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Case Western Reserve University, 1990
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CAREGIVING IN CHRONIC ILLNESS:
THE EXPERIENCE OF MARRIED PERSONS WHOSE SPOUSES HAVE MS

by
DEBORAH M. MILLER

Submitted in partial fulfillment of the requirements
for the Degree of Doctor of Philosophy

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CAREGIVING AND SUBJECTIVE BURDEN:
THE EXPERIENCE OF MARRIED PERSONS WHOSE SPOUSES HAVE MS

Abstract
by
DEBORAH M. MILLER

Multiple Sclerosis (MS) is among the most commonly disabling conditions of young adults. A neurological disease, its symptoms usually begin between 20 and 40. Physical symptoms include episodic visual loss, weakness, bowel and bladder dysfunction, loss of coordination and gait disturbance. Approximately 50% to 60% of people with MS experience some difficulty in cognitive functioning. An estimated 250,000 Americans have the disease. Two-thirds are female.

Little information is available in the psychosocial literature about the family caregivers of persons disabled by MS. The best information available is based
on clinical experience which indicates that spouses provide the majority of this family care. Consequently, spouses were made the focus of this investigation.

Demographic profiles of the family caregivers to the frail elderly and adults who have been disabled since childhood provide the basis for most profession long term care programs. These do not take into account the younger disabled population.

The current study of extends the understanding of family caregivers to a previously undescribed population. If these caregiving spouses differ in important ways from other family care providers, current health care programs and support programs may be inappropriate for the former group and fail to meet their needs.

This study had four purposes
* To examine the characteristics of married persons whose mates have MS
* To investigate the ways that these spouse caregivers participate in this caregiving responsibility

1Throughout the document spouses who do not have MS are referred to as "spouse caregivers". Spouses who are disabled by the disease are referred to as "MS patients". Although the purpose of this investigation was to establish the involvement of spouses as caregivers, this nomenclature was adopted for the sake of clarity and consistency.
* To describe the association of spouse caregivers' characteristics and their reactions to caregiving involvement
* To discuss the implications of these findings for current professional provision of long term care

Major findings from this data include:
* Spouses are the primary caregivers to working age MS patients who have significant physical and cognitive impairments
* Spouse caregivers have many role involvements, including full time employment, in addition to assisting their spouses
* Wife and husband caregivers provide very similar types and amounts of care
* The greatest amounts of explained variance of the time spent caregiving are produced by the physical and cognitive disability of the MS patient
* The greatest amount of explained variance of spouse caregiver burden is produced by that spouse's marital adjustment
This work is dedicated to John P. Conomy,
my mentor, advocate, and friend.
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Introduction

This study concerns the marriage partners or lifemates (spouse caregivers) of individuals who are significantly disabled by multiple sclerosis (MS). It describes the characteristics of these spouse caregivers, as well as their involvement in, and emotional response to, managing the care needs of their mates. The examination of this group of spouse caregivers is intended to be an initial exploration of the consequences of chronic illness and disability on the spouses of disabled persons who develop impairment after childhood and before old age. As will be documented in the following sections of this paper, this young to middle age disabled adult group is the least well described of the long term care population. Even less is known about their spouses, those individuals who are presumed to meet the majority of disabled people’s care needs.

Chronic care is a priority agenda in considerations of the American health care (Callahan and Wallack, 1981; Doty, Liu and Weiner, 1985; Issacs and Tames, 1986). Chronic conditions have become the prevalent form of illness since the availability of antibiotics, vaccinations and improved sanitary conditions has reduced
the impact of infectious or parasitic disease (Strauss, 1987). Chronic illnesses may appear at any age and must be thought of as conditions that require lifelong management. Although these chronic conditions have different phases including acute, comeback, stable, continually unstable, deteriorating and dying, only the acute illness phases are usually managed by health care professionals. Such acute care is often delivered in hospital. Strauss notes that in contrast, the majority of chronic illness management occurs at home and is provided by the ill persons and family members. He adds that chronic illness and its management "can and often does profoundly affect the lives of the ill and their families - financially, emotionally, sexually, biographically and in the running of a household or the raising of children." (p.34).

Although most individuals who require chronic care are aged, it is estimated that 23% of individuals age 25-64 experienced some limitation in the amount or kind of participation in their age appropriate major activity (Spiegel, 1987). Using earlier data, Coudrouglou and Poole (1985) used 1977 Census data to calculate that 14.3 million Americans 20-64 years of age are disabled.
The study of spouses of persons with MS can serve as a model of the consequences of family management of chronic illness among working age adults. It is assumed, but remains undocumented, that spouses are primary caregivers (provide the greatest number of hours of assistance) to disabled people of this age population. If, in fact, spouse caregivers are the primary caregivers to these disabled working age adults, they provide care under circumstances and with additional responsibilities that family caregivers to other generations of care recipients may not face. These distinguishing characteristics may in turn influence the type and amount of care provided by spouse caregivers to their disabled partners. Spouse caregiver availability for, and reaction to, involvement in providing chronic care has significant implications for those spouse caregivers, their disabled mates, other family members, and those individuals and agencies that constitute the long term care system. Following sections of this paper explore the nature of those characteristics that potentially distinguish these spouse care providers from other family caregivers to disability groups of different ages. A primary purpose of this research is to describe
the characteristics of those spouse caregivers who are married to persons with MS who became disabled while of working age. Another goal of the study is to explore the association of those spouse caregiver characteristics with spouse caregiver involvement in the provision of ongoing assistance to mates who are MS patients. An additional goal is to explore the association of those spouse caregiver characteristics with spouse caregiver emotional reaction to that caregiving.

