25.0	11	17.2	13	20.3	13	20.3	11	17.2	2.88	1.44
59. I no longer have somebody to talk things over with.	33	51.6	9	14.1	9	14.1	4	6.3	9	14.1	2.17	1.48
60. Our sexual life was greatly affected.	22	32.8	11	16.4	7	10.4	4	6.0	23	34.3	2.93	1.72
61. I had to take over handling all the finances.	32	48.5	9	13.6	4	6.1	3	4.5	18	27.3	2.48	1.73
62. I feel it is my duty to take care of things.	14	20.6	11	16.2	11	16.2	12	17.6	20	29.4	3.19	1.53
63. We have to live near appropriate doctors and hospitals.	38	56.7	10	14.9	3	4.5	7	10.4	9	13.4	2.09	1.50
64. Days are often long and boring.	43	65.2	11	16.7	6	9.1	3	4.5	3	4.5	1.67	1.11
65. Reduced companionship.	36	53.7	13	19.4	7	10.4	6	9.0	5	7.5	1.97	1.30

66. Spouse's thinking and memory problems cause poor communications.	24	36.9	11	16.9	13	20.0	9	13.8	8	12.3	2.48	1.43
67. Reduced greatly my free time to do many little things.	27	39.7	11	16.2	12	17.6	9	13.2	9	13.2	2.44	1.46
68. More sharing of responsibilities.	15	23.1	13	20.0	17	26.2	11	16.9	9	13.8	2.78	1.35
69. I had to learn to live more day by day.	21	31.3	8	11.9	14	20.9	14	20.9	10	14.9	2.76	1.47
70. I am constantly concerned about my partner's health.	3	4.3	8	11.6	8	11.6	21	30.4	29	42.0	3.94	1.19
71. I didn't tell people so there was a lot of covering up.	41	62.1	7	10.6	10	15.2	3	4.5	5	7.6	1.85	1.28
72. I feel depressed a lot of the time.	31	46.3	15	22.4	11	16.4	3	4.5	7	10.4	2.10	1.33
73. I feel I have to be stronger and more independent.	16	23.5	10	14.7	9	13.2	12	17.6	21	30.9	3.18	1.58
74. I fear my partner being totally dependent on me.	27	39.1	13	18.8	9	13.0	4	5.8	16	23.2	2.55	1.60
75. I feel insecure about the future.	21	30.9	14	20.6	17	25.0	6	8.8	10	14.7	2.56	1.40
76. There was a shattering of our dreams for the future.	21	30.9	13	19.1	14	20.6	4	5.9	16	23.5	2.72	1.54
77. I withdrew from people.	40	59.7	13	19.4	7	10.4	3	4.5	4	6.0	1.78	1.18
78. I feared that my partner would no longer be able to work.	27	41.5	12	18.5	5	7.7	9	13.8	12	18.5	2.49	1.58
79. Financially it's been difficult.	22	32.4	19	27.9	7	10.3	5	7.4	15	22.1	2.59	1.55
80. I'm impressed with how my spouse has coped with the disease.	3	4.3	2	2.9	8	11.6	12	17.4	44	63.8	4.33	1.08
81. One area of conflict is I try to do too much for my partner.	21	30.4	17	24.6	11	15.9	12	17.4	8	11.6	2.55	1.39
82. I get angry and annoyed about having to live with MS.	24	34.8	18	26.1	9	13.0	9	13.0	9	13.0	2.43	1.42
83. We have had to make some decisions we wouldn't have made without the MS.	12	17.6	12	17.6	10	14.7	11	16.2	23	33.8	3.31	1.53
84. Purchased new house that was an open floor plan.	23	53.5	0	0.0	0	0.0	4	9.3	16	37.2	2.77	1.94

