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

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.

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ABSTRACT

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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.

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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