The two national agencies which are most prominently involved in the provision of care to persons with MS and their families are the National Multiple Sclerosis Society and the Consortium of Multiple Sclerosis Centers. Representatives of these agencies are very concerned about spouse caregivers and have noted that the needs of these families, MS patients and their family caregivers alike, go unaddressed by most aspects of the long term care system (Consortium of Multiple Sclerosis Centers [CMSC], 1989; National Multiple Sclerosis Society [NMSS], 1988). Representatives of both agencies have noted that spouse caregivers to MS patients are in many important ways different than those family caregivers of two other
chronic care populations, the frail elderly and adults disabled since childhood.

These two latter disability groups and their family caregivers have been closely studied. Those research findings have influenced health care providers and policy makers in the development and delivery of chronic care services. Health care professional (CMSC, 1989; NMSS, 1988) involved in the management of MS are concerned that relevant characteristics of the spouse caregivers of the MS population which may influence their involvement in caregiving distinguish them from the family caregivers who have been studied. The same health care professionals are concerned that such differences should be demonstrated and considered in future health care and service delivery planning.

**Symptomatology of Multiple Sclerosis**

Multiple Sclerosis is the most commonly disabling neurological disease that affects young adults in America. The initial symptoms of the disease usually occur in individuals between 20 and 40 years of age. It is a disease that affects women twice as frequently as men (Baum and Rothchild, 1981; Booz-Allen and Hamilton,
Inc., 1980; Brunel-ARMS Research Unit, 1983).

Approximately 250,000 Americans have this illness. It is estimated that 2,000 to 5,000 Greater Cleveland residents are diagnosed as having MS, (Northeast Ohio Chapter, National Multiple Sclerosis Society statistics). However, because it is difficult to establish a confirmed diagnosis of MS, it is likely that the impact of the illness is understated by these figures.

Multiple sclerosis is difficult to accommodate and manage because of the nature of the disease (Brooks and Matson, 1987). The cause of the disease remains unknown and there is no available prevention or cure. It is difficult to predict the likely course of the disease for an individual at the time that person is diagnosed with MS (Herndon and Rudick, 1987). MS produces a variety of physical symptoms that include episodic visual loss, imbalance, weakness, sensory loss, bowel and bladder dysfunction, loss of upper extremity coordination and gait disturbance. At least one third of people with Multiple Sclerosis experience progressive neurological difficulty that causes inability to walk without assistance (Scheinberg, Giesser and Slater, 1983).
People who experience this kind of motor impairment face concurrent dependence for personal care, toileting, home management and getting around in their homes and communities (Kraft, Freal and Croyel, 1986; Frankel, 1984; Scheinberg and Smith, 1987). Often individuals are in their thirties and forties when they experience this level of disability (Herndon and Rudick, 1987). It is a time of life when couples are building careers, raising families, possibly managing a house payment, likely caring for an aged family member, and planning for retirement financial security. It is not a time of life when they are prepared to change, give-up, or take on unanticipated responsibilities, lose the companionship of a spouse to disability, or manage the financial consequences that disability can produce. Although it may not be unusual to contemplate adjustment to infirmity in old age, few couples of working age prepare themselves emotionally, financially or environmentally to manage such disability while in the "prime" of their lives. Approximately 50 to 60% of persons with MS experience some difficulty in cognitive functioning (Peyser and Poser, 1986; Rao, 1986). MS-produced cognitive impairment is not related to disease duration or physical
incapacity. Although cognitive changes produced by MS are usually minor, 10 to 20% of the MS population experience global impairment than affects ability to learn or remember new material, produces attention deficits, in combination with or in addition to visual/spatial difficulties. Individuals who are cognitively impaired to this extent are unable to plan, initiate or carry through complex tasks. Judgement and problem solving difficulties leave persons with such forms of cognitive impairment in need of close supervision. Because environmental complications from these cognitive deficits so significantly affect treatment planning and home management, it is important to assess cognitive functioning independent of physical functioning in MS patients.

Individuals and their families who confront MS face: an uncertain future that includes no effective ways to manage the disease; a normal life expectancy that will include progressive physical and/or cognitive disability; and the knowledge that the management of this disease and its consequences will be left almost entirely to the family.
Medical Management of Multiple Sclerosis

Because of the limits of current scientific and medical knowledge, individuals and families dealing with the consequences of MS are limited in the treatments, services and supports they can reasonably anticipate from the health care community. Health care for persons with MS focuses first on diagnostic confirmation and then on crisis management during acute phases of the disease. Consequently, medical care for MS is often initiated after the person has had a dramatic change in functional ability, an obvious infection or worsening bed sore. Much of this care is hospital-based. Often this approach to medical care does not aggressively incorporate health maintenance, physical restoration, cognitive rehabilitation, management of family reactions, or planning for long term care needs (Slater, 1980).