85. Entertaining much less because my partner gets too tired.	14	21.5	15	23.1	10	15.4	13	20.0	15	20.0	2.94	1.46
86. We've refocused on priorities in life like health, friends, and family.	8	11.8	7	10.3	17	25.0	17	25.0	19	27.9	3.47	1.32
87. I'm more supportive of my spouse.	1	1.4	11	15.9	14	20.3	17	24.6	26	37.7	3.81	1.15
88. Made us more aware of other people's problems.	2	2..9	12	17.6	16	23.5	19	27.9	19	27.9	3.60	1.16
89. Keep a quiet home for rest periods.	14	21.2	11	16.7	13	19.7	12	18.2	16	24.2	3.08	1.48
90. I have to do many activities on my own.	15	22.4	10	14.9	10	14.9	16	23.9	16	23.9	3.12	1.50
91. Roles have changed.	18	27.3	9	13.6	12	18.2	13	19.7	14	21.2	2.94	1.52
92. Traveling more difficult.	10	14.5	14	20.3	10	14.5	8	11.6	27	39.1	3.41	1.53
93. We spend more time together.	6	8.8	10	14.7	19	27.9	16	23.5	17	25.0	3.41	1.26
94. It shattered our dreams about having children.	29	80.6	0	0.0	3	8.3	1	2.8	3	8.3	1.58	1.27
95. We've had to plan financially more for the future.	13	19.7	9	13.6	15	22.7	10	15.2	19	28.8	3.20	1.49
96. Time together is in sedentary activities.	21	31.8	6	9.1	15	22.7	10	15.2	14	21.2	2.85	1.54
97. Stressful relationship because of constant and unpredictable change.	25	36.2	14	20.3	13	18.8	10	14.5	7	10.1	2.42	1.38
98. Embarrassed about my partner's behavior around other people.	51	72.9	12	17.1	2	2.9	2	2.9	3	4.3	1.49	1.00

Appendix T

T-tests - Patients

Gender Differences

Statement	Male	Female	p
15. I didn't tell people I had MS.	1.50	2.54	.001
58. My partner is supportive.	4.75	4.02	.001
74. It's difficult to have time to myself.	1.45	2.35	.001

Age Differences

Statement	Age 45 and over	Under 45	p
46. Physically I was able to have a sexual relationship.	2.83	4.11	.000

Marital Status

Statement	Married	Divorced/ Separated	p
1. We are closer because of MS	3.03	1.14	.000
13. My partner couldn't come to terms with living with an invalid.	1.76	4.00	.000
14. We decided not to have children because of MS.	2.29	1.00	.001
39. My partner didn't cope well.	2.02	3.67	.001
43. MS causes financial burden.	2.82	4.55	.000
44. I feel emotionally alone.	2.72	4.40	.001
49. The marriage relationship has become less and less.	2.07	4.14	.000
55. My partner worries about me.	3.58	1.86	.001
94. MS has shown me that our marriage is not as secure as I thought it was.	1.83	4.13	.000
95. Previous problems are just magnified now.	2.13	3.78	.001
97. Our marital troubles cause me stress which I believe has worsened my MS.	2.05	4.33	.000

Years Since Diagnosis

Statement	10 years or more	less than 10 years	p
57. We bought a bungalow, one floor plan.	4.48	2.75	.001

Disease Course

Statement	Remitting Relapsing or Benign	Chronic Progressive	p
65. I'm more dependent on my partner.	2.27	3.59	.000

MS Symptoms

Statement	Emotional and/or Cognitive in Addition to Physical	Physical Symptoms Only	p
16. Thinking and memory problems have been the most difficult to deal with.	3.20	1.85	.000

Employed Outside Home

Statement	Employed	Not Employed	p
27. I had to give up a lot of my previous types of recreation.	3.26	4.36	.001
42. I felt that I had none of my roles left.	1.54	3.06	.000
48. I rely on other people.	2.15	3.10	.000
65. I'm more dependent on my partner.	2.00	3.31	.000
73. My partner had to be the sole breadwinner.	1.71	3.07	.001

