Social Support and health of partners of people with multiple sclerosis
by Laura Jean Burns

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Nursing
Montana State University
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Abstract:
The purpose of this secondary analysis was to determine the relationship between social support and health in partners of people with multiple sclerosis, and to identify factors which affect this relationship. Data collected as part of the Family Health Study in 1993 served as the database for this analysis.

Pearson correlation coefficients were computed to determine the relationship between social support and physical health, social support and psychological health, and social support and psychosocial health. Multiple regression was used to determine the influencing effect that social support, gender, degree of disability, age, geographic locale, and income had on the social support and health relationship.

Significant correlations were demonstrated between social support and each of three health variables (physical health, psychological health, and psychosocial health).

Nine percent of the variance in physical health, thirty-one percent of the variance in psychological health, and twenty-six percent of the variance in psychosocial health was attributed to social support, gender, degree of disability, age, degree of rurality, and income. A significant interaction effect was demonstrated between social support and gender, which influenced physical health. No significant interactions were found between social support and any of the variables that influenced psychological health or psychosocial health.

Results from this study add further support to the volume of research linking social support and health. It is important that nursing care includes strategies for fostering, facilitating and evaluating the social support systems of partners experiencing a long-term illness with another person.
APPROVAL

of a thesis submitted by

Laura Jean Burns

This thesis has been read by each member of the graduate committee and has been found to be satisfactory regarding content, English usage, format, citations, bibliographic style, and consistency, and is ready for submission to the College of Graduate Studies.

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ABSTRACT

The purpose of this secondary analysis was to determine the relationship between social support and health in partners of people with multiple sclerosis, and to identify factors which affect this relationship. Data collected as part of the Family Health Study in 1993 served as the database for this analysis.

Pearson correlation coefficients were computed to determine the relationship between social support and physical health, social support and psychological health, and social support and psychosocial health. Multiple regression was used to determine the influencing effect that social support, gender, degree of disability, age, geographic locale, and income had on the social support and health relationship.

Significant correlations were demonstrated between social support and each of three health variables (physical health, psychological health, and psychosocial health). Nine percent of the variance in physical health, thirty-one percent of the variance in psychological health, and twenty-six percent of the variance in psychosocial health was attributed to social support, gender, degree of disability, age, degree of rurality, and income. A significant interaction effect was demonstrated between social support and gender, which influenced physical health. No significant interactions were found between social support and any of the variables that influenced psychological health or psychosocial health.

Results from this study add further support to the volume of research linking social support and health. It is important that nursing care includes strategies for fostering, facilitating and evaluating the social support systems of partners experiencing a long-term illness with another person.
CHAPTER 1

INTRODUCTION

Multiple sclerosis (MS) is a chronic, progressive, unpredictable disease of the central nervous system. This neurological disease is characterized by periods of remissions and exacerbations, leading to disabilities that affect motor, sensory, and interpersonal functions. The chronic, progressive, and debilitating nature of the disease often leads to a time when the afflicted person is at least partially dependent on others for activities of daily living. Since it is often the spouse or partner who assumes these caregiving responsibilities, it is conceivable that their health may be at risk. There is empirical evidence to link social support to health (Cohen & Syme, 1985). Increased caregiving responsibilities and insufficient social support may collectively place spouses at a greater morbidity risk. The focus of this study is an examination of the impact that social support has on the health status of partners of people with multiple sclerosis.

Caregiving is not limited to the provision of physical aid. It can also encompass participation in the management of an illness. Managing a long-term illness includes addressing physical, psychological, social, and financial
issues. Although the degree of involvement in the management of another individual's illness may vary, caregivers are nevertheless affected by the disease experience.

Participating in the care of a person with multiple sclerosis can be overwhelming. Multiple sclerosis typically occurs between the ages twenty and forty, a time when individuals are assuming many social, economic, and career responsibilities (O'Brien, 1993a). The added responsibility of caring for a person with a chronic illness can lead to stress related to one's role, time, freedom restrictions, financial concerns, employment changes (Bunting, 1989; Dellasega, 1991; O'Brien, 1993b), and adverse effects on marital, familial, and social relationships (Nolan, Grant, & Ellis, 1990; Robinson, 1990). The psychological stress experienced by the caregiver may lead to feelings of fatigue, sleep disturbances, headaches, and gastrointestinal upset (Wykle, 1994). Caregivers often neglect their own health and fail to realize the impact that stress and the burden of caregiving can have (Bunting, 1989; Wykle, 1994). Over time, the stress of caregiving can place the caregiver's health at risk (Bunting, 1989; de Meneses & Perry, 1993; Gaynor, 1990; Neundorfer, 1991; Sayles-Cross, 1993; Schulz, Visintainer, & Williamson, 1990; Sexton & Munro, 1985).
A positive correlation between social support and health among the elderly and people with chronic illnesses has been reported (Gallo, 1982; Mor-Barak, Miller, & Syme, 1991; Moser, 1994; Ploeg & Faux, 1989; Sugisawa, Liang, & Liu, 1994), although little is known concerning the relationship between social support and health of partners of people with long-term illnesses. Information concerning social support and health of this population is necessary to optimize the well-being of those who share unique challenges and difficulties as they experience a chronic illness with their partner.

Problem Statement and Purpose

The stressors and the potential negative health outcomes facing partners of people with MS create a need to know more concerning the relationship between social support and health in this group of people. The purpose of this study was to determine the relationship between social support and health of partners of people with MS and to identify factors which affect this relationship. This study addressed two questions: a) What is the relationship between perceived social support and perceived health of partners of persons with MS?, and b) What are the factors that influence the relationship between perceived social support and perceived health?
Significance to Nursing

Although it is the individual who is diagnosed with MS, the entire family experiences life with the chronic illness (Woods, Yates, & Primono, 1989). Partners, in particular, can experience multiple difficulties as a result of their significant other’s illness (Manne & Zautra, 1990). These difficulties may include the challenge of providing care to the afflicted partner, disruption in social, sexual, and recreational activities caused by the partner’s disability, and dealing with the partner’s emotional response to the long-term, incurable illness. Each of these stressors may place the healthy partner at risk for greater psychological and physical distress.

Integrating the concept of social support into the treatment plan may be one way of enhancing the total well being of partners of people with MS, which may have a reciprocal effect on the adjustment of the person with MS. Manne and Zautra (1989) found that partners experiencing their own difficulties can exert a potent influence upon the coping and psychological adjustment of the partner with the chronic illness. Assisting healthy partners to assess and utilize social support resources may promote a higher level of health among themselves as well as their partners.

Partners of people with MS are faced with profound stressors, which place them at risk for health disorders. This reality creates a need to examine factors that may
promote higher levels of health among this at-risk group. Based on the empirical evidence linking social support and health (Cohen & Syme, 1985), the focus of this research was to address the relationship between social support and health specifically of partners of people experiencing MS.
CHAPTER 2

REVIEW OF LITERATURE

Social Support

Social support is a multifaceted concept which has been conceptualized differently by various researchers. Caplan (1974, p. 7) spoke of a support system, as "an enduring pattern of continuous or intermittent ties, that plays a significant part in maintaining the psychological and physical integrity of the individual over time." Cobb (1976) defined social support as information leading to an individual's belief that he or she is cared for and loved, esteemed and valued, and a member of a network of communication and mutual obligation. Of note is the fact that Cobb defined social support as being only informational in nature. The exchange of tangible materials was not viewed as being part of the social support concept.

Kaplan, Cassel, and Gore (1977, p. 50) suggested that "Support is defined by the relative presence or absence of psychosocial support resources from others", although support resources were undefined. Thoits (1982, p. 147) interpreted social support to be "the degree to which a person's basic social needs are gratified through interaction with others." Cohen and Syme (1985) defined
support as resources, or potentially useful information or things, provided by other persons. By viewing social support in these terms, they allowed for the possibility that support may have negative as well as positive effects on health and well-being.

Despite the varied definitions of social support found in the literature, House (1981, p. 39) noted similar components. Social support is "an interpersonal transaction involving one or more of the following: a) emotional concern (liking, love, empathy), b) instrumental aid (goods and services), c) information (about the environment), or d) appraisal (information relevant to self-evaluation)." Social support is a phenomenon resulting from meaningful relationships; it is not the relationship itself.

Weiss (1969, 1974) went beyond the definition of interpersonal relationships, and examined the functions of social relationships. He proposed that there are different kinds of relationships, providing different functions, all of which are necessary for overall well-being. Six categories of relational functions were identified: attachment/intimacy, social integration, opportunity for nurturant behavior, reassurance of worth, a sense of reliable alliance, and the obtaining of guidance.

Much of the research on social support has been based on one of two main theories: the "buffer theory" and the "main effect" theory. According to the buffer theory,
social support buffers or reduces the stressful effects of negative life events on a person’s well-being (Antonovsky, 1974; Caplan, 1974; Cassel, 1976; Cobb, 1976). Persons with strong social support are thought to be more capable of coping with stressful experiences. Social support buffers the stress of life events, and therefore, has an indirect positive effect on health outcomes.

According to the main effect theory, social support has a direct effect on health, irrespective of whether persons are under stress (Cohen, 1988). Social support can influence health through the generally positive experiences it provides for people. Cohen and Wills (1985) suggested that social support may affect overall well-being because it provides a positive affect, a sense of predictability and stability in one’s life, and a recognition of self-worth. Integration into a social network may assist one to avoid experiences that can have a potentially negative impact on one’s psychological or physical level of health.

Although there is a lack of agreement on what social support is and how it functions, there seems to be an underlying suggestion that there is a relationship between social support and overall well-being. Further examination of this phenomenon is needed to contribute to the growing body of knowledge regarding the relationship between social support and health.
Health

Health is a multidimensional concept, defined and understood in a variety of ways. It is defined in Webster’s Dictionary (1973) as the condition of being sound in body, mind, or spirit; freedom from physical disease or pain. A widely accepted definition is the 1947 World Health Organization description which is "health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity" (World Health Organization, 1958, p. 459).

Nursing theorists have defined health differently. Florence Nightingale (1938) emphasized the interaction between the environment and one’s health, and addressed health as a reparative process. According to Parse (1981), health was a continuously changing process of becoming. Watson (1988) recounted health as the subjective concepts of unity and harmony within the mind, body, and soul of each person. Both Parse and Watson advocated that a person defined his or her own state of health. Health was what the person said it was. King’s (1981) interpretation of health was that it was a dynamic state of well-being, as a result of continuous adjustment to stressors in the environment. Orem (1985) supported the World Health Organizations’s definition and stated that physical, psychological, interpersonal, and social aspects of health were inseparable in the individual. Although conceptualizations have
differed, there is a consensus among nurse theorists that health is a state or a process of the whole person existing independently of disease (Woods et al., 1988).

Two major paradigms have been used to conceptualize health (Newman, 1991). One was the wellness-illness continuum which portrayed health and illness in many different configurations ranging from high-level wellness on the positive end, to depletion of health or death on the negative end. Movement towards the positive end of the continuum resulted in a sense of well-being, life satisfaction, and quality of life. Movement towards the negative end included adaptation to disease and disability.

In the other paradigm, health was depicted as a unidirectional developmental phenomenon resulting from person-environment interaction (Newman, 1991). Health was conceptualized as an expanding consciousness, pattern or meaning recognition, personal transformation, and self-actualization.

Newman (1991) noted that the predominant criterion of health was a person's ability to interact and function in a changing environment. The major difference in the conceptualizations was that health was either viewed in a quantitative way, moving along the continuum between higher and lower levels of wellness and illness, or as a unidirectional, unitary process of development.
Smith (1981) relied on a positive-negative continuum from wellness to illness to conceptualize health, the structure of which was dependent upon the human traits or conditions being evaluated. According to Smith, health could be conceptualized according to one of four models: a) the eudaimonistic model, which included overall well-being and self-realization; b) the adaptive model, which characterized health as a state which enabled a person to adapt to his physical and social environment; c) the role performance model, which equated health with the ability to perform one's role in life; and d) the clinical model, which viewed health as a disease-free condition.

Although the four models were viewed as alternative ideas of health, they were not considered to be mutually exclusive ideas. If the models were placed on a continuum, with the clinical model on the left, followed by the role performance model, then the adaptive model, and finally the eudaimonistic model on the right, each model from left to right portrayed individuals in increasingly broader contexts. For example, although the adaptive model was more expansive than the clinical or the role performance model, it incorporated them. According to the adaptive role perspective, healthy people were not only disease free and performed their roles adequately, but they also exhibited adaptive behavior to the physical and social environment.
Each model on the continuum embraced the preceding models in the series.

The use of Smith's (1981) models of health was apparent when the definitions of health, given by different groups, were explored. Upon examination of responses from 528 women to the question, "What does being healthy mean to you?", Woods et al. (1988) found evidence of the clinical, role performance, adaptive, and eudaimonistic models of health. Additionally, multiple dimensions of health, reflective of the eudaimonistic model, were reported. These included actualizing self, practicing healthy life ways, self-concept, body image, social involvement, fitness, cognitive function, positive mood, and harmony. The most frequently reported health images included the clinical, positive affect, fitness; practicing healthy life ways; and harmony categories. The least reported images included the positive self-concept, cognitive function, social involvement, and actualizing self categories. Although the women's images were suggestive of the clinical, role performance, adaptive, and eudaimonistic models of health, the eudaimonistic model was the most strongly represented.

The eudaimonistic model of health was also represented in a study completed by Bruenjes (1994). Participants, all of whom were female, identified three interacting aspects of health: a) physical, b) emotional, and c) spiritual. Health was maintained by balancing the physical, emotional, and
spiritual aspects of one's life in a given environment in relationship with others, again reflective of the eudaimonistic model. Weaknesses inherent to this study were the small sample size (N=7) and the homogenous nature of the sample.