Care Needs and Sources of Help

Based on anecdotal evidence it is likely that families who care for individuals with MS provide assistance similar to the help relatives and friends give to other chronically ill people. Care needs of persons with MS (Herndon and Rudick, 1987; Kraft, Freal and
Croyel, 1986; Frankel, 1984; Scheinberg and Smith, 1987) are similar to the needs of other disabled people, like the frail elderly or adults disabled since childhood (Cantor, 1983; Stephens and Christianson, 1986; Stone, 1986; Stone, Cafferata and Sangl, 1987; The Travelers Companies, 1985). These typical needs have been described in various ways by Walker, McBride and Vichon (1977), Dunkel-Schetter (1984), Berrarra (1981), and Lawton, Moss, Fulcomer and Kleban (1982) and include: assistance with usual daily routines (ADL’s); assistance with personal care activities; emotional support; help understanding the condition and management strategies; and organizing the care that may be obtained from a variety of sources.

Available information indicates that among all married persons who are disabled, including the clinical impressions about persons with MS, spouses are the most frequent source of help (Cantor, 1983; CMSC, 1989; Johnson and Catalano, 1983; NMSS; 1988; Stephens and Christianson, 1986; Stoller and Earl, 1983; Stone, 1986; Stone, Cafferata and Sangl, 1987; The Travelers Companies, 1985). At onset, most persons affected by MS are married (National Multiple Sclerosis Society, 1989).
This finding is consistent with that of Ireys and Burr (1984) who report that most young adults who acquire a chronic disability have left their families of origin and that most of that group of emancipated young adults have married. The clinical experience of health care professionals involved in the comprehensive care of patients and families affected by MS indicates that, similar to married members other disabled groups, spouses assume primary caregiving responsibilities among married persons in this population (Miller, 1987; National Multiple Sclerosis Society, 1988). There are many apparent similarities between the spouse caregivers of MS patients and family caregivers to persons from other disability groups. However, it is important to determine if these similarities are outweighed by differences in the groups of caregivers to an extent that influences the amount and kind of care they provide as well as their reactions to that caregiving involvement.

Some of the relevant characteristics that are thought to distinguish these spouses from family members who manage care needs for the frail elderly or the developmentally delayed include the gender of the family caregiver; characteristics of the marriage at the time of
caregiving; and the roles and responsibilities in which the spouse caregivers usually participates. Other considerations that may be relevant include the availability of additional family caregivers and the availability of formal caregiving assistance. Financial considerations, including spouse caregiver need to assure income for the family and provide health insurance for the family and disabled spouse, are potentially significant.

Problem Statement

Family caregiving is an issue of concern in the psychosocial literature because of its significant position in the arena of long term care and because of impact that caregiving is thought to have on patient and caregiver well-being alike. Problems common to caregivers include the physical stress of caregiving as well as the emotional strain associated with it. That strain is thought to result from loss of personal time and conflict with other responsibilities (Morycz, 1985) Caregiver reaction can have significant consequences as well for the disabled persons. Such consequences can lead to the neglect, abuse, or decision to
institutionalize the disabled persons (Conomy, unpublished manuscript; Morycz, 1985).

Even though there is good reason to believe that spouses are most involved in meeting the care needs of MS patients or other disabled working age adults, such involvement has not been documented in the psychosocial literature. Factors that may influence availability or willingness to participate in spouse caregiving, such as satisfaction with the marriage or the impact of other responsibilities and personal interests of the spouse caregivers, have not been described among those married to MS patients. Neither have such spouse caregiver characteristics been described among the mates of any other disabled group of comparable age. Only a limited literature addresses the emotional reactions of the well spouses of this age group to the experience of having a disabled spouse. Because the involvement of spouses is assumed to be so crucial to the care of MS patients, it is important for health care providers to understand the availability and capacity of these spouse caregivers to provide care to their spouses who are MS patients. This knowledge will hopefully facilitate the development of reasonable plans of care and service delivery mechanisms
that take into account the realities of the lives of people of this age; do not place unreasonable expectations on the spouse caregivers; and do not harm the well-being of either the spouse caregivers or the MS patients.

MS is a disease that affects women more frequently than it does men (Kurtzke, 1965). Husbands are called upon to provide care during a life phase when they have a tradition of limited involvement in such caregiving activities for either their children or aged parents. This can have major implications in the MS population if husbands are unwilling to assume these responsibilities, lack the skills to perform them correctly, or experience distress as a result of being involved in them. Often increasing disability in the MS patient and consequent caregiving involvement by the spouse caregiver occur during one of the most difficult stages of married life, that of "family formation" (Lavee, McCubbin and Olson, 1987). It is often thought that the presence of young children in the family produces much of this stress. This phase of marriage is thought to be associated with relatively low marital satisfaction (Lavee, McCubbin and Olson, 1987). In addition to the normative stresses that
families of this age face, management of a chronic
disability within the family poses an increased burden
(Crain, Sussman, and Weil, 1966; Fendler and Goodrich,
1979; Johnson, 1985; Peyrot, McMurry and Hedges, 1988;
Shapiro, 1983). Little is known about the association
that exists between marital satisfaction and spouse
involvement in care provision to a disabled mate.