Marital Satisfaction

Statement	Moderately or Very Satisfied	Neutral and Dissatisfied	p
1. We are closer because of MS	3.31	1.79	.000
11. We make a conscious effort to find things we can still share.	3.63	2.31	.001
37. My partner withdrew from me.	1.48	3.33	.001
39. My partner didn't cope well.	1.85	3.33	.000
49. The marriage relationship has become less and less.	1.75	4.00	.000
58. My partner is supportive.	4.70	2.93	.001
64. We spend a lot of time apart.	2.29	3.60	.001
78. Made us focus on priorities.	3.82	2.62	.001
92. Spouse runs away from the problem.	1.35	3.36	.000
93. Spouse does not understand what I'm going through.	2.37	3.57	.001
96. I am disappointed that my partner has not been as supportive as I thought he/she would be.	1.52	3.50	.000
97. Our marital troubles cause me stress which I believe has worsened my MS.	1.82	3.60	.001

Appendix U

T-tests - Partners

Gender

Statement	Male	Female	p
4. In a sense I have lost my spouse.	1.80	3.08	.001
78. I feared that my partner would no longer be able to work.	2.05	3.41	.001

Age Differences

Statement	45 years and older	under 45 years	p
49. I often feel guilty because my partner is ill.	1.71	2.86	.001

Years Since Diagnosis

Statement	10 years and over	under 10 years	p
1. We have to plan our days, our weeks ahead of time.	3.30	2.24	.001
3. I feel like everybody depends on me.	3.83	2.69	.001
11. I miss some of the activities we used to do together.	3.83	2.64	.001
14. I feel like I have to do everything.	3.48	2.28	.001
21. Much of the household responsibilities are on my shoulders.	3.94	2.75	.001
24. Caregiving creates a lot of stress.	3.59	2.29	.000
36. Conversation seems to be centered on the needs of the person with MS.	3.42	2.00	.000
84. Purchased new house that was an open floor plan.	3.44	1.65	.001
89. Keep a quiet home for rest periods.	3.65	2.50	.001
90. I have to do many activities on my own.	3.74	2.54	.001
92. Traveling more difficult.	4.39	2.62	.000

Disease Course

Statement	Remitting Relapsing and Benign	Chronic Progressive	p
8. We had to adapt the house to accommodate the wheelchair.	1.26	3.04	.000
9. There were a lot of added expenses.	1.96	3.39	.000
14. I feel like I have to do everything.	2.19	3.38	.001
23. My partner really needs me.	3.29	4.56	.000
53. Evening social events are a thing of the past.	1.70	2.94	.001

MS Symptoms

Statement	Emotional and/or Cognitive as well as Physical	Physical Symptoms Only	p
80. I'm impressed with how my spouse has coped with the disease.	4.22	5.00	.000

Employed Outside Home

Statement	Employed	Not Employed	p
89. Keep a quiet home for rest periods.	2.67	3.75	.001
93. We spend more time together.	3.04	4.25	.000

Marital Satisfaction

Statement	Moderately or Very Satisfied	Neutral or Dissatisfied	p
17. We understand each other better.	3.29	1.56	.001
31. We find ways to adapt so we can still do some things we enjoy.	3.77	2.80	.001
32. At times I feel very begrudging for the things I'm doing for my partner.	1.84	3.50	.000
34. We're aware of the preciousness of what we have.	4.15	2.70	.000
39. The person that I'd married no longer existed in many ways.	2.02	3.80	.000
40. It takes an incredible amount of emotional awareness and energy to cope.	2.68	4.10	.001
42. I find I need space away from my partner.	2.46	4.10	.001
50. With MS I cannot look at my partner and assume he or she is fine.	2.62	4.22	.001
51. It's very stressful dealing with a chronic illness.	3.04	4.56	.000
60. Our sexual life was greatly affected.	2.63	4.60	.000