In studies done in rural communities, rural people were more likely to define health in terms consistent with the role performance model of health. Weinert and Long (1987) noted that rural people repeatedly defined health as the ability to work or to be productive in one's role. Pain was more likely to be tolerated as long as it did not interfere with what needed to be done. Being healthy implied the ability to carry out customary role functions.

Despite the various definitions and conceptualizations concerning health, most views reflect an individual's level of functioning in physiologic, psychologic, and or psychosocial dimensions within their environment. Because nursing is concerned with the wholeness of humans, all of the various dimensions are assessed, with consideration directed towards the person's overall sense of well-being.

Social Support and Health

Social support has been implicated as a factor contributing to positive effects on physical health, psychological adjustment, and psychosocial well-being.
Social support was examined in each of these dimensions in an attempt to foster a holistic perspective of health.

Social Support and Physical Health

Cobb (1976) contended that social support protected people confronted with stressful situations from a wide variety of pathological states, including but not limited to low birth weight, pregnancy complications, arthritis, tuberculosis, and ultimately death. It was also his contention that social support may decrease the amount of medication required, facilitate recovery from illness, and promote compliance with prescribed medical regimens.

Research by Nuckolls, Cassel, and Kaplan (1972) was used as supportive data in Cobb's research, and has continued to be very influential in the development of knowledge concerning social support. In this study, the influence of social support on complications of pregnancy among 170 army wives was examined. All the women were primiparas, of similar social class, and delivered by the same obstetrical service. Social support was imbedded in a construct termed psychosocial assets, which included measures of ego strength and attitudes towards the pregnancy. Stressors in the women's lives were measured by a life change score. When analyzed separately, neither the life change score nor the psychosocial asset (social support) score were significantly correlated with pregnancy
complications. However, when life change and psychosocial asset scores were jointly considered, 91 percent of the women with a high life-change score and a low asset score had complications, whereas 33 percent of the women with a high life-change score but with a high asset score experienced complications. This study suggested that social support during pregnancy may provide a protective mechanism against stressful stimuli.

Correlation between social support and physical health has continued to be supported by research. A strong relationship between social support and health has been demonstrated in the elderly (Gallo, 1982; Mor-Barak, Miller, & Syme, 1991; Ploeg & Faux, 1989). Cardiac patients who reported greater social support demonstrated less severe cardiac symptoms during their recovery period (Siegrist, Dittman, Rittner, & Weber, 1982). Patients who had a greater number of social support resources following hip surgery demonstrated more complete recovery of their prefracture level of function (Cummings et al., 1988). For patients with chronic obstructive pulmonary disease, fewer physical symptoms, higher forced expiratory volume scores, and a greater level of psychological well-being were significantly correlated with higher levels of functioning (Lee, Graydon, & Ross, 1991). Those patients with higher levels of social support had significantly less disruption in their functioning than those with lower levels.
The powerful impact of social support on physical health can also be appreciated by looking at studies of mortality (Berkman & Syme, 1979; Blazer, 1982; House, Robbins, & Metzner, 1982; Ruberman, Weinblatt, Goldberg, & Chaudhary, 1984; Schoenback, Kaplan, Fredman, & Kleinbaum, 1986). In analyzing nine year old mortality data from a probability sample of 4775 adults in Alameda County, California, Berkman and Syme (1979) demonstrated that mortality was higher for people with limited social ties. In a study of 2754 adults in Tecumseh, Michigan, composite indices of social relationships and activities were inversely associated with mortality over a 10-12 year period (House, Robbins, & Metzner, 1982). Similarly, Schoenback, Kaplan, Fredman, and Kleinbaum (1986) found an increased mortality risk in subjects with fewer social ties for an 11-13 year follow-up period in Evans County, Georgia. The positive association between lack of social support and increased mortality was present in all of these studies despite controlling for behavioral, sociodemographic, and clinical variables known to affect mortality.

Social Support and Psychological Health

Social support appears to influence not only physical health, but psychological health as well. In their study of community dwelling elderly people, Ploeg and Faux (1989) found not only strong linkages between perceived physical
health and social support, but perceived social support was also strongly associated with psychological well-being.

Similarly, satisfaction with social support was significantly related to psychological well-being in a group of women suffering from rheumatoid arthritis (RA) (Lambert, Lambert, Klipple & Mewshaw, 1989), as well as patients recovering from cardiac malfunctions (Ben-Sira & Eliezer, 1990). Cardiac patients who reported greater degrees of social support also reported lower levels of depression (Waltz, Badura, Pfaff, & Schott, 1988).

Revenson and Majerovitz (1991) examined the effects of RA on spouses' psychological well-being, and the role of social support resources in facilitating spousal adaptation to this chronic disease. Neither the level of social support received from the person with RA, nor that received from family and friends was significantly related to the spouses' depression. However, the interaction between disease severity and friends' and family support was highly significant, explaining 31 percent of the variance in spouses' depression.

The relationship between social support and psychological health is also confirmed in the caregiving literature. For example, caregivers experiencing low social support are at a significantly higher risk for psychological distress and depression (Baillie, Norbeck, & Barnes, 1988).
Social Support and Psychosocial Health

The role of social support has dynamic implication on health and psychosocial wellness throughout the life cycle (Horman, 1989). Throughout the development of the child's life, the family serves as the primary source of social support and social interaction (Cohen & Syme, 1985). The lack of such attachment in infancy has been shown to carry deleterious consequences for the child's health, development, and capacity for successful social interactions. Family social support remains the greatest contributor to adolescent health and behavior. Adolescents lacking parental support are more likely to experience depression and low self-esteem, and confide in inappropriate sources during times of crisis (Andrews & Brown, 1988). The need for social support continues throughout the young adult, middle-age, and elder years. In the event of significant life changes or crises, social support is critical; the absence of which can lead to depression (Andrews & Brown, 1988).

Summary

Research, focusing on the relationship between social support and health, has been conducted with young adults, middle aged persons, and the elderly. Studies have also been done among people with various acute and chronic health conditions, including pregnancy, and cardiac, respiratory,
neurological, musculoskeletal, and post-surgical conditions. Overall, a higher degree of social support has been associated with more optimum outcomes. Yet, there appears to be a gap in the literature relevant to the relationship between social support and health, specifically in partners of people with ongoing, long-term, chronic illnesses.

Factors Affecting Social Support and Health

Social support has been implicated as a factor contributing to health. However, factors which influence the relationship between social support and health are unknown. Following a review of the literature, four factors were identified that may affect the social support and health relationship. These included: gender, degree of disability, age, and geographic locale.

Gender

Gender may be an influencing factor in the relationship between social support and health. In a study of coping strategies, social support, and general health status in individuals with diabetes mellitus, Kvam and Lyons (1991) found that men and women differed in their primary perceived source of social support. Men perceived greater support from family, while women reported more support from friends. Perceived social support from friends and family increased with education. Yet, there was no relationship between income and perceptions of family and friend support or
general well being. In another study of diabetic clients, social support specific to one's regimen affected metabolic control for men, but not for women (Connell, Fisher, & Houston, 1992).

In studies among people affected with multiple sclerosis (MS), there are somewhat conflicting findings concerning the influence gender has on the perception of social support. Gulick (1994) found that men perceived significantly higher average available levels of affect, affirmation, and aid support than women. Yet, Harper, Harper, Chambers, Cino, and Singer (1986) found no relationship between gender and the quantity of social contacts and resources.

Weinert and Long (1993) examined the support systems for spouses of people with MS, and noted several differences between men and women. Women whose husbands had MS reported a higher level of social support and a significantly higher number of social support resources than men whose wives had MS. Women, more than men, indicated they could rely on parents, friends, and professionals as their sources of support. Men with ill wives sought support from their spouses, and reported less ability to rely on other persons. Based on the researchers' findings, it appears that social support may be perceived and experienced differently among men and women.
Degree of Disability

Findings concerning the relationship between degree of disability, social support, and health are inconclusive. Revenson and Majerovitz (1991) found in their study of the effects of rheumatoid arthritis on spouses, a small, nonsignificant correlation between patients’ disease severity and spouses’ psychological health. The correlation between disease severity and spouses’ perceived support was also nonsignificant.

Gulick (1994) found that the perception of social support did not differ across MS subject groups as the duration of the disease increased, despite the progressive declining nature of functional status. This is in agreement with Wineman’s (1990) conceptualization that overall social support was unrelated to functional disability.

Age

Data concerning the relationship between age and social support are somewhat conflicting. Following a review of five studies concerning age differences in support, Vaux (1985) found that support from outside the family increases during late adolescence, whereas family support increases for girls but not boys. Aspects of support, such as network resources and support from friends, decrease over the adult life cycle, although the correlation between support and well-being does not vary with age. However, Schoenback, Kaplan, Fredman, and Kleinbaum’s (1986) mortality study
demonstrated an overall pattern of increased mortality with a low cumulative index of social support measures for Caucasian men and women over 60 years of age. For women under 60, this relationship was reversed. Although more studies are beginning to examine age differences in the perception of social support, no conclusive evidence is yet available.

Geographic Locale

Social support in the rural versus urban populations has also been examined. Strong community ties, characteristic of rural areas, often lead to a high level of perceived social support (Weinert & Long, 1991). Weinert and Long (1987) found that a sample of rural dwellers had higher perceived social support scores than age-comparable urban groups. Findings also indicate that rural people prefer to use informal sources of help and support rather than formal sources when accessing health care (Long & Weinert, 1989; Weinert & Long, 1987).

Modest differences emerged by gender and geographic locale when the social integration and mortality studies were re-examined (House, Landis, & Umberson, 1988). Results were similar for men and women in urban populations, but not for small town and rural populations. Findings among the non-urban populations suggested that risk ratios for women were consistently weaker than those for men in the same rural population. Also, the risk ratios for men in more
rural populations assumed a threshold form. Mortality was clearly elevated among the most socially isolated, but declined only modestly, if at all, between moderate and high levels of social integration.

Conceptual Framework

A positive correlation between social support and health outcomes has been supported by a volume of research. Based on this, social support was hypothesized to have a positive effect on the health status of partners of people with multiple sclerosis. Health was defined as an individualized, self-interpreting, multifaceted concept, with physical, psychological, and psychosocial components. The physical component of health was determined by examining the participants’ responses to a general health question, while the psychological component was ascertained by examining each participant’s reported level of depression. Lastly, the psychosocial component was established, based on the degree to which situations in life were perceived as stressful for the partner of someone with MS. The measurements of these three components of health were not intended to provide a comprehensive appraisal of health, but provided indicators for one’s level of physical, psychological, and psychosocial well-being.

There may be factors influencing the social support and health relationship. Yet, the literature is inconclusive.
For this reason, the factors of gender, degree of disability, age, and geographic locale, were examined for their influencing effect upon the social support and health relationship.

**Definition of Terms**

**Social support** - the outcome of a relationship between at least two people which contains the following dimensions: attachment, social integration, opportunity for nurturance, reassurance of worth, alliance, and acquisition of guidance (Weiss, 1974).

**Health** - a state of well-being, which includes physical, psychological, and psychosocial components.

**Partner** - an adult, married to or living with a person diagnosed as having multiple sclerosis.

**Person with MS** - an adult with a health history and or symptoms consistent with the medical diagnosis of multiple sclerosis.
CHAPTER 3

METHODOLOGY

This study is a secondary data analysis. The data were a subset of a large scale longitudinal study, the Family Health Study (FHS).

Family Health Study

The Family Health Study is an ongoing national study, funded by the National Institute of Health/National Institute for Nursing Research (1R01NR01852), and conducted by Drs. Clarann Weinert (Montana State University) and Marci Catanzaro (University of Washington). The purpose of the FHS is to isolate factors, important to individuals and families experiencing a long-term illness, and to identify the relationships among those factors.

Data collection for the primary study occurred annually for a span of five years (1989-1993) and included data from 1572 people. All of the families included an adult member diagnosed as having multiple sclerosis (MS). Participants in the study were recruited through newsletters and published announcements of the National Multiple Sclerosis Society and its local chapters. Adults were eligible to participate if they had MS; were living with their spouses.
or partners; were between the ages of 30 years and 69 years; and had spouses or partners willing to participate in the study.

Questionnaire packets, including a booklet for the person with MS and a booklet for the spouse/partner, were sent by mail to all couples. The return of the completed booklets was considered consent to participate. Approval for the FHS was granted by the Human Subjects Review Committees at Montana State University and the University of Washington (See Appendix A).

**Critique of Primary Study**

Secondary analysis involves reanalysis of data collected and analyzed by another investigator. Because the quality and accuracy of a secondary analysis is largely dependent on the research methods used in the primary study, the primary study was examined for principles of external and internal reliability, and external and internal validity.

External reliability refers to the likelihood that independent researchers would discover the same phenomena if the study was replicated (Woods & Catanzaro, 1988). Precise and complete reporting of data collection methods is needed for study replication. The data collection methods reported by the researchers who conducted the primary study were specific and comprehensive. The code book was developed
prior to data collection, and is completed in sufficient detail to allow for replication of the study.

Internal reliability addresses the consistency in which data are coded by all investigators analyzing the data (Woods & Catanzaro, 1988). Participants were asked in the primary study to supply data either through fixed-alternative responses, or fill in the blank responses requiring one to two words. The possibility of data misinterpretation is minimal with these types of responses, and therefore, did not pose a threat to the internal reliability of the study.