Any of these factors may negatively influence the
manner in which the caregiving assistance is provided and
may result in abusive relationships (Conomy, unpublished
manuscript). Clinical evidence indicates that it may also
result in marital abandonment (Frankel, 1984; Weaver,
1978).

The provision of MS patient care is but one role
that the spouse caregiver will have to assume in addition
to many other responsibilities. In American society both
men and women have "ambitions and commitments in both
work and family arenas simultaneously" (Amatea, Cross,
Clark and Bobby, 1986, p. 831). These family commitments
may include caring for offspring and well as frail elders
(Brody, 1985; Lavee, McCubbin and Olson, 1987). Husbands
of this age are not traditionally involved in homemaking
responsibilities (Barnett and Baruch, 1987; Rexroat and
Shehan, 1987). However, they may be called upon to assume these responsibilities when their wives become disabled. Although many women work as a matter of choice, caregiving wives whose husbands are disabled may assume commitments in the work arena more as a matter of necessity rather than because of a desire for a career. This is because the financial consequences of disability at this age are profound and last for many years (Packard, 1987).

Other role commitments, such as being a marriage partner, participating in educational or avocational endeavors, and contributing to the welfare of the community, are common roles that people of this age assume. Involvement in these other roles are significant in so far as they contribute to the sense that people have about who and what they are (Super, 1980).

The role overload that may be produced by the assumption of spouse caregiving may well have serious consequences for the emotional well-being of spouse caregivers (Jennings, 1987; Morycz, 1985; Sommers and Shields, 1987; Zarit, Reever, Bach-Peterson, 1980; Zarit, Todd and Zarit, 1986) that may in turn impact their caregiving involvement.
It is assumed but remains undocumented that among married couples, spouse caregivers provide greater number of hours of help to MS patients than do any other informal or formal caregiver. Although undocumented, the involvement of spouses as primary caregivers to MS patients appears evident. It is less clear what other persons replace or assist spouses in these caregiving responsibilities. That is, the composition of the secondary caregiving network remains less apparent than the characteristics of those who serve as primary care providers. It is the impression of health care professional working with the MS population that, for reasons that remain unclear, there is limited utilization of secondary care providers. None the less, this apparent lack of additional family assistance for caregiving may mean that well-spouses have little hope for respite from or an opportunity to share this responsibility. Such a lack of support might intensify the sense of role overload and consequent burden that has been noted to occur among other family members who are primary caregivers (Morycz, 1985).

Because the care needs of the MS patient are not considered "skilled" according to insurance reimbursement
criteria, it is unlikely that formal systems of care will be used to supplement the family caregiving. (Shamansky, 1988).

The financial consequences of chronic illness are pronounced both in lost wages and cost of care (Rutgres, 1986). Multiple Sclerosis alone produces $1.6 billion in consumption costs per year in 1984 dollars (Inman, 1985). This rather astounding figure somehow diminishes the financial consequences of MS to individual families. None the less, anecdotal reports obtained from the more than 1,000 clients and their families who have received services at the Cleveland Clinic Foundation Mellen Center for Multiple Sclerosis Treatment and Research, reveal some of these personal consequences. Innumerable caregiving wives have described their undesired entry into unskilled, minimum wage jobs that offer no health insurance benefits. Often this employment becomes necessary at a time when the wife had planned to stay home and raise children or care for aged parents. Working men and women describe frustration and concern about the welfare of their spouses who are left at home, immobile and unattended, for meals and toileting needs during the 8-hour shift that the spouse caregiver is
working. Many spouses of bother genders who work in professional capacities have described transitions to the "Mommy Track" because of the need to balance career and spouse-care.

An additional financial liability that these families face is that of insurance coverage. Staff at the National Multiple Sclerosis Society, Office of Health Services Research, estimate that 15% of people with MS have no insurance and greater than 50% are underinsured (NMSS, 1989). Similar patterns of coverage have been identified at the Cleveland Clinic Mellen Center (Miller, 1988). It is known that working age families are the least well insured segment of the American population (Berk and Wilenski, 1987; Blumberg, 1980; Lewin/ICF, 1988; Muurinen, 1985; Regula, 1987). There are no estimates about the rates at which insurance coverage is available to the families of MS patients. It is possible that the families of persons with MS may be more underinsured that the MS patients themselves. This would occur when a disabled worker receives Medicare but has no source of employer based insurance for the rest of his family. Whether concern for the cost of health care in this underinsured population is for the MS patient or
other family members, there rests burden a burden of financial responsibility on the spouse caregiver to manage.