External validity is the extent that findings in one study can be generalized to other potential samples or to an entire population (Woods & Catanzaro, 1988). Three dimensions are considered when evaluating a study for external validity: the participants of the study, the setting for the study, and the observations made. In the primary study, data were obtained from a large convenient sample, residing across the United States. Respondents completed the mailed questionnaire at their convenience and in the setting of their choice. Included in the cover letter of the questionnaire was the researchers' assurance of confidentiality, and a request not to discuss or compare answers with one's partner prior to the completion of the questionnaire. Established tools were primarily used throughout the study.
Internal validity refers to the accuracy of the relationships between the variables being studied (Woods & Catanzaro, 1988). Contemporaneous events, maturation of the respondents, testing effects, and instrumentation error can threaten internal validity. During the time of data collection for the primary study, there were no major scientific discoveries concerning the diagnosis, treatment, or prognosis of MS. All data were collected annually over a span of two months (January and February) at the same time each year. Participation was entirely voluntary and all respondents received the same instruments.

Based on these findings, it is apparent that principles of external and internal reliability, and external and internal validity were adhered to in the primary study. There were no findings that led the researcher to question the integrity or quality of the database used for this secondary analysis.

Secondary Analysis

The data collected as part of the Family Health Study in 1993 (FHS:93) served as the database for this secondary analysis. No new data were collected.

Design

A cross sectional analysis of existing data from the FHS:93 was conducted to determine the relationship between
perceived social support and perceived health of partners of people with multiple sclerosis. Factors which influence this social support and health relationship were identified.

Sample

The 1993 phase of the FHS consisted of 899 individuals, who had previously participated in the FHS. Only families in which both partners participated in 1993 were selected (N = 442). Most of the participating couples were married (99%), with an average marital duration of 21.5 years. This study focuses on partners of people with MS. Hereafter, the spouses/partners of persons with MS will be referred to as partners.

Partners were middle age (mean = 44.1 years), men (71%), Caucasian (98%), well educated (mean = 14.7 years in school), and employed full-time for pay (72%). See Table 1 for a more complete description of the characteristics of the partners. The mean time span between the onset of symptoms and the FHS:93 data collection was 17.5 years (SD = 9.2), while the length of time since diagnosis was 12.8 years (SD = 7.9).
Table 1. Partner characteristics.

<table>
<thead>
<tr>
<th>Age (years)</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>16-30</td>
<td>37</td>
<td>8</td>
</tr>
<tr>
<td>31-40</td>
<td>103</td>
<td>23</td>
</tr>
<tr>
<td>41-50</td>
<td>170</td>
<td>39</td>
</tr>
<tr>
<td>51-64</td>
<td>132</td>
<td>30</td>
</tr>
<tr>
<td>Mean = 44.1 (SD = 9.4)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Gender</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Women</td>
<td>128</td>
<td>29</td>
</tr>
<tr>
<td>Men</td>
<td>314</td>
<td>71</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education (years)</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;12</td>
<td>20</td>
<td>4</td>
</tr>
<tr>
<td>12</td>
<td>122</td>
<td>28</td>
</tr>
<tr>
<td>13-16</td>
<td>188</td>
<td>43</td>
</tr>
<tr>
<td>17-20</td>
<td>103</td>
<td>23</td>
</tr>
<tr>
<td>&gt;20</td>
<td>9</td>
<td>2</td>
</tr>
<tr>
<td>Mean = 14.7 (SD = 3.1)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Employment</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Full time</td>
<td>319</td>
<td>72</td>
</tr>
<tr>
<td>Part time</td>
<td>24</td>
<td>5</td>
</tr>
<tr>
<td>Full time homemaker</td>
<td>25</td>
<td>6</td>
</tr>
<tr>
<td>Unemployed-disability</td>
<td>6</td>
<td>1</td>
</tr>
<tr>
<td>Retired</td>
<td>44</td>
<td>10</td>
</tr>
<tr>
<td>Other</td>
<td>23</td>
<td>5</td>
</tr>
</tbody>
</table>

The families were from rural as well as non-rural areas (see Table 2) and lived in 45 different states (see Table 3). The MSU Rurality Index (Weinert & Boik, 1995), which is a locally-normed measure of the degree of rurality, ranged from a -2.31 to 4.99. Using this index, an interval level score is assigned for each participant in a study. A positive score reflects a more rural residence, while a negative score reflects a more urban residence. By calculation, the mean is set at zero, indicating the average
degree of rurality for the sample being studied. Two variables are needed to compute the index: county population and distance to emergency care. When compared to another rurality index calculated by using eleven county-based economic variables, the validity of the MSU Rurality Index did not appear to be threatened, despite its more simplistic structure. The MSU Rurality Index was demonstrated to be associated with various health care variables as strongly or more strongly than the eleven variable county-based index.

The sample were primarily middle income families with an average annual income category of $45,000 to $49,999. Forty-four percent of the families were comprised of couples only. Most of the families with children in the household had two or fewer children. See Table 4 for family characteristics.

Table 2. Family residence.

<table>
<thead>
<tr>
<th>Place of residence</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Farm/ranch</td>
<td>41</td>
<td>9</td>
</tr>
<tr>
<td>Rural area (not farm or ranch)</td>
<td>74</td>
<td>17</td>
</tr>
<tr>
<td>Small rural town</td>
<td>44</td>
<td>10</td>
</tr>
<tr>
<td>Town</td>
<td>80</td>
<td>18</td>
</tr>
<tr>
<td>Medium size city</td>
<td>67</td>
<td>15</td>
</tr>
<tr>
<td>Large city</td>
<td>28</td>
<td>6</td>
</tr>
<tr>
<td>Suburban area</td>
<td>76</td>
<td>17</td>
</tr>
<tr>
<td>Major metropolitan area</td>
<td>27</td>
<td>6</td>
</tr>
</tbody>
</table>
Table 3. Number of Families by State or Territory.

<table>
<thead>
<tr>
<th>State/Territory</th>
<th>Frequency</th>
<th>State/Territory</th>
<th>Frequency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alaska</td>
<td>3</td>
<td>Montana</td>
<td>47</td>
</tr>
<tr>
<td>Arizona</td>
<td>3</td>
<td>Nebraska</td>
<td>3</td>
</tr>
<tr>
<td>Arkansas</td>
<td>3</td>
<td>New Hampshire</td>
<td>2</td>
</tr>
<tr>
<td>California</td>
<td>19</td>
<td>New Jersey</td>
<td>3</td>
</tr>
<tr>
<td>Colorado</td>
<td>2</td>
<td>New Mexico</td>
<td>3</td>
</tr>
<tr>
<td>Connecticut</td>
<td>6</td>
<td>New York</td>
<td>21</td>
</tr>
<tr>
<td>Delaware</td>
<td>2</td>
<td>North Carolina</td>
<td>7</td>
</tr>
<tr>
<td>Florida</td>
<td>9</td>
<td>Ohio</td>
<td>13</td>
</tr>
<tr>
<td>Georgia</td>
<td>3</td>
<td>Oklahoma</td>
<td>2</td>
</tr>
<tr>
<td>Hawaii</td>
<td>3</td>
<td>Oregon</td>
<td>9</td>
</tr>
<tr>
<td>Idaho</td>
<td>10</td>
<td>Pennsylvania</td>
<td>12</td>
</tr>
<tr>
<td>Illinois</td>
<td>9</td>
<td>Rhode Island</td>
<td>1</td>
</tr>
<tr>
<td>Indiana</td>
<td>1</td>
<td>South Carolina</td>
<td>1</td>
</tr>
<tr>
<td>Iowa</td>
<td>11</td>
<td>Tennessee</td>
<td>3</td>
</tr>
<tr>
<td>Kansas</td>
<td>3</td>
<td>Texas</td>
<td>29</td>
</tr>
<tr>
<td>Kentucky</td>
<td>4</td>
<td>Utah</td>
<td>3</td>
</tr>
<tr>
<td>Louisiana</td>
<td>2</td>
<td>Vermont</td>
<td>3</td>
</tr>
<tr>
<td>Maine</td>
<td>3</td>
<td>Virginia</td>
<td>15</td>
</tr>
<tr>
<td>Maryland</td>
<td>1</td>
<td>Washington</td>
<td>105</td>
</tr>
<tr>
<td>Massachusetts</td>
<td>7</td>
<td>West Virginia</td>
<td>3</td>
</tr>
<tr>
<td>Michigan</td>
<td>25</td>
<td>Wisconsin</td>
<td>13</td>
</tr>
<tr>
<td>Minnesota</td>
<td>6</td>
<td>Wyoming</td>
<td>3</td>
</tr>
<tr>
<td>Mississippi</td>
<td>3</td>
<td>Washington DC</td>
<td>2</td>
</tr>
<tr>
<td>Missouri</td>
<td>1</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 4. Family Characteristics.

<table>
<thead>
<tr>
<th>Income</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;$15,000</td>
<td>16</td>
<td>4</td>
</tr>
<tr>
<td>$15,000-19,999</td>
<td>21</td>
<td>5</td>
</tr>
<tr>
<td>$20,000-24,999</td>
<td>35</td>
<td>8</td>
</tr>
<tr>
<td>$25,000-29,999</td>
<td>33</td>
<td>8</td>
</tr>
<tr>
<td>$30,000-34,999</td>
<td>36</td>
<td>8</td>
</tr>
<tr>
<td>$35,000-39,999</td>
<td>29</td>
<td>7</td>
</tr>
<tr>
<td>$40,000-44,999</td>
<td>55</td>
<td>13</td>
</tr>
<tr>
<td>$45,000-49,999</td>
<td>34</td>
<td>8</td>
</tr>
<tr>
<td>$50,000-54,999</td>
<td>33</td>
<td>8</td>
</tr>
<tr>
<td>$55,000-59,999</td>
<td>16</td>
<td>4</td>
</tr>
<tr>
<td>$60,000-64,999</td>
<td>25</td>
<td>6</td>
</tr>
<tr>
<td>$65,000-69,999</td>
<td>14</td>
<td>3</td>
</tr>
<tr>
<td>$70,000-74,999</td>
<td>20</td>
<td>5</td>
</tr>
<tr>
<td>$75,000-79,999</td>
<td>10</td>
<td>2</td>
</tr>
<tr>
<td>&gt;$80,000</td>
<td>57</td>
<td>13</td>
</tr>
<tr>
<td>Mean range = $45,000 - 49,999</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Median range = $40,000 - 44,999</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Children living in household</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>194</td>
<td>44</td>
</tr>
<tr>
<td>1</td>
<td>114</td>
<td>26</td>
</tr>
<tr>
<td>2</td>
<td>89</td>
<td>20</td>
</tr>
<tr>
<td>3</td>
<td>35</td>
<td>8</td>
</tr>
<tr>
<td>4</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

Instruments

Partner and family demographic information was obtained from the individual and family background portion of the questionnaire used for the FHS:93. Social support was measured using the Personal Resource Questionnaire, Part 2, which is a measure of perceived social support (Brandt & Weinert, 1981). Physical health, psychological health, and psychosocial health were measured using a general health question (Davies & Ware, 1981), the Center for Epidemiologic
Studies Depression Scale (Devine & Orme, 1985), and the Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983). The degree of disability was determined using one of the scales from the Minimal Record of Disability in Multiple Sclerosis (International Federation of Multiple Sclerosis Societies, 1984). See Appendix B for a copy of the instruments used. See Table 5 for each construct, its measurement, and the reliability and validity of the corresponding instrument.

Table 5. Construct Measurement.

<table>
<thead>
<tr>
<th>Construct</th>
<th>Instrument</th>
<th>Reliability</th>
<th>Validity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Demographic information</td>
<td>Individual/family background</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social support</td>
<td>PRQ85-Part 2</td>
<td>alpha .88-.90</td>
<td>Content, criterion, construct</td>
</tr>
<tr>
<td>Degree of disability</td>
<td>MRD</td>
<td>item-total correlation .25-.86</td>
<td>construct</td>
</tr>
<tr>
<td></td>
<td></td>
<td>alpha .93 inter-rater correlation coefficient .94</td>
<td></td>
</tr>
<tr>
<td>Physical health</td>
<td>General health question</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Psychological health</td>
<td>CES-D</td>
<td>alpha .84-.92</td>
<td>content, criterion, construct</td>
</tr>
<tr>
<td></td>
<td></td>
<td>retest .67</td>
<td></td>
</tr>
<tr>
<td>Psychosocial health</td>
<td>PSS</td>
<td>alpha .84-.86</td>
<td>content, criterion, construct</td>
</tr>
<tr>
<td></td>
<td></td>
<td>retest .85</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>retest .55</td>
<td></td>
</tr>
</tbody>
</table>
Individual/family Background

Individual and family background information was provided by the partner as part of the questionnaire used in the primary study. The individual background portion consisted of twelve fixed-alternative response or fill in the blank type questions, related to information about the partner only. Information concerning the family unit was obtained through the use of nine questions using the same format.

Personal Resource Questionnaire

Social support was measured using the Personal Resource Questionnaire (PRQ85). The PRQ85 (Brandt & Weinert, 1981) is a measure of social support, developed based on the relational dimensions as described by Weiss (1974). These dimensions include: a) provisions for attachment/intimacy, b) social integration, c) opportunity for nurturant behavior, d) reassurance of worth both as an individual and in role accomplishments, and e) the availability of informational, emotional, and material help. The PRQ85 consists of two parts, and only Part 2 was used in this analysis. Part 1 provides information concerning a person's social support network, while Part 2 addresses the respondent's perceived level of social support.

Part 2 measures the person's level of perceived support on a 25-item Likert scale. There are seven choices for each
statement, ranging from "1 = STRONGLY DISAGREE" to
"7 = STRONGLY AGREE". A higher score reflects a greater
level of perceived social support. Extensive psychometric
testing of the PRQ85 has been conducted. Results obtained
from four study samples indicate that the measure has strong
internal consistency reliability, with alpha coefficients
ranging from .88 to .90 (Weinert & Brandt, 1987).
Test-retest reliability coefficient over a four to six week
period was .72. Construct validity has also been
established (Weinert & Tilden, 1990).

General Health Question

Physical health of the partners was ascertained by
asking the participants to rate their health. The response
categories of excellent, good, fair, or poor were assigned
the values of 40, 34, 26, and 15 according to the weights
suggested by Davies and Ware (1981). Self-rated health has
been found to correlate significantly with measures of
objective health status (Ferraro, 1980; Fillenbaum, 1979;
Maddock & Douglass, 1973). Since objective health
measurements were not feasible in the primary study,
self-ratings of health were used as the measure for physical
health in this secondary analysis.

Center for Epidemiologic
Studies Depression Scale

The psychological component of health was measured
using the Center for Epidemiologic Studies Depression Scale
(CES-D) (Devine & Orme, 1985). The CES-D is a 20 item self-report measure, which measures the frequency and duration of cognitive, affective, behavioral, and somatic symptoms associated with depression. Positive affect is also assessed through the use of the instrument. Participants were asked to indicate the frequency they had experienced a specific symptom in the previous week, by circling a number ranging from zero to three ("0" = RARELY OR NONE OF THE TIME to "3" = MOST OR ALL OF THE TIME). The reverse items were recoded and a total score calculated. Higher scores indicated a greater level of depressive symptomatology.

Psychometric testing for the CES-D has been extensive. Radloff (1977) reported alpha coefficients ranging from .84 to .90 and test-retest reliability estimates of .67, .48, .54, and .49 at one, three, six and twelve month intervals. In their study among adults with MS, Long and Weinert (1992) reported an alpha coefficient of .92. The mean scores on the CES-D scale have been shown to be consistent across three sample groups from different parts of the country, despite controlling for demographic factors including gender, marital status, employment status, age, education, and income. Correlation between the CES-D scale and other scales measuring depression range from .50 to .70 (Enslen, 1986).
Perceived Stress Scale

The psychosocial component of health was measured using the Perceived Stress Scale (PSS) (Cohen, Kamarck, & Mermelstein, 1983), under the assumption that the lower the PSS score, the greater one’s psychosocial health. The PSS measures the degree to which situations in one’s life are perceived as stressful. A higher score is indicative of greater stress as perceived by the respondent. Fourteen items were posed in the primary study regarding thoughts and feelings experienced in the previous month related to events or conditions in one’s life. Participants were asked to indicate how often they felt or thought a certain way by circling a number between zero and four ("0" = NEVER; "4" = VERY OFTEN). A perceived stress scale score was calculated following recoding of the reverse items.

Psychometric testing, conducted using three sample groups, yielded coefficient alpha values of .84, .85, and .86 (Cohen, Kamarck, & Mermelstein, 1983). A test-retest correlation for a group of 82 college students following a two day interval was .85. The test-retest correlation for 64 subjects in a smoking cessation study, following a six week time span, was .55. Although the PSS has been found to be significantly related to the CES-D (depression symptoms scale), both scales independently predicted physical symptomatology. Neither gender nor age appeared to influence the relationship between the PSS and the validity
Minimal Record of Disability in Multiple Sclerosis

The degree of disability experienced by the persons with MS was measured using one of the five sections comprising the Minimal Record of Disability in Multiple Sclerosis (MRD): the Incapacity Status Scale (International Federation of Multiple Sclerosis Societies, 1984). The MRD is an internationally developed tool representing a synthesis of several scales, designed to assess disability and handicap in people with multiple sclerosis. The Incapacity Status Scale (ISS) is a sixteen-item, self-report addressing the degree of impairment experienced when performing activities of daily living, such as stair climbing, ambulation, transfers, bowel and bladder function, bathing, dressing, grooming, and feeding. Participants are also asked to designate the extent of their difficulties related to vision, speech and hearing, medical problems, mood and thought processes, mentation, fatigability, and sexual function. A higher score indicates a greater level of impairment when performing activities of daily living.

LaRocca, Scheinberg, and Slater (1984) have reported a Cronbach’s alpha of .93 for the ISS. Inter-rater agreement on examination of twenty patients by two physicians was
reported at .94. Item-total correlations ranged from .25 to .86 (Slater, LaRocca, & Scheinberg, 1984).

Human Subjects

This secondary analysis was submitted to and approved by the Human Subjects Review Committee at Montana State University, College of Nursing on April 17, 1995 (See Appendix C). Permission to use selected variables on the data set collected in 1993 was received from Dr. Weinert (See Appendix D). Data, relevant to the spouse/partner for the FHS:93, were used for this analysis. No new data were collected.
CHAPTER 4

RESULTS

Social Support and Health Relationship

The instruments used to measure the various concepts were described fully in Chapter 3. The Personal Resource Questionnaire (PRQ85) was used to measure social support. Physical health was represented by the general health question score; psychological health by the Center for Epidemiologic Studies Depression Scale (CES-D) score; and psychosocial health by the Perceived Stress Scale (PSS) score. The Minimal Record of Disability in Multiple Sclerosis (MRD) was used to measure the degree of disability experienced by the person with multiple sclerosis (MS). With the exception of the MRD, all other data were collected from partners of persons with MS. The accepted level of significance throughout this secondary analysis was .05.

Scale Reliability

Internal-consistency reliability of the scales was examined using Cronbach’s alpha, which is based on the intercorrelation of all the items in a scale examined simultaneously (Woods & Catanzaro, 1988). See Table 6 for alpha reliability on each scale. When used for
group-level comparisons, the reliability coefficient for mature scales typically must exceed 0.8 (Woods & Catanzaro, 1988). Each scale demonstrated an alpha reliability of .89 or greater, which is adequate for the purposes of this study.

Table 6. Scale Reliability.

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Reliability</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRQ-85</td>
<td>.93</td>
</tr>
<tr>
<td>CES-D</td>
<td>.92</td>
</tr>
<tr>
<td>PSS</td>
<td>.89</td>
</tr>
<tr>
<td>MRD</td>
<td>.90</td>
</tr>
</tbody>
</table>

Perceived Social Support and Perceived Health of Sample

The mean score for the study sample on the PRQ85 was 139.11. This is lower than the mean for nonclinical samples, but very similar to that reported by other caregivers. Two samples of people not experiencing a chronic illness with a significant other had PRQ85 scores of 149.20 (Gibson & Weinert, 1986) and 145.01 (Weinert, 1995). Caregivers of persons with cancer (N = 406) reported a score of 139.00 (Weinert & Bender, 1995).

Most of the respondents (57%) reported their health as "good". The general health mean for this sample was 34.38 (SD = 4.90), which closely approximates the group mean for a large scale study by Rand’s Health Insurance Experiment (Davies & Ware, 1981). The general health mean for 4717 respondents in the health insurance experiment, encompassing six study sites, was 34.85 (SD = 4.72).
The level of depressive symptomatology, as measured by the CES-D, for the study sample was 9.81 (SD = 9.15). This is lower than that reported by people with a chronic illness, but within the range reported among nonclinical groups. The mean score on the CES-D for a study sample with MS was 15.56 (SD = 11.13) (Weinert & Catanzaro, 1994). Mean values for CES-D scores among community residents ranged from 8.5 to 12.7 (Lewinsohn & Teri, 1982; Lin & Ensel, 1984). The level of depressive symptomatology among this study's participants was also well below 16, a score usually considered to indicate depressive symptomatology requiring intervention (Devine & Orme, 1985).

The mean score of study participants on the PSS was 22.49 (SD = 8.10). This is lower than two samples of college students (N = 332, mean age = 19.01, SD = 2.75; N = 114, mean age = 20.75, SD = 4.41), who had mean PSS scores of 23.18 (SD = 7.31) and 23.67 (SD = 7.79) (Cohen, Kamarck, & Mermelstein, 1983). It is also less than the mean PSS score obtained from a more heterogeneous community group, a smoking-cessation sample (N = 64, mean age = 38.4, SD = 11.57), who had a PSS mean score of 25.0 (SD = 8.00) (Cohen, Kamarck, & Mermelstein, 1983).

See Table 7 for the range of scores for each measure, and a comparison of the means for the study sample with the means for other groups. The perceived social support, perceived physical health, and level of depressive
symptomatology of the respondents were comparable to the results found for other groups. The CES-D mean score did not indicate high depressive symptomatology, and the PSS mean score reflected a higher level of psychosocial health relative to three other community groups examined.

Table 7. Range of Scores, Sample Means, and Means for Comparable Groups for Social Support and Health Measures.

<table>
<thead>
<tr>
<th>Instrument</th>
<th>Scale Range</th>
<th>Mean and SD for Sample</th>
<th>Mean for Comparable Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRQ85</td>
<td>25-175</td>
<td>139.11 (20.87)</td>
<td>149.20 (145.01)</td>
</tr>
<tr>
<td>General</td>
<td>15 - 40</td>
<td>34.38 (4.90)</td>
<td>34.85</td>
</tr>
<tr>
<td>Health</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CES-D*</td>
<td>0-60</td>
<td>9.81 (9.15)</td>
<td>15.56 (8.5-12.7)</td>
</tr>
<tr>
<td>PSS*</td>
<td>0-56</td>
<td>22.49 (8.10)</td>
<td>23.18 (23.67)</td>
</tr>
</tbody>
</table>

Note. Higher CES-D and PSS scores are less desirable. An asterisk indicates reverse direction is necessary when interpreting results.

Intercorrelation Among Health Measures

Health was defined in this study as a state of well-being with physical, psychological, and psychosocial components. Three separate measures were used to assess health: the general health question, the CES-D, and the PSS. To gain a greater understanding of the construct from a holistic perspective, the intercorrelations among the dependent health measures were examined. Pearson
correlations were computed to examine the intercorrelation among physical health, psychological health, and psychosocial health (see Table 8). All of the intercorrelations were significant. A positive correlation of .72 (p = .001) was demonstrated between psychological health and psychosocial health. Correlations of -.24 (p = .001) and -.20 (p = .001) were demonstrated between physical health and psychological health, and between physical health and psychosocial health.

Higher scores on the CES-D and the PSS are indicative of greater depressive and stressful symptomatology. Lower scores reflect greater psychological and psychosocial health. As physical health increased, the CES-D score decreased. Because a lower CES-D score is reflective of better psychological health, this indicates that as physical health increased, so did psychological health. Likewise, as physical health increased, the PSS score decreased. A lower PSS score reflects better psychosocial health. Therefore, as physical health increased, so did psychosocial health.

Table 8. Intercorrelation Among Dependent Health Measures.

<table>
<thead>
<tr>
<th></th>
<th>Psychological Health</th>
<th>Psychosocial Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Health</td>
<td>-.24 (.001)</td>
<td>-.20 (.001)</td>
</tr>
<tr>
<td>Psychological Health</td>
<td>.72 (.001)</td>
<td></td>
</tr>
</tbody>
</table>
Determination of Independent Variables

Because of inconclusive findings in the literature, the researcher initially chose to examine the influence that social support, gender, degree of disability, age and geographic locale have on physical, psychological, and psychosocial health. For exploratory purposes, the relationships between other factors available in the data set (time since symptom onset, time since diagnosis, years of school, income, number of children living at home, and length of marriage) and physical health, psychological health, and psychosocial health were also examined. Pearson correlations were computed for time since symptom onset, time since diagnosis, years of school, income, number of children living at home, and length of marriage with each of the three dependent variables (physical health, psychological health, and psychosocial health). Of the six additional demographic variables examined, only income had a correlation above .20 with a dependent variable. A correlation of .23 (p = .001) was demonstrated between income and physical health. Since income was a potentially relevant factor, it was included in the subsequent data analysis.

Intercorrelation Among Independent Variables

The intercorrelation of social support, gender, degree of disability, age, degree of rurality, and income was
examined, using Pearson correlations. Multicollinearity occurs when independent variables are highly intercorrelated. When multicollinearity occurs, the regression equation is very unstable from one sample of data to another (Howell, 1989). Two random samples from the same population become at risk for producing regression equations that appear to be totally different from one another. As a preliminary step to multiple regression, the intercorrelation between each of the independent variables was computed. As shown in Table 9, there were no strong intercorrelations demonstrated among social support, gender, degree of disability, age, degree of rurality and income.

Table 9. Intercorrelation Among Independent Variables.

<table>
<thead>
<tr>
<th></th>
<th>Gender</th>
<th>Degree of Disability</th>
<th>Age</th>
<th>Degree of Rurality</th>
<th>Income</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Support</td>
<td>.12</td>
<td>-.09</td>
<td>-.07</td>
<td>-.04</td>
<td>.18</td>
</tr>
<tr>
<td></td>
<td>.01**</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>.001***</td>
</tr>
<tr>
<td>Gender</td>
<td>.18</td>
<td>-.14</td>
<td>-.09</td>
<td>-.01</td>
<td></td>
</tr>
<tr>
<td></td>
<td>.001***</td>
<td>.003**</td>
<td>NS</td>
<td>NS</td>
<td></td>
</tr>
<tr>
<td>Degree of Disability</td>
<td>.17</td>
<td>.03</td>
<td>-.22</td>
<td></td>
<td>.001***</td>
</tr>
<tr>
<td></td>
<td>.001***</td>
<td>NS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
<td>.01</td>
<td>-.11</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>NS</td>
<td>.029*</td>
<td></td>
</tr>
<tr>
<td>Rurality</td>
<td></td>
<td></td>
<td></td>
<td>-.27</td>
<td>.001***</td>
</tr>
</tbody>
</table>

*p<.05. **p<.01. ***p<.001.
Correlation Between Independent Variables and Dependent Variables

To get a preliminary estimate of the relationship between each independent variable (gender, degree of disability, age, degree of rurality, and income), and each dependent variable (physical health, psychological health, and psychosocial health), Pearson correlations were computed for each independent variable with each of the three dependent variables. See Table 10 for the correlation of gender, degree of disability, age, degree of rurality, and income with physical health, psychological health, and psychosocial health. No strong correlations were noted when the independent variables were correlated with the dependent measures, although modest significant correlations were found between age and physical health (-.21, p = .001), and between income and physical health (.23, p = .001).