As families affected by MS and health care providers work to devise ways of managing, if not controlling, the disease an understanding of these spouse caregivers is crucial. The above discussion raises questions that, if addressed, will lead to an increased understanding of these spouse caregivers. These research questions include the following:

* Who, in fact, are the principal caregivers of married adults with MS?

* What factors are associated with the amount of caregiving assistance provided by spouse caregivers to their disabled mates?

* What are the factors associated with the perceived burden experienced by the spouse caregivers?

**Theoretical Framework**

The perceived burden associated with the stress and strain of family caregiving has received increasing attention in recent years. The importance of this concept relates to the physical and emotional health consequences
it may produce for the caregiver (Brody, 1985; Cantor, 1983; Cicerelli, 1983; Fittings and Rabins, 1985; Stone, 1986). Also of importance is the connection that this experience of burden can have with a caregiver’s desire and decision to discontinue care provision (Ross and Kedward, 1977; Tobin and Kulis, 1981; Morycz, 1985).

In his theoretical description of perceived burden among caregivers to people with senile dementia of the Alzheimer’s type, Morycz (1985) uses the role concepts of role strain, role conflict (competing roles) and role overload (too many roles) to explain this phenomena. Burden, in his model, is the negative outcome of role demands that are produced through three sets of variables. These variables include patient, caregiver, and social/environment characteristics. Patient characteristics include background information, symptoms, and functional incapacities. Caregiver characteristics, in his model, include background characteristics, health conditions and feelings about the care recipient. Social/environmental characteristics include the physical environment in which the caregiving occurs, financial considerations, and availability of supports.
In order to assess correlates of burden experienced by spouse caregivers of MS patients, the study incorporated all of the patient and caregiver characteristics and some of the environmental characteristics that are discussed by Morycz. Because of the preliminary nature of this investigation in comparison to the more extensive description of Alzheimer family caregivers and because of limitations of sample size, this investigation concentrated on the MS patient and spouse caregiver characteristics. Less attention was given to the environmental factors described by Morycz.

Zarit and his colleagues (Zarit, Reever and Bach-Peterson, 1980; Zarit, Todd and Zarit, 1986; Zarit, 1989) used a conceptual model similar to that of Morycz to construct an empirical measure of subjective burden. This measure has proved useful in Zarit's studies of the caregivers of people with Alzheimer disease. Zarit advocates the importance of using a normed measure such as he has developed to assess the consequences of caregiving. The use of such an instrument allows comparisons of the experiences of caregivers who assist family members of different generations and disabilities. It also makes possible comparisons of these caregiving
groups with normative populations. He advocates an initial assessment of caregiver burden from a number of perspectives. These include the perceived burden associated with the physical demands of caregiving, the financial consequences of meeting that responsibility, and the emotional distress that results from lack of personal time and unmet responsibilities or other family members. For research purposes, Zarit recommends that the scores on these individual domains be summed to obtain a global measure of burden. This global score then represents the accumulation of negative changes caregivers have experienced because of, or related to, their care providing responsibilities. It is his measure of subjective burden which yields a global measure that will be used in the present study.

A recurrent theme in discussions of caregiver burden is that of the role strain that family caregivers experience. Most theoretical and empirical studies allude to the pervasive nature of this strain but limit treatment of this construct to roles as they relate to the caregiver-care recipient relationship, work involvement, and child rearing responsibilities (Brody, 1985; Soldo and Myllyluoma, 1983; Stone, 1986; Stoller,
1983; The Travelers Companies, 1985). During the years of working age adulthood there are many roles in addition to those three which people may partake (Super, 1980). The nine roles that Super identifies as relevant across a person’s life time include (1) child, (2) student, (3) leisurite, (4) citizen, (5) worker, (6) spouse, (7) homemaker, (8) parent, (9) pensioner (p. 283). He further notes that people occupy different numbers of roles during the life cycle and that the greatest number of roles is assumed during the working years. Role conflict, in his theoretical model, occurs when commitment to one role makes it difficult to participate in another. This is likely to be a common occurrence among the spouse caregivers of MS patients. Super’s constructs of role involvements were helpful to the current study for determining the number of role involvements in which spouse caregivers were engaged.

Review of the Literature

Although there has been no systematic study of the consequences of caregiving for working age well spouses, Maggie Strong (1988) has recently published an account of her life with her husband, significantly disabled by MS,
and their two children. Her book, Mainstay, describes her family from the time of her husband’s diagnosis through the next ten years. She describes the family’s adjustments to the loss of her husband’s publishing job. She writes of the children’s confusion at leaving their private school education in Manhattan and moving to more affordable rural New England. She recalls her sense of frustration and wonder when her husband expressed shame to apply for Social Security. She recollects understanding that shame when she was forced to borrow money from her parents for unexpected home repairs. She details her frustrating job hunt, concern that she support her family and still devote time to her children. She reports fright about not having insurance when both she and her daughter became ill. She admits anger when left without energy to pursue her own writing interests. She, with a certain level of detachment, describes her loss of a "husband" as she became increasingly involved in meeting her spouse’s care needs. Maggie Strong’s is not an unusual story although it is one that many spouses are reluctant to relate for fear of what "outsiders" may think. Her book does much to advance an understanding and awareness about the circumstances and needs of
these caregiving spouses.