In the bivariate analysis, the relationship between each independent variable and each dependent variable was examined. No strong correlations were noted. However, it was unknown what association the independent variables would have with the dependent variables, if the independent variables were analyzed as a group. Because of this, multivariate analysis was conducted, the results of which will be discussed later.
Table 10. Correlation Between Independent Variables and Dependent Measures.

<table>
<thead>
<tr>
<th></th>
<th>Physical Health</th>
<th>Psychological Health</th>
<th>Psychosocial Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>-.03</td>
<td>.12</td>
<td>.18</td>
</tr>
<tr>
<td></td>
<td>NS</td>
<td>.011*</td>
<td>.001***</td>
</tr>
<tr>
<td>Degree of Disability</td>
<td>-.07</td>
<td>.15</td>
<td>.18</td>
</tr>
<tr>
<td></td>
<td>NS</td>
<td>.001***</td>
<td>.001***</td>
</tr>
<tr>
<td>Age</td>
<td>-.21</td>
<td>-.05</td>
<td>-.12</td>
</tr>
<tr>
<td></td>
<td>.001***</td>
<td>NS</td>
<td>.014*</td>
</tr>
<tr>
<td>Rurality</td>
<td>-.14</td>
<td>-.01</td>
<td>-.06</td>
</tr>
<tr>
<td></td>
<td>.003**</td>
<td>NS</td>
<td>NS</td>
</tr>
<tr>
<td>Income</td>
<td>.23</td>
<td>-.17</td>
<td>-.08</td>
</tr>
<tr>
<td></td>
<td>.001***</td>
<td>.001***</td>
<td>NS</td>
</tr>
</tbody>
</table>

*p<.05. **p<.01. ***p<.001.

Differences in Social Support and Health by Gender

Differences between women and men on the level of social support and the number of social network resources have been noted (Weinert & Long, 1993). Women whose husbands have MS have reported a higher level of social support, and a higher number of network resources than men whose wives have MS. Based on this finding and the empirical evidence linking social support and health (Cohen & Syme, 1985), exploratory analysis was conducted to compare the social support and health levels of the women and men in this study. The mean score of men and the mean score of women on the PRQ85, general health question, CES-D, and the PSS were compared using two-tailed t tests. See Table 11 for the means of the total sample, with a comparison by gender.
Women's level of social support (143.20) was significantly ($p = .009$) higher than men's (137.46). No significant difference was noted between the physical health of the two groups. Sixty-six percent of the women and sixty percent of the men reported their health as "good". The mean CES-D score for women (11.52) was significantly higher than the mean for men (9.10). The mean PSS score for women (24.80) was also significantly higher than the mean for men (21.54). Because higher CES-D and PSS scores are less desirable, this indicates that although women reported higher levels of social support, and perceived their physical health the same as men, they reported lower levels of psychological health and psychosocial health.

Table 11. Social Support and Health Measure Scores by Gender.

<table>
<thead>
<tr>
<th>Instrument</th>
<th>All Mean (SD)</th>
<th>Women Mean (SD)</th>
<th>Men Mean (SD)</th>
<th>p Value Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>PRQ85</td>
<td>139.11 (20.87)</td>
<td>143.20 (22.33)</td>
<td>137.46 (20.06)</td>
<td>.009**</td>
</tr>
<tr>
<td>General Health</td>
<td>34.38 (4.90)</td>
<td>34.20 (5.02)</td>
<td>34.46 (4.86)</td>
<td>NS</td>
</tr>
<tr>
<td>CES-D</td>
<td>9.81 (9.15)</td>
<td>11.52 (10.48)</td>
<td>9.10 (8.46)</td>
<td>.011*</td>
</tr>
<tr>
<td>PSS</td>
<td>22.49 (8.10)</td>
<td>24.80 (8.28)</td>
<td>21.54 (7.85)</td>
<td>.001***</td>
</tr>
</tbody>
</table>

*p<.05. **p<.01. ***p<.001.

Social Support and Health

The first research question addressed in this study was: What is the relationship between perceived social
support and perceived health of partners of persons with MS? Pearson correlation coefficients were computed between social support and each of the three dependent health measures. See Table 12 for the bivariate relationship between these variables. A significant correlation was demonstrated between social support and physical health (.11, p = .019). Stronger significant correlations were demonstrated between social support and psychological health (-.54, p = .001), and between social support and psychosocial health (-.44, p = .001).

Table 12. Bivariate Relationship Between Social Support and Physical, Psychological, and Psychosocial Health.

<table>
<thead>
<tr>
<th></th>
<th>Physical Health</th>
<th>Psychological Health</th>
<th>Psychosocial Health</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Support</td>
<td>.11</td>
<td>-.54</td>
<td>-.44</td>
</tr>
<tr>
<td></td>
<td>.019*</td>
<td>.001***</td>
<td>.001***</td>
</tr>
</tbody>
</table>

* p < .05.  **p < .01.  ***p < .001.

Factors Influencing Social Support and Health Relationship

The second research question addressed was: What are the factors that influence the relationship between perceived social support and perceived health? Multiple regression was used to address this question. The purpose of multiple regression analysis is to describe the extent, direction, and strength of the relationship between multiple independent variables and one dependent variable (Woods & Catanzaro, 1988). The independent variables in this study
were: social support, gender, degree of disability, age, degree of rurality, and income. The dependent variables were: physical health, psychological health, and psychosocial health. In order to develop the most adequate model of the relationship of the six independent variables with each of the three dependent variables, a variety of regression analyses were completed. Since there was no appreciable difference in the findings when stepwise, forward, backward, or forced entry regression techniques were used, only the results of the backward regression equation are reported.

Physical health. Physical health was regressed on social support, gender, degree of disability, age, degree of rurality, and income with a resulting $R^2$ of .09. The significant variables in this equation were age and income, both of which had similar Beta coefficients (see Table 13). The beta coefficient of -.188 for age indicates that for every one unit change in age, the predicted physical health will decrease by .188 unit/ assuming that the other variables are held constant. The beta coefficient of .185 for income indicates that for every one unit change in income, the predicted physical health will increase by .185 unit, again assuming that the other variables are held constant. In the bivariate analysis, social support had a limited association with physical health (.11, $p = .019$), and this was again demonstrated in the multivariate
analysis, when a group of variables were considered concurrently. Even in combination with gender, degree of disability, age, degree of rurality, and income, social support had little impact on physical health. This analysis indicated that partners who had higher incomes and were younger tended to have higher physical health scores.

Table 13. Regression of Physical Health on Social Support, Gender, Degree of Disability, Age, Degree of Rurality, and Income.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>Sig. Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-.188</td>
<td>.0001</td>
</tr>
<tr>
<td>Income</td>
<td>.185</td>
<td>.0002</td>
</tr>
<tr>
<td>R² = .09</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Psychological health. Psychological health was regressed on social support, gender, degree of disability, age, degree of rurality, and income, with a resulting R square of .31. The significant variables in the equation were social support, gender, degree of disability, and age. The Beta coefficient of social support (-.540) was noticeably larger than the other significant variables (see Table 14). In the bivariate analysis, social support had a moderate association with psychological health (-.54, p = .001), and this was again demonstrated in the multivariate analysis. In combination with gender, degree of disability, and age, social support continued to have a moderately strong impact on psychological health. Younger women with lower social support and whose partners had
greater disability tended to have more depressive symptomatology.

Table 14. Regression of Psychological Health on Social Support, Gender, Degree of Disability, Age, Degree of Rurality, and Income.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>Sig. Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Support</td>
<td>-.540</td>
<td>.0001</td>
</tr>
<tr>
<td>Gender</td>
<td>.130</td>
<td>.0020</td>
</tr>
<tr>
<td>Disability</td>
<td>.102</td>
<td>.0152</td>
</tr>
<tr>
<td>Age</td>
<td>-.088</td>
<td>.0339</td>
</tr>
</tbody>
</table>

\[ R^2 = .31 \]

Psychosocial health. Psychosocial health was regressed on social support, gender, degree of disability, age, degree of rurality, and income, with a resulting R square of .26. The significant variables in the equation were social support, gender, degree of disability, and age. The same variables were significant when psychological health was regressed on the equation. Likewise, the Beta coefficient of social support (-.458) was again noticeably larger than the other significant variables (see Table 15). Similar to the bivariate relationship between social support and psychosocial health (-.44, p = .001), social support, in combination with the other variables, was demonstrated to have a notable impact on psychosocial health. Younger women with lower social support and whose partners had greater disability not only tended to have more depressive symptomatology, but also had poorer psychosocial health.
Table 15. Regression of Psychosocial Health on Social Support, Gender, Degree of Disability, Age, Degree of Rurality, and Income.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>Sig. Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Support</td>
<td>-.458</td>
<td>.0001</td>
</tr>
<tr>
<td>Gender</td>
<td>.174</td>
<td>.0001</td>
</tr>
<tr>
<td>Disability</td>
<td>.130</td>
<td>.0029</td>
</tr>
<tr>
<td>Age</td>
<td>-.142</td>
<td>.0010</td>
</tr>
</tbody>
</table>

$R^2 = .26$

**Intervening variables.** Following multiple regression of physical health, psychological health, and psychosocial health on social support, gender, degree of disability, age, degree of rurality, and income, the model was re-examined to determine if there were any variables interacting with social support to influence the relationship between social support and health. Interaction terms entered into the equation consisted of the product between social support and gender (social support x gender); social support and degree of disability (social support x degree of disability); social support and age (social support x age); social support and degree of rurality (social support x degree of rurality); and social support and income (social support x income). Each of the three dependent variables (physical health, psychological health, and psychosocial health) was regressed on social support, gender, degree of disability, age, degree of rurality, income, social support x gender, social support x degree of disability, social support x age, social support x degree of rurality, and social support x income.
When physical health was regressed on the equation, age, income, and social support x gender were noted to be significant. Social support did not have a significant effect on physical health in the simple multiple regression equation, and this was again demonstrated when physical health was regressed on the independent and interaction variables. However, there was a significant interaction between social support and gender, which had an effect on physical health (see Table 16). For women, social support positively affected health. For men, social support negatively affected health.

Table 16. Regression of Physical Health on Independent Variables and Interaction Terms.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Beta</th>
<th>Sig. Level</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>-.19</td>
<td>.0001</td>
</tr>
<tr>
<td>Income</td>
<td>.20</td>
<td>.0001</td>
</tr>
<tr>
<td>Social support x Gender</td>
<td>.51</td>
<td>.05</td>
</tr>
</tbody>
</table>

$R^2 = .09$

When psychological health was regressed on the equation, social support, gender, degree of disability, and age were noted to be significant variables. There were no significant interactions between social support and any of the variables that affected psychological health.

Similar findings were found when psychosocial health was regressed on the equation. Social support, gender, degree of disability, and age were noted to be significant variables. Again, there were no significant interactions
between social support and any of the variables that affected psychosocial health.

Conclusion

Well established scales were used throughout this study. Each scale surpassed the minimum reliability coefficient of 0.8 set for mature scales, which indicates that the reliability of the scales were adequate for the purposes of this secondary analysis.

The perceived social support and perceived health scores of the sample were not atypical of other groups studied. Social support was similar to that reported by partners of people with cancer. Physical health, psychological health, and psychosocial health scores were not excessively different than that found among other community groups.

The first research question addressed the relationship between perceived social support and perceived health in partners of persons with MS. Significant correlations were demonstrated between social support and each of the three health variables (physical health, psychological health, and psychosocial health). The correlation between social support and psychological health, and between social support and psychosocial health, was stronger than the correlation between social support and physical health.

The second research question addressed what factors influenced the relationship between perceived social support
and perceived health. Nine percent of the variance in physical health, 31 percent of the variance in psychological health, and 26 percent of the variance in psychosocial health can be attributed to social support, gender, degree of disability, age, degree of rurality, and income. A significant, although borderline, interaction was found between social support and gender which affected physical health. No significant interactions were found between social support and any of the independent variables that affected psychological or psychosocial health.
CHAPTER 5

DISCUSSION, IMPLICATIONS, AND RECOMMENDATIONS

Discussion

The purpose of this secondary analysis was to determine the relationship between social support and health of partners of people with multiple sclerosis (MS) and to identify factors which affect this relationship. Social support was defined as the outcome of a relationship between at least two people containing the following dimensions: attachment, social integration, opportunity for nurturance, reassurance of worth, alliance, and acquisition of guidance (Weiss, 1974). Health was defined as an individualized, self-interpreting, multifaceted concept, with physical, psychological, and psychosocial components. Social support was measured using the Personal Resource Questionnaire (PRQ85). Health was assessed using three separate measures: a general health question with responses of excellent, good, fair, and poor, to assess the physical component of health, the Center for Epidemiological Studies Depression Scale (CES-D) to assess the psychological component of health, and the Perceived Stress Scale (PSS) to assess the psychosocial component of health.
Two research questions were addressed: a) What is the relationship between perceived social support and perceived health of partners of persons with MS?, and b) What are the factors that influence the relationship between perceived social support and perceived health? Social support was hypothesized to have a positive effect on the health status of partners of people with multiple sclerosis. The determination of potential factors that could influence the social support and health relationship was based on a literature review, and an explorative analysis of data from the primary study. The influencing factors/concepts in this study were: social support, gender, degree of disability, age, degree of rurality, and income. Physical health, psychological health, and psychosocial health were the outcome concepts.

Social Support and Health

The first research question was directed toward identification of the relationship between social support and health of partners of persons with multiple sclerosis. As hypothesized, a significant relationship was found between social support and health. Although the relationship between social support and psychological health, and between social support and psychosocial health supports the results reported by previous researchers (Andrews & Brown, 1988; Ben-sira & Eliezer, 1990; Lambert, Lambert, Klipple & Mewshaw, 1989; Ploeg & Faux, 1989; Waltz,
Badura, Pfaff, & Schott, 1988), the relationship between social support and physical health was not striking.

The limited relationship between social support and physical health in this study may be a result of the use of a single-item measure used to assess physical health. Respondents were asked to rate their health as excellent, good, fair, or poor. Although self-ratings of health have been found to correlate with measures of objective health status (Ferraro, 1980; Fillenbaum, 1979; Maddox & Douglass, 1973), the limited number of possible responses (four) restricted expression of one's physical health. It is possible that the single-item measure with four fixed responses was not sufficiently sensitive to assess gradations in health among the study sample. It is also possible that the single-item measure used to assess overall physical health may not have been an adequate reflection of the concept.

The relationship between social support and psychological health was not unlike findings of other researchers (Ben-Sira & Eliezer, 1990; Lambert, Lambert, Klipple & Mewshaw, 1989; Ploeg & Faux, 1989; Waltz, Badura, Pfaff, & Schott, 1988). Social support had a moderately strong association with psychological health. The higher the level of perceived social support, the less likely the person was to experience depressive symptomatology. Although a relationship between social support and
psychological health was demonstrated, it cannot be argued based on the results of this study, that social support precipitated a higher level of psychological health. The cause and effect association between social support and psychological health was not addressed.

A moderately strong relationship was demonstrated between social support and psychosocial health. The higher the level of perceived social support, the less likely the person was to view life events in the previous month as stressful. Again, the cause and effect association between social support and psychosocial health was not possible to examine in this study. Perhaps, a greater level of psychosocial health allowed one to develop more intense supportive relationships. Conversely, perhaps a higher level of social support fostered a greater degree of psychosocial health. These issues were not the intent of this study, but would undoubtedly contribute to the knowledge base concerning the relationship between social support and health.

Factors Influencing Social Support and Health Relationship

The second research question addressed factors that influence the relationship between perceived social support and perceived health. Since only a small percent of the variance in physical health could be attributed to social support, gender, degree of disability, age, degree of
rurality, and income, it is suggested there are other factors of greater influence.

Older partners with lower incomes tended to have lower physical health scores. Old age is often associated with lower levels of physical health. However, it has been demonstrated that caregivers with longer caregiving experience have more physical health problems than those with less time dedicated to caregiving (Gaynor, 1990). Although it was beyond the scope of this study, perhaps aging and caregiving responsibilities create mutually reinforcing adverse effects on physical health of partners of people with chronic illnesses.

The relationship between higher incomes and higher levels of physical health was similar to the results reported by Robinson (1990). In Robinson's study, socioeconomic status was a significant predictor of caregiver burden, which was significantly related to health. Caregivers who reported lower burden reported better health. The association between income and higher levels of physical health among caregivers indicates the need to examine health issues for caregivers of varying income levels. Perhaps caregivers with higher financial resources are able to disperse the responsibilities of caregiving, which may lead to higher levels of physical health.

One-third of the variance in psychological health was attributed to social support, gender, degree of disability,
age, degree of rurality, and income. Variables having the greatest impact on psychological health included social support, gender, degree of disability, and age. Depressive symptomatology was greater among younger women with lower social support and whose partners had greater levels of disability. Revenson and Majerovitz (1991) reported somewhat different results among partners of people with rheumatoid arthritis. In their study, neither gender, disease severity of the patient nor age was significantly related to the partners’ depression. However, the interaction between disease severity of the patient and social support was highly significant, explaining 31 percent of the variance in partners’ psychological health. This suggests that disease severity and social support may collectively influence psychological health, although this was not demonstrated in this study.

Twenty-six percent of the variance in psychosocial health was attributed to social support, gender, degree of disability, age, degree of rurality and income. Variables having the greatest impact on psychosocial health included social support, gender, degree of disability, and age. Younger women with lower social support, and whose partners had a greater degree of disability perceived greater stress in the previous month. Of the six variables examined (social support, gender, degree of disability, age, degree of rurality, and income), social support clearly had the
greatest effect on psychosocial health and psychological health. This is valuable information for health care workers addressing health promotion strategies with partners of people with MS.

Differences in Social Support and Health by Gender

Social support, psychological health, and psychosocial health levels differed for women and men in this study. Women reported a higher level of social support than men, which is consistent with the results reported by Weinert and Long (1993). Women also reported a higher level of depressive symptomatology, and perceived life events as stressful to a greater degree than men. According to the conceptual framework used for this study, social support was hypothesized to have a positive effect on the health status of partners of people with multiple sclerosis. However, based on this finding, it is conceivable that something else may be happening. Perhaps higher levels of depression, higher levels of stress, or a combination of greater depression and greater stress prompt one to access social support resources.

It is conceivable that caregiving may affect women differently than it does men. Throughout history, women have often assumed many roles within a family, including nurturer, caregiver, mother, wife, and homemaker. The added responsibility of participating in the management of a
chronic, progressive, unpredictable disease may be perceived as overwhelming, which could potentially lead to greater stress and or depression. This may account for the higher level of depression and stress reported by the women in this study. It is also possible that women and men in this study perceived caregiving differently.

The fact that women had higher levels of depressive and stressful symptomatology and yet perceived greater social support could indicate that women are more likely than men to access social support resources during difficult times. Weinert and Long (1993) reported that men whose wives had MS not only reported less social support, but tended to handle problems on their own, and relied most heavily on their ill wives as their source of support. These men become particularly vulnerable to lower levels of health as their wives' disease progresses. Further research is indicated in this area.

**Nursing Implications**

The findings in this study indicate that there is an association between social support and the physical, psychological, and psychosocial health of partners of people with multiple sclerosis. Knowledge of these findings is valuable in that nursing care should include plans for fostering, facilitating, and evaluating the social support systems of partners experiencing a long-term illness. A
baseline social support and health assessment should be completed in the initial phase of the nurse-client relationship. Risk factors, such as an ineffective social support system, need to be identified. A plan of care that delineates strategies for health promotion and health maintenance among this at risk group needs to be instituted. Nursing interventions may include such things as assisting partners to identify and access social support resources. The formation of a social support group or an informational meeting may be appropriate. Counseling may be indicated. With appropriate assessment, planning, intervention, and evaluation, the health level of this group of people may be enhanced.

Age and income were significant predictors of physical health in this study. Partners who were older and had a lower income tended to have poorer physical health. The age of the partner and the family income level could be part of the initial social history. Recognition of these factors and their reported association with lower health levels may indicate the need to advocate on the patient's behalf. Assistance with accessing public funds may be necessary. Referrals to other members of the health care team might also be beneficial.

When considered together, social support and gender had a significant effect on physical health. An increase in social support was associated with an increase in physical
health for women, but not for men. Since social support seems to affect health differently in women and men, it is important to assess the partner's perception of social support. Partners' responses to interventions with their social support network must be evaluated on an on-going basis. Included in the family health assessment should be a description of the problem solving techniques used by the partner in the past. If a positive relationship with one's social support network is reported, the nurse may want to consider interventions which would allow continued participation in the relationship. Respite care or homemaker assistance may be indicated. If a negative experience with one's social support network is reported, the nurse and partner may need to pursue other options, based on the needs of the partner.

Social support, gender, degree of disability, and age were significant predictors of psychological health and psychosocial health, with social support having the strongest impact. Younger women with lower social support whose partners had greater disability tended to have lower levels of psychological health and lower levels of psychosocial health. An awareness of these findings may be beneficial in identifying high-risk families. Ongoing health monitoring, including an assessment of the partners' emotional health and psychosocial health is indicated. Nurses must be attentive and responsive to signs of
increasing depression and increasing stress. Partners who lack social support resources, and are experiencing increasingly greater levels of disability with their spouse, may be candidates for more intense nursing intervention.

The provision of assistance must be within a context that is accepted by the client. For example, men in particular, may need assistance establishing, accessing, and maintaining a social support network, other than their wives. It is important to gather data from the partner throughout this process. Involving partners in the creation of the care plan can optimize the chances of meeting the specific needs of each partner.

Recommendations for Future Research

This study was limited by the nonrandom sample. Therefore, generalization cannot be made beyond the study sample. Most of the study sample were middle age, Caucasian, well educated, and from middle income families, which is consistent with the general profile of partners of people with multiple sclerosis. Researchers are challenged to explore further the relationship between social support and health in the small number of people who are outside the general profile. Research is needed among people of different ages, with varying cultural beliefs, from different educational backgrounds, and from varying socioeconomic levels. Future quantitative and qualitative
longitudinal studies are also needed to evaluate the relationship between social support and health over the disease trajectory.

One of the limitations in this study was the use of a single-item scale to measure physical health. Perhaps a more sensitive scale with known internal-reliability and validity would have yielded different results. Future researchers might want to examine the relationship of social support and physical health utilizing subjective and objective measurements of health.

The nature and course of chronic illnesses differ. For example, the course of some chronic illnesses is relatively stable, while others are characterized with bouts of remissions and exacerbations. Because of the variation in the nature and course of chronic illnesses, the needs of the partners are also likely to differ. Further research concerning the relationship between social support and health of partners of people experiencing various chronic illnesses is needed.

The researcher chose to examine the influence that social support, gender, degree of disability, age, degree of rurality, and income had on the relationship between perceived social support and perceived health. More research is needed to detect other factors affecting this relationship.
Nurses are in key positions to help partners live with the ongoing demands associated with their loved one’s ongoing illness. To meet the unique needs of partners of chronically ill persons effectively, nursing interventions intended to benefit this group of people will need to be supported by research.

Conclusion

Results from this study add further support to the volume of research linking social support and health. A notable relationship was demonstrated between social support and psychological health, and between social support and psychosocial health. Not only did social support have an impact on psychological and psychosocial health, but it also was a profound predictor of psychological and psychosocial health.

Partners of people with multiple sclerosis are faced with numerous challenges, which can be overwhelming. Stressors, in the absence of social support, can jeopardize one’s physical, psychological, and or psychosocial health status. Because of this, nurses are challenged to incorporate social support into the treatment plan for partners of people with multiple sclerosis. Continued research in this area is needed to optimize the health status of those experiencing a chronic illness with a loved one.


APPENDIX A

HUMAN SUBJECTS LETTER OF APPROVAL FOR PRIMARY STUDY
January 7, 1994

TO: Clarann Weinert
FROM: Stephen Guggenheim
Chair, Human Subjects Committee

SUBJ: Families Living With Long-Term Illnesses: A National Study

The above proposal has been reviewed and approved by the Human Subjects Committee for a period of one year. At the end of this period you will receive a followup form which will be used to evaluate this proposal for renewal. Please remember that subjects should receive a copy of the consent form. If there are any changes in the research protocol or if there are any adverse effects of the research on the subjects, the committee should be informed as soon as possible.
APPENDIX B

INSTRUMENTS
The next questions are about you.

Q-01. Which of the following best describes your racial or ethnic identification?

1. CAUCASIAN/WHITE
2. AFRO-AMERICAN
3. HISPANIC/MEXICAN AMERICAN
4. ASIAN AMERICAN
5. NATIVE AMERICAN INDIAN
6. OTHER (please specify) __________________________

Q-02. What is your present marital status?

1. MARRIED
2. DIVORCED
3. SEPARATED
4. WIDOWED
5. NEVER MARRIED
6. COMMON-LAW
7. LIVING TOGETHER

Q-03. How long have you been in your present marital status?

____ NUMBER OF YEARS

Q-04. How many years of school have you completed?

____ NUMBER OF YEARS OF SCHOOL

Q-05. What is the highest degree you have earned?

1. HIGH SCHOOL DIPLOMA
2. GED
3. ASSOCIATE ARTS DEGREE
4. BACHELORS DEGREE
5. MASTERS DEGREE
6. DOCTORAL DEGREE
7. VOCATIONAL TRAINING CERTIFICATE
8. NO DEGREE
Q-06. What is your employment status? Please CIRCLE only ONE choice.

1 I WORK FULL-TIME FOR PAY (Includes farm/ranch work)
2 I WORK PART-TIME FOR PAY (Includes farm/ranch work)
3 I AM A FULL-TIME HOMEMAKER
4 I AM A FULL-TIME HOMEMAKER AND ALSO HELP WITH FARM/RANCH WORK
5 I AM A FULL-TIME HOMEMAKER AND WORK PART-TIME AT ANOTHER JOB
6 I AM UNEMPLOYED DUE TO AGE
7 I AM UNEMPLOYED DUE TO DISABILITY
8 I AM LAID OFF
9 I HAVE BEEN FIRED
10 I AM A FULL-TIME STUDENT
11 I AM A STUDENT (FULL OR PART-TIME) AND ALSO WORK FOR PAY (Includes farm/ranch work)
12 I HAVE BEEN UNABLE TO FIND SUITABLE WORK BECAUSE OF WHERE I LIVE
13 I AM RETIRED

Q-07. If you answered Q-06 with a 1, 2, 4, 5, 11, how many hours per week do you usually work for pay?

_____ HOURS PER WEEK

Q-08. If you work, in what kind of business or industry do you work (e.g. retail shoe store, custodial service, breakfast cereal manufacturing, ranch/farm)?

________________________

Q-09. I do volunteer work approximately _____ HOURS PER WEEK.

Q-10. What type of volunteer work do you do?

________________________

Q-11. What is your date of birth?

______/______/______
MONTH DAY YEAR
Q-12. Your gender.

1. WOMAN
2. MAN
Now here are some questions about your family and yourself.

Q-01. How far must you and your family travel for emergency medical care?