The following review of the psychosocial literature includes a great deal of information about caregivers of the frail elderly and adults who have been disabled since childhood. Research in the area of family caregiving has concentrated on these two populations. Consideration of the limited literature about the emotional well-being of spouses to working age adults who experience limited levels of disability is also included. However, these later studies do not address the realities of caregiving for working age spouse caregivers who manage the consequences of significant disability, which is a criterion for inclusion in the proposed research. Rather, they describe the experiences of aged spouses who have reduced their usual role involvements; adult children who do not have clear societal responsibilities to their frail parents; or mothers and fathers who can presumably share caregiving responsibilities for their disabled children. The theoretical and empirical investigations that are reviewed provide a foundation for a preliminary study of the spouse caregivers of disabled working age adults.
Demographic Characteristics of Caregivers Who Have Been Studied

Across all categories of caregivers, regardless of the age or reasons for providing care, certain characteristics influence the amount, type, and consequences of caregiving by family members. Some of the most extensively described attributes are the demographic characteristics of the caregivers. Among the most salient of these characteristics is the relationship of the caregiver to the care recipient (Bass and Noelker, 1987; Cantor, 1983; Coward, 1987; Jennings, 1987; Johnson and Catalano, 1983; Shanas, 1979; Soldo and Myllyluoma, 1983; Stone, 1986; The Travelers Companies, 1985). Spouses, when available, are the most frequent primary sources of support. Daughters are the next most frequent. Studies report great variability in others who provide this primary level of care in the absence of spouses or daughters. Among informal caregivers there appears to be limited differences in the demographics of those who provide care in urban and rural areas (Bass and Noelker, 1987; Stoller and Earl, 1983; Stone, 1986).

Gender differences among caregivers have been extensively
described in the literature (Brody, 1985; Bass and Noelker, 1987; Cantor, 1983). Elderly spouses of both genders provide their mates with comparable amounts and types of care although husbands report an increase in housekeeping responsibilities. Gender differences do prove significant to the caregiving involvement of adult children for their aged and infirmed parents. Daughters clearly spend more hours and are more involved in the provision of personal care (Fittings and Rabins, 1985; Stoller and Earl, 1983; Stoller, 1983; Stone, 1986; Stone, Cafferata and Sangl, 1987; The Travelers Companies, 1985). Among parents of disabled adult children (Glueckauf and Quitter, 1984; Hirst, 1985; Jennings, 1987; Wasow, 1985), differences in the ways that men and women are involved in caregiving appear quite pronounced. Women spent greater amounts of time and performed a greater variety of tasks than did men.

Differences between daughters and sons in the relationship of employment responsibilities and caregiving involvement to frail elderly have been investigated. Stoller (1983) studied the caregiving offspring of 753 noninstitutionalized elders in northeastern New York. She determined that 69.4% of the
caring giving daughters were employed outside the home as were 83.4% of the sons. Even when accounting for the lower employment rate among the women, a disproportionate amount of the caregiving responsibility fell to the female offspring. Daughters' predominant involvement resulted from the variety of personal care tasks they performed. Daughters, unlike sons, modified their involvement in caregiving in relation to the health status of their parents. Daughters' involvements increased as the parents' level of disability increased. Sons' involvements did not show similar increases related to parents' levels of disability. This pattern was assumed to reflect daughters' greater involvement in the provision of personal care.

These cross-sectional studies of the caregivers of elders benefited from large randomly selected samples. Their findings are of significance for the present study, but do not address the circumstances of the proposed study population. Elderly husbands in the reported studies were providing care during their retirement years, a time when a number of role involvements are diminishing. Studies of adult children caregivers investigated caregivers who chose to assume "filial
responsibility" but labored under no strident societal mandate to provide parent care (Brody, 1985).

In the literature, gender distinctions in caregiving involvement are also demonstrated between the fathers and mothers of disabled young adults. In an investigation of the parental caregivers of 291 young adults who were disabled from childhood and never emancipated from families of origin, Hirst (1985) concluded that parental care in fact amounted to maternal care. Those fathers who were involved in their children's care for the most part performed tasks that were too physically demanding for the mothers to manage. Fathers never assumed major care responsibility. Rather, they most often assisted with their children's mobility at home and in the community. The 33% of fathers who assisted with personal care activities did so only on an intermittent basis. Their involvement was not related to levels of disability of the adult child. Fathers who usually performed manual labor, regardless of current employment status, provided less care to their disabled adult children than did those who performed nonmanual types of paid employment, regardless of current employment status. Younger
fathers (under 45 years of age) were more likely to be involved in provision of care than older fathers (45-54 years old). Fathers were more likely to help with the personal care of their sons than with the personal care of their daughters, but this association was weak.

This study demonstrates differential involvement in caregiving between genders. It also indicates that among men, gender role expectation as demonstrated by age and type of work, may influence caregiving involvement. Two factors limit the generalizability of this study to the proposed study population. Because Hirst’s study was conducted in England, cultural differences between the two populations may exist. Secondly, this study of caregivers to adult children studies two-parent households in which caregiving could be shared.