_________ NUMBER OF MILES (one way)

_________ APPROXIMATE TRAVEL TIME

Please describe your source of emergency care (For example: Nurse Practitioner, Hospital, Physician’s office, etc.)

Q-02. How far must you and your family travel for routine health care? (For example: physical exam, dental work, immunization)

_________ NUMBER OF MILES (one way)

_________ APPROXIMATE TRAVEL TIME

Q-03. Counting all sources of income, including wages, interest, welfare payments, and gifts, etc., what was your total family income during 1992? (CIRCLE one number)

1 LESS THAN $15,000
2 $15,000 TO $19,999
3 $20,000 TO $24,999
4 $25,000 TO $29,999
5 $30,000 TO $34,999
6 $35,000 TO $39,999
7 $40,000 TO $44,999
8 $45,000 TO $49,999
9 $50,000 TO $54,999
10 $55,000 TO $59,999
11 $60,000 TO $64,999
12 $65,000 TO $69,999
13 $70,000 TO $74,999
14 $75,000 TO $79,999
15 OVER $80,000
Q-04. How many children live IN YOUR HOUSEHOLD at this time?

NUMBER OF CHILDREN LIVING HERE _______

Please fill in the age and gender of the oldest child CURRENTLY LIVING IN YOUR HOUSEHOLD. Continue filling in each line with the second oldest, the third oldest and so forth.

AGE OF OLDEST CHILD    _______ GENDER OF OLDEST CHILD: GIRL BOY
AGE OF SECOND CHILD     _______ GENDER OF SECOND CHILD: GIRL BOY
AGE OF THIRD CHILD      _______ GENDER OF THIRD CHILD: GIRL BOY
AGE OF FOURTH CHILD     _______ GENDER OF FOURTH CHILD: GIRL BOY
AGE OF YOUNGEST CHILD   _______ GENDER OF YOUNGEST CHILD: GIRL BOY

Q-05. Are there others living in your household besides your spouse and the children listed in Q-04?

2 NO
1 YES

_________ NUMBER OF PERSONS

_________ AGES OF PERSONS

Q-06. How long have you and your family lived in your present home?

_________ NUMBER OF YEARS

Q-07. How many addresses have you and your family had in the past five years?

1 ONE
2 TWO
3 THREE
4 FOUR
5 FIVE
6 SIX OR MORE
Q-08. Please help us understand where you live. Check ONLY ONE option form "a" to "e" and fill in the requested information for that option, then complete "f" and "g".

a.____ WE LIVE IN A CITY/TOWN WITH AN APPROXIMATE POPULATION OF _______.

b.____ WE LIVE IN A SUBURBAN AREA OR A COMMUNITY THAT IS CONSIDERED AN EXTENSION OF ANOTHER MAJOR CITY. THE POPULATION OF THE SUBURBAN AREA IN WHICH WE LIVE IS _______ AND THE POPULATION OF THE MAJOR CITY IS _______.

c.____ WE LIVE OUTSIDE THE CITY LIMITS OF A CITY/TOWN OF APPROXIMATELY _______ NUMBER OF PEOPLE. THE CITY/TOWN IS ABOUT _______ MILES FROM OUR HOME.

d.____ WE LIVE ON A FARM/RANCH THAT IS ABOUT _______ MILES FROM A CITY/TOWN. THE POPULATION OF THAT CITY/TOWN IS _______ NUMBER OF PEOPLE.

e.____ OTHER (Please describe) __________________________

f.____ COUNTY OF YOUR RESIDENCE: _______

g.____ STATE OF YOUR RESIDENCE: _______

Q-09. I would describe myself as living: (Please CIRCLE only ONE response.)

1 ON A FARM/RANCH
2 IN A RURAL AREA (NOT ON A FARM/RANCH)
3 IN A SMALL RURAL TOWN
4 IN A SMALL TOWN
5 IN A MEDIUM SIZE CITY
6 IN A LARGE CITY
7 IN A SUBURBAN AREA
8 IN A MAJOR METROPOLITAN AREA
PERSONAL RESOURCE QUESTIONNAIRE—Part 2
Brandt and Weinert

Below are some statements with which some people agree and others disagree. Please read each statement and circle the response most appropriate for you. There is no right or wrong answer.

1 STRONGLY DISAGREE
2 DISAGREE
3 SOMEWHAT DISAGREE
4 NEUTRAL
5 SOMEWHAT AGREE
6 AGREE
7 STRONGLY AGREE

1. There is someone I fell close to who makes me feel secure ............ 1 2 3 4 5 6 7

2. I belong to a group in which I feel important ....................... 1 2 3 4 5 6 7

3. People let me know that I do well at my work (job, homemaking) ...... 1 2 3 4 5 6 7

4. I can’t count on my relatives and friends to help me with problems.... 1 2 3 4 5 6 7

5. I have enough contact with the person who makes me feel special.... 1 2 3 4 5 6 7

6. I spend time with others who have the same interests that I do........ 1 2 3 4 5 6 7

7. There is little opportunity in my life to be giving and caring to another person ......................... 1 2 3 4 5 6 7

8. Others let me know that they enjoy working with me (job, committees, projects) ........................ 1 2 3 4 5 6 7

9. There are people who are available if I needed help over an extended period of time .................. 1 2 3 4 5 6 7

10. There is no one to talk to about how I am feeling .................. 1 2 3 4 5 6 7
11. Among my group of friends we do favors for each other.................. 1 2 3 4 5 6 7

12. I have the opportunity to encourage others to develop their interests and skills.............................. 1 2 3 4 5 6 7

13. My family lets me know that I am important for keeping the family running.................................. 1 2 3 4 5 6 7

14. I have relatives or friends that will help me out even if I can’t pay them back.......................... 1 2 3 4 5 6 7

15. When I am upset there is someone I can be with who lets me be myself................................. 1 2 3 4 5 6 7

16. I feel no one has the same problems as I......................................................... 1 2 3 4 5 6 7

17. I enjoy doing little "extra" things that make another person’s life more pleasant.......................... 1 2 3 4 5 6 7

18. I know that others appreciate me as a person..................................................... 1 2 3 4 5 6 7

19. There is someone who loves and cares about me................................................. 1 2 3 4 5 6 7

20. I have people to share social events and fun activities with.................. 1 2 3 4 5 6 7

21. I am responsible for helping provide for another person’s needs........ 1 2 3 4 5 6 7

22. If I need advice there is someone who would assist me to work out a plan for dealing with the situation........................................ 1 2 3 4 5 6 7

23. I have a sense of being needed by another person.............................................. 1 2 3 4 5 6 7

24. People think that I’m not as good a friend as I should be........................... 1 2 3 4 5 6 7

25. If I got sick, there is someone to give me advice about caring for myself...................................................... 1 2 3 4 5 6 7
Q-1. In general, would you say you health is excellent, good, fair, or poor?

1 POOR
2 FAIR
3 GOOD
4 EXCELLENT
CES-D
Center for Epidemiological Studies

This series of questions is about your feelings and how often you experienced them in the PAST WEEK. Answer each question, but do not spend a great deal of time on any one question.

<table>
<thead>
<tr>
<th>RARELY</th>
<th>SOME OR</th>
<th>MODERATE</th>
<th>MOST</th>
</tr>
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<tr>
<td>OR NONE</td>
<td>LITTLE</td>
<td>AMOUNT</td>
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<td>TIME</td>
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<td>(LESS</td>
<td>THAN</td>
<td>(1-2</td>
<td>(3-4</td>
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<td>1X/DAY)</td>
<td>DAYS)</td>
<td>DAYS)</td>
<td>DAYS)</td>
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</tbody>
</table>

Q-1. I was bothered by things that usually don’t bother me...........

Q-2. I did not feel like eating; my appetite was poor.............

Q-3. I felt that I could not shake off the blues even with help from my family or friends.

Q-4. I felt that I was just as good as other people......

Q-5. I had trouble keeping my mind on what I was doing..

Q-6. I felt depressed..

Q-7. I felt that everything I did was an effort.....
<table>
<thead>
<tr>
<th>Question</th>
<th>Description</th>
<th>Rarely</th>
<th>Occasionally</th>
<th>Moderately</th>
<th>Most</th>
<th>(Less Than 1 Day)</th>
<th>(1-2 Days)</th>
<th>(3-4 Days)</th>
<th>(5-7 Days)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q-8</td>
<td>I felt hopeful about the future...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
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<tr>
<td>Q-9</td>
<td>I thought my life had been a failure...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<td></td>
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<tr>
<td>Q-10</td>
<td>I felt fearful...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Q-11</td>
<td>My sleep was restless...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Q-12</td>
<td>I was happy...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Q-13</td>
<td>I talked less than usual...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>Q-14</td>
<td>I felt lonely...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
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<td>Q-15</td>
<td>People were unfriendly...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
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<tr>
<td>Q-16</td>
<td>I enjoyed life...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td></td>
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<td>Q-17</td>
<td>I had crying spells...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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<tr>
<td>Q-18</td>
<td>I felt sad...</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
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This series of questions asks you about your feelings and thoughts during the LAST MONTH. In each case, you will be asked to indicate how often you felt or thought a certain way. Although some of the questions are similar, there are differences between them and you should treat each one as a separate question. The best approach is to answer each question fairly. That is, do not try to count up the number of times you felt a particular way, but rather indicate the response alternative that seems like a reasonable estimate.

0 NEVER
1 ALMOST NEVER
2 SOMETIMES
3 FAIRLY OFTEN
4 VERY OFTEN

Q-1. In the last month, how often have you been upset because of something that happened unexpectedly?........... 0 1 2 3 4

Q-2. In the last month, how often have you felt that you were unable to control the important things in your life?..................... 0 1 2 3 4

Q-3. In the last month, how often have you felt nervous and "stressed?"........... 0 1 2 3 4

Q-4. In the last month, how often have you dealt successfully with irritating life hassles?..................... 0 1 2 3 4

Q-5. In the last month, how often have you felt that you were effectively coping with important changes that were occurring in your life?........... 0 1 2 3 4

Q-6. In the last month, how often have you felt confident about your ability to handle your personal problems?........... 0 1 2 3 4

Q-7. In the last month, how often have you felt confident that things were going your way?..................... 0 1 2 3 4

Q-8. In the last month, how often have you found that you could not cope with all the things that you had to do?.... 0 1 2 3 4
Q-9. In the last month, how often have you been able to control irritations in your life? ..................... 0 1 2 3 4

Q-10. In the last month, how often have you felt that you were on top of things?.. 0 1 2 3 4

Q-11. In the last month, how often have you been angered because of things that happened that were outside of your control? ......................... 0 1 2 3 4

Q-12. In the last month, how often have you found yourself thinking about things that you have to accomplish?......... 0 1 2 3 4

Q-13. In the last month, how often have you been able to control the way you spend your time? ..................... 0 1 2 3 4

Q-14. In the last month, how often have felt difficulties were piling up so high that you could not overcome them?..... 0 1 2 3 4
MINIMAL RECORD OF DISABILITY IN MULTIPLE SCLEROSIS
International Federation of Multiple Sclerosis Societies

Below are a list of activities of daily living. For each activity please CIRCLE the number which best indicates your level of ability.

Q-1. **Stair Climbing** - Ability to ascend and descend 12 steps.

0 NORMAL
1 SOME DIFFICULTY BUT PERFORMED WITHOUT AID
2 NEED FOR CANES, BRACES, PROSTHESIS, OR DEPENDENT UPON BANISTER TO PERFORM
3 NEED HUMAN ASSISTANCE TO PERFORM
4 UNABLE TO PERFORM; INCLUDES MECHANICAL LIFTS

Q-2. **Ambulation** - Ability to walk on level ground indoors some 50 feet without rest.

0 NORMAL
1 SOME DIFFICULTY BUT PERFORMED WITHOUT AID
2 NEED FOR CANES, BRACES, PROSTHESIS TO PERFORM
3 NEED FOR HUMAN ASSISTANCE OR USE OF MANUAL WHEELCHAIR WHICH PATIENT ENTERS, LEAVES, AND MANEUVERS WITHOUT AID
4 UNABLE TO PERFORM; INCLUDES PER AMBULATION WITH A WHEELCHAIR AND MOTORIZED WHEELCHAIR

Q-3. **Toilet/Chair/Bed Transfer** - Ability to enter and leave regular toilet, chair and/or bed; includes wheelchair transfer as indicated. The worst transfer function determines the grade.