Davis (1980) in her consideration of the process by which 30 families cared for disabled adults at home (adult children, spouses, and parents) also established that women provided more care that did men. She reports that:

The main responsibility for care fell on the wife, and the husband remained in a psychologically, physically and financially peripheral position. Generally the differences in the male caretaking role can be summarized as (1) a lower level of support, participation and responsibility, (2) a
lower degree of emotional involvement, sharing, talking and expressive and (3) an attitude of defensiveness (minimizes problems, denial, self-insulation and withdrawal, feels hopeless, impotent, exhibits a narcissistic wound or 'ego shock'). In only two families the 'head of household' male was the disabled adult.... On the other hand, the woman in the family perceived the care taking role as the essence of mothering (vs. fathering), nurture, and the apex of dependency, which she viewed positively under these circumstances... With very few exceptions she accepted the traditional female role definitions. (p.480).

This study provides further support for the potential importance of gender differences on caregiving involvement, but is limited to a sample with intact marriages in which care giving responsibilities can be distributed.

Characteristics of the Marriage

The literature provides documentation about the significance of family stress on marital functioning and the potential effect of that functioning on availability for caregiving (Brown, Rawlinson and Hardin, 1982; Menaghan, 1982; Olson, McCubbin, Barnes, Larsen, Muxen and Wilson, 1983). There is indication in the theoretical literature that the impact of spouse ill health is likely to be influenced by the stage of family
development the couple is experiencing (Olson, McCubbin, Barnes, Larsen, Muxen and Wilson, 1983).

In their study of chronic illness in couples, Hafstrom and Schram (1984) interviewed wives of 147 couples in which neither spouse experienced chronic illness, wives of 43 families whose husbands had chronic illness, and wives of 26 families who themselves had chronic illness. Findings demonstrated few differences among study groups in the couples' household income, number of hours husbands worked or number of hours wives spent in housekeeping. Wives whose husbands were disabled expressed lower marital satisfaction than wives who were themselves disabled. The Hafstrom and Schram study did not report the severity of chronic illness that these families experienced. However, the disability levels must have been relatively low given the limited impact it produced for household income or limitation of participation in major life activity. Although this study did benefit from a design that included comparison groups, data analysis preceded by comparing one of the "illness-affected" wife sample groups (e.g., wives who were themselves disabled) to a second group that was
constituted by combining the other "illness-affected" wife sample (e.g., wives who were married to disabled husbands) and the sample of "non-illness-affected" wives. This methodology may have diluted the actual differences among the three groups.

Cicerelli (1983) compared the availability for aged parent caregiving of 141 adult children who experience marital disruption (never married, divorced and remarried, divorced and never remarried) and 164 adult children with intact marriages. He determined that there existed few differences in the amount of parental caregiving provided by children who experienced different types of marital disruption. However, those who experienced marital disruption were significantly less involved (p<.05) than their counterparts with intact marriages. Those who experienced marital disruption provided fewer hours of help and a smaller number of specific services. They did not perceive their parents needs to be as high as did offspring with intact marriages. In comparison to their counterparts with intact marriages, adult children who experienced marital disruption felt less filial obligation, and felt less available for caregiving primarily. These offspring
attributed their limited availability for caregiving to work responsibilities. Those children who experienced marital disruption provided the same amount of psychological support as their counterparts with intact marriages. Cicerelli’s study was composed of comparable numbers of sons and daughters in both the disrupted and intact marriage groups, demonstrating the influence of this factor on both sexes.

Competing Roles and Responsibilities

The impact of responsibilities faced by family members in addition to adult caregiving may well influence the provision of care to disabled family members. Current research indicates that elderly spouses do not have many competing demands that conflict with their availability for giving care. Other data suggested that the next younger generation of caregivers, of comparable age to spouse caregivers of MS patients experienced conflicts as a result of assuming such responsibility (Soldo and Myllyluoma, 1983). Brody (1985) pointed out that when families were faced with the need to provide parent care, adult role expectations and societal norms influenced which adult children took on
that responsibility. In her assessment of the assignment of parent caregiving responsibility, Brody noted that working age men were expected to maintain employment outside the home, thus curtailing their availability for family caregiving.

The expected behavior about and by working women when faced with reconciling paid employment and family caregiving is a complex issue. These conflicts are most apparent regarding women's decisions about managing child rearing and career/employment. There are few models to guide decisions about how women should manage employment and the care of disabled adult family members. It is likely that young adult women involved in adult care will have to reconcile that activity with working. Stoller (1983) reported statistics that as early as 1979, 58.3% of women of all marital statuses between 45 and 54 years of age were employed outside the home as were 53.9% of married women in the same age range were working outside the home; 62.9% of women of all marital statuses between 35 and 44 and 59.1% of all married women of that age worked outside the home during the same year. These data demonstrate that working age men and women alike may
experience employment interruption if extensively involved in caregiving.