0 NORMAL
1 SOME DIFFICULTY BUT PERFORMED WITHOUT AID
2 NEED FOR ADAPTIVE OR ASSISTIVE DEVICES SUCH AS TRAPEZE, SLING, BARS, LIFT, SLIDING BOARD TO PERFORM
3 REQUIRES HUMAN AID TO PERFORM
4 MUST BE LIFTED OR MOVED ABOUT COMPLETELY BY ANOTHER PERSON
Q-4. Bowel Function

0 NORMAL
1 BOWEL RETENTION NOT REQUIRING MORE THAN HIGH FIBER DIETS, LAXATIVES, OCCASIONAL ENEMAS OR SUPPOSITORIES, SELF-ADMINISTERED
2 BOWEL RETENTION REQUIRING REGULAR LAXATIVES, ENEMAS, OR SUPPOSITORIES, SELF-ADMINISTERED, IN ORDER TO INDUCE EVACUATION; CLEANSES AND DISIMPACTS SELF
3 BOWEL RETENTION REQUIRING ENEMAS OR SUPPOSITORIES ADMINISTERED BY ANOTHER; DISIMPACTED BY ANOTHER; NEED ASSISTANCE IN CLEANSING; OCCASIONAL INCONTINENCE; PRESENCE OF COLOSTOMY TENDED BY SELF
4 FREQUENT SOILING DUE EITHER TO INCONTINENCE OR A POORLY MAINTAINED OSTOMY DEVICE OR AN OSTOMY DEVICE WHICH YOU CANNOT MAINTAIN WITHOUT ASSISTANCE

Q-5. Bladder Function

0 NORMAL (EVEN IF MAINTAINED BY DRUGS)
1 OCCASIONAL HESITANCY OR URGENCY; OCCASIONAL NEED FOR DRUGS
2 FREQUENT HESITANCY, URGENCY, OR RETENTION; USE OF INDWELLING OR EXTERNAL CATHETER APPLIED AND MAINTAINED BY SELF; INTERMITTENT SELF-CATHETERIZATION, MANUAL COMPRESSION TO EVACUATE BLADDER, REGULAR USE OF DRUGS
3 OCCASIONAL INCONTINENCE; USE OF INDWELLING OR EXTERNAL CATHETER APPLIED AND MAINTAINED BY OTHERS; ILEOSTOMY OR SUPRAPUBIC CYSTOSTOMY MAINTAINED BY SELF; INTERMITTENT CATHETERIZATION BY OTHERS
4 FREQUENT INCONTINENCE; OSTOMY DEVICE WHICH PATIENT CANNOT MAINTAIN WITHOUT ASSISTANCE

Q-6. Bathing

0 NORMAL
1 SOME DIFFICULTY WITH WASHING AND DRYING SELF THOUGH PERFORMED WITHOUT AID WHETHER IN TUB OR SHOWER OR BY SPONGE-BATHING, WHICHEVER IS USUAL FOR YOU
2 NEED FOR ASSISTIVE DEVICES (TRAPEZE, SLING, LIFT, SHOWER OR TUB BAR) IN ORDER TO BATHE YOURSELF; NEED TO BATHE OUTSIDE OF TUB OR SHOWER IF THAT IS THE USUAL METHOD
3 NEED FOR HUMAN ASSISTANCE IN BATHING PARTS OF THE BODY OR IN ENTRY/EXIT/POSITIONING IN TUB OR SHOWER
4 BATHING PERFORMED BY OTHERS (ASIDE FROM FACE AND HANDS)
Q-7. **Dressing**

0  NORMAL
1  SOME DIFFICULTY CLOTHING YOURSELF COMPLETELY IN STANDARD GARMENTS, BUT ACCOMPLISHED BY YOURSELF
2  SPECIALLY ADAPTED CLOTHING (SPECIAL CLOSURES, ELASTIC-LACED SHOES, FRONT-CLOSING GARMENTS) OR DEVICES (LONG SHOE HORNS, ZIPPER EXTENDERS) REQUIRED TO DRESS YOURSELF
3  NEED FOR HUMAN AID TO ACCOMPLISH; PERFORM CONSIDERABLE PORTION YOURSELF
4  NEED FOR ALMOST COMPLETE ASSISTANCE; UNABLE TO DRESS YOURSELF

Q-8. **Grooming** - Care of teeth or dentures and hair, shaving, application of cosmetics.

0  NORMAL
1  SOME DIFFICULTY BUT ALL TASKS PERFORMED WITHOUT AID
2  NEED FOR ADAPTIVE DEVICES (ELECTRIC RAZORS OR TOOTHBRUSHES, SPECIAL COMBS OR BRUSHES, ARM RESTS SLINGS) BUT PERFORMED WITHOUT AID
3  NEED FOR HUMAN AID TO PERFORM SOME OF THE TASKS
4  ALMOST ALL TASKS PERFORMED BY ANOTHER PERSON

Q-9. **Feeding** - Ingestion, mastication, swallowing, of solids and liquids, and manipulation of appropriate utensils.

0  NORMAL
1  SOME DIFFICULTY BUT PERFORMED WITHOUT AID
2  NEED FOR ADAPTIVE DEVICES (SPECIAL FEEDING UTENSILS, STRAWS OR SPECIAL PREPARATION, PORTIONS PRE-CUT OR MINCED, BREAD BUTTERED) TO FEED YOURSELF
3  NEED FOR HUMAN AID IN THE DELIVERY OF FOOD; DYSPHAGIA PREVENTING SOLID DIET; ESOPHAGOSTOMY OR GASTROSTOMY MAINTAINED AND UTILIZED BY YOURSELF; TUBE-FEEDING PERFORMED BY YOURSELF
4  UNABLE TO FEED YOURSELF OR TO MANAGE OSTOMIES
Q-10. **Vision** - Rate on the basis of the worse of either visual acuity or diplopia.

0 NORMAL VISION. CAN READ PRINT FINER THAN STANDARD NEWSPRINT WITH OR WITHOUT CORRECTIVE LENSES. NO DIPLOPIA.
1 CANNOT READ PRINT FINER THAN STANDARD NEWSPRINT EVEN WITH CORRECTIVE LENSES. OCCASIONAL DIPLOPIA
2 MAGNIFYING LENSES OR LARGE PRINT NECESSARY FOR READING. FREQUENT DIPLOPIA
3 CAN ONLY READ VERY LARGE PRINT SUCH AS MAJOR NEWSPAPER HEADLINES. CONSTANT DIPLOPIA OR MOVEMENT OF OBJECTS
4 LEGAL BLINDNESS

Q-11. **Speech and Hearing** - Verbal output and input for interpersonal communication purposes.

0 NORMAL; NO SUBJECTIVE HEARING LOSS; ARTICULATION AND LANGUAGE APPROPRIATE TO CULTURE
1 IMPAIRED HEARING OR ARTICULATION NOT INTERFERING WITH COMMUNICATION
2 DEAFNESS SUFFICIENT TO REQUIRE HEARING AID AND/OR DYSARTHRIA INTERFERING WITH COMMUNICATION. NEED COMMUNICATION AIDS SUCH AS SPECIAL KEYBOARD, ETC.
3 SEVERE DEAFNESS COMPENSATED FOR BY SIGN LANGUAGE OR LIP READING FACILITY AND/OR SEVER DYSARTHRIA COMPENSATED FOR BY SIGN LANGUAGE OR SELF-WRITTEN COMMUNICATION
4 SEVERE DEAFNESS AND/OR DYSARTHRIA WITHOUT EFFECTIVE COMPENSATION

Q-12. **Medical Problems** - Presence of general medical and/or neurological and/or orthopedic disorders. This would include MS as well as MS related problems such as decubiti, contractures, and urinary tract infections.

0 NO SIGNIFICANT DISORDER PRESENT
1 DISORDER(S) NOT REQUIRING ACTIVE CARE; MAY BE ON MAINTENANCE MEDICATION; MONITORING NOT REQUIRED MORE OFTEN THAN EVERY THREE MONTHS
2 DISORDER(S) REQUIRING OCCASIONAL MONITORING BY PHYSICIAN OR NURSE, MORE OFTEN THAN EVERY THREE MONTHS BUT LESS OFTEN THAN WEEKLY
3 DISORDER(S) REQUIRING REGULAR ATTENTION (AT LEAST WEEKLY) BY PHYSICIAN OR NURSE
4 DISORDER(S) REQUIRING ESSENTIALLY DAILY ATTENTION BY PHYSICIAN OR NURSE USUALLY IN A HOSPITAL
Q-13. Mood and Thought - This includes anxiety, depression, mood swings, euphoria, delusions, hallucinations, and thought disorders. The rating should reflect current behavior even if you are being maintained on medication.

0  NO OBSERVABLE PROBLEMS
1  DISTURBANCE IS PRESENT AT TIMES, BUT DOES NOT INTERFERE WITH DAY TO DAY FUNCTIONING
2  DISTURBANCE DOES INTERFERE WITH DAY TO DAY FUNCTIONING, BUT YOU CAN MANAGE WITHOUT PROFESSIONAL ASSISTANCE EXCEPT FOR OCCASIONAL VISITS TO MAINTAIN MEDICATION
3  DISTURBANCE INTERFERES WITH DAY TO DAY FUNCTIONING AND CONSISTENTLY REQUIRES PROFESSIONAL INTERVENTION BEYOND THAT REQUIRED TO MAINTAIN MEDICATION; E.G., REQUIRES PSYCHOTHERAPY OR HOSPITALIZATION
4  DESPITE MEDICATION AND/OR OTHER INTERVENTION, DISTURBANCE IS SEVERE ENOUGH TO PRECLUDE DAY TO DAY FUNCTIONING

Q-14. Mentation - Disturbances in memory, reasoning, calculation, judgement, or orientation.

0  NO OBSERVABLE PROBLEM
1  DISTURBANCE IS PRESENT BUT DOES NOT INTERFERE WITH PERFORMANCE OF EVERYDAY ACTIVITIES
2  DISTURBANCE INTERFERES WITH PERFORMANCE OF EVERYDAY ACTIVITIES; YOU MAY NEED TO USE LISTS OR OTHER PROMPTING DEVICES, BUT MANAGE WITHOUT THE HELP OF OTHER PEOPLE; YOU ARE LIKELY TO BE A POOR HISTORIAN
3  DISTURBANCE IS SEVERE ENOUGH TO REQUIRE PROMPTING OR ASSISTANCE FROM OTHERS FOR PERFORMANCE OF EVERYDAY ACTIVITIES
4  DISTURBANCE PRECLUDES THE PERFORMANCE OF MOST EVERYDAY ACTIVITIES; MAY INCLUDE SEVERE CONFUSIONS, DISORIENTATION, OR MEMORY LOSS

Q-15. Fatigability

0  NO FATIGABILITY
1  FATIGABILITY PRESENT BUT DOES NOT NOTABLY INTERFERE WITH BASELINE PHYSICAL FUNCTION
2  FATIGABILITY CAUSING INTERMITTENT AND GENERALLY TRANSIENT IMPAIRMENT OF BASELINE PHYSICAL FUNCTION
3  FATIGABILITY CAUSING INTERMITTENT TRANSIENT LOSS OR FREQUENT MODERATE IMPAIRMENT OF BASELINE PHYSICAL FUNCTION
4  FATIGABILITY WHICH GENERALLY PREVENTS PROLONGED OR SUSTAINED PHYSICAL FUNCTION
Q-16. Sexual Function

0 SEXUALLY ACTIVE AS BEFORE AND/OR NOT EXPERIENCING SOME SEXUAL PROBLEMS. NO CHANGES IN USUAL PATTERN OF SEXUAL ACTIVITY, E.G., NO CHANGES IN FREQUENCY AND TYPE OF SEX ACTIVITIES; NO CHANGES IN PREVIOUS GENITAL SENSATION, ERECTIONS, AND EJACULATION IN MEN, AND VAGINAL LUBRICATION AND ORGASM IN WOMEN. THIS INCLUDES PERSONS WITHOUT PREVIOUS SEXUAL EXPERIENCE

1 SEXUALLY LESS ACTIVE THAN BEFORE, AND/OR NOW EXPERIENCING SOME SEXUAL PROBLEMS BUT NOT CONCERNED. LESS FREQUENT OR LESS VARIED SEXUAL ACTIVITY; AND/OR SOME CHANGES IN PREVIOUS GENITAL SENSATION, ERECTION, AND EJACULATION IN MEN, AND VAGINAL LUBRICATION AND ORGASM IN WOMEN BUT DOES NOT CONSIDER THIS AN ISSUE. MAY BE USING A PROSTHESIS OR SEXUAL AIDS

2 SEXUALLY LESS ACTIVE THAN BEFORE, AND NOW EXPERIENCING SOME SEXUAL PROBLEMS AND CONCERNED. WOULD LIKE TO REGAIN FORMER SEXUAL ACTIVITY PATTERN AND/OR WOULD LIKE TO REGAIN PREVIOUS GENITAL SENSATIONS, ERECTION, EJACULATION, AND/OR ORGASMIC EXPERIENCES

3 SEXUALLY INACTIVE BUT STILL CONCERNED. SEXUAL ACTIVITY HAS CEASED FOR WEEKS, MONTHS, OR YEARS, BUT YOU WISH TO REGAIN PREVIOUS PATTERN AND FUNCTIONAL ABILITY

4 SEXUALLY INACTIVE AND NOT CONCERNED. SEXUAL ACTIVITY HAS CEASED FOR SEVERAL WEEKS, MONTHS, OR YEARS, BUT YOU DO NOT CONSIDER THIS AN ISSUE.
APPENDIX C

HUMAN SUBJECTS LETTER OF APPROVAL
April 17, 1995

TO: Laura Burns

FR: Marty Rhea, PhD, RN, CS
Interim Chair, College of Nursing Human Subjects Committee

RE: Proposal

The College of Nursing Human Subjects Committee met on Monday, April 17, 1995 at which time your proposal was considered. The Committee has ruled your research as exempt. You may proceed with your project immediately.

The Committee wishes you success and looks forward to learning of your results!
APPENDIX D

CONSENT LETTER TO USE SELECTED DATA
March 24, 1995

Laura Burns, BSN, RN
625 Coyote Lane
Great Falls, MT 59404

Dear Ms. Burns:

Thank you for your request to use a portion of the Family Health Study 1993 data. Please know that I am delighted that you will be using these data. I look forward to working with you on the analysis and to your contributions to our research efforts. I will prepare for you a SPSS file containing the appropriate demographic information, the health data, the Perceived Stress scale, the Personal Resource Questionnaire, the CES-D scale for the partners of persons with MS.

All data must be returned to the Family Health Study following your research. In addition, it is expect that within one year of completion of your thesis you will have a manuscript out for publication. I will be happy to co-author with you or help you in any way that I can in the preparation of a manuscript. If you do not meet the one year deadline the right to publish returns to the project and we will prepare a manuscript based on your research.

Again, know that you are most welcome to be part of our research efforts. I look forward to your results and to seeing your thesis research to a successful completion.

Sincerely,

Clarann Weinert, SC, PhD, RN, FAAN
Principal Investigator