In her own research regarding the adult offspring who are caregivers to 753 impaired elders, Stoller determined that the marital status of the caregiving offspring was significantly related to amounts of caregiving provided. Married daughters provided less assistance than unmarried daughters and married sons contributed less than married daughters. In general, Stoller determined that:

... the predictor variables (functional characteristics of impaired elder; availability of elder’s spouse; competing demands on the adult child’s time, including employment and marital status and presence of young children in the helper’s household, and age of adult child caregiver) explained a greater proportion of the variance in hours of assistance reported by sons than by daughters....This difference is consistent with earlier research which suggests that daughters provide as much assistance as they can to their ailing parents and respond to increased family responsibilities by decreasing their leisure. The amount of time allocated to parent caregiving is less responsive to the pull of competing demands on daughters than on sons. This difference was especially pronounced with respect to employment. (p. 856).

In a study comparing the work status of women who provided elder parent care, Brody, Kleban, Johnsen, Hoffman and Schoonover (1987) determined that daughters'
modifications of work status depended both on the importance and status of the job as well as the extent of the care needs of the impaired parents. The authors noted in their discussion of this research finding:

Data reported here underline the vulnerability of women to potential conflict between work and parent care. Sons, in contrast, are less likely to stop working to care for an elderly parent, having been socialized to work as their major role. ....Differential socialization may not be a constant, however. In the main, the cohorts of daughters represented in this study were socialized to being wife, homemaker, mother. But as Lopata and Knorr (1980) point out, it is no longer accurate to speak of women's typical work cycle or life course, given the increasing diversity of patterns in women's lives. (p. 207).

In an earlier writing, Brody (1985) noted that in comparable caregiving situations women who held occupations that were high status and considered careers were less inclined to modify their work status and experienced more strain when they did make such modification in order to provide parent care than did women who viewed their work as "just jobs". She reported that the majority of all respondents, regardless of work status, in her cross-generational study of women caregivers believed that it is better for a working woman to arrange paid attendant care for elderly parents than to leave employment to perform the tasks herself.
The studies described above demonstrate the impact that work responsibilities can have on caregiving involvement. They indicate that the impact of work involvement on caregiving varies with gender. However, they also present evidence that the importance of these gender differences may diminish as women become more active participants in the workforce and more invested in career-oriented employment.

Studies indicate that in many cases women who care for infirmed elders also care for children under the age of 18 (Soldo, 1985; Stone, 1986; The Travelers Companies, 1985). Due to the small number of studies about the caregivers of young to middle age adults, there is limited information regarding the proportion of these spouses who provide child care as well as meet the needs of their disabled mates involvement in adult caregiving. Neither has the extent to which this child care responsibility impacts adult caregiving been assessed.

The association of caregiving and poor health in studies of the caregivers of the frail elderly has also been evaluated and found to be significant (Brody, 1985; Stephens and Christianson, 1986; Stone, Cafferata and Sangl, 1987). It is generally thought that the physical
and emotional demands of caregiving are responsible for the relatively poor health of these family caregivers. Comparable information is not available about the caregivers to young to middle age adults. If this health effect does occur it is yet one additional and "off-time" experience that these spouse caregivers may suffer in addition to spouse caregiving.

A family member's capacity to provide ongoing care has, in part, to do with that individual's inclination to become involved in various caregiving activities. Brody (1985) in her discussion of "parent care as a normative family stress" hypothesized that the decision to provide parent care is not a normal developmental task as compared to the rearing of one's own child. Brody formulated "parent care" to be a societal expectation that arises out of a sense of filial responsibility and personal values. This expectation has been institutionalized as an expected behavior as the number of families involved in parent care continues to increase with the aging of America. Brody also noted that despite societal expectations that this adult care be provided, there is an "absence of behavioral norms" for how this caregiving will be managed.
Reactions to Caregiving Involvement

The above discussion explores characteristics of these family caregivers. These factors are important for two reasons. The first reason is the likely influence that caregiver characteristics will have on the provision of care to the impaired family member. An understanding these characteristics will lead to a more complete appreciation of how disabled adults get their care needs met. The other important reason to investigate these factors is to anticipate and hopefully assist the family caregivers in the management of their reactions to the caregiving situations.

Wasow (1985) when comparing the responses of parent, spouse and offspring caregivers to schizophrenics and Alzheimer Disease patients notes that among the comparatively younger spouses married to schizophrenics there is "the sense of being trapped and a life ruined is greater than elsewhere." (p. 715).

Simmons and Ball (1984) used the Dyadic Adjustment Scale to assess the relative marital satisfaction of spouses who married mates with existing spinal cord injuries and spouses whose mates experienced spinal care
injury after marriage. Although satisfaction was reported to be high in both groups, it was higher for those who married mates with existing injuries. The Simmons and Ball study investigated the experience of couples managing severe but stable conditions in which care needs remained relatively constant. Couples in the proposed study will be managing a disease that is full of uncertainty and disease variability.

In his longitudinal analysis of relative levels of subjective burden between elderly caregiving husbands and wives, Zarit (1986) reported that although women initially experienced a relatively higher level of burden compared to their male counterparts, those wives who continued to provide care in the community experienced a limited decline in their subjective distress over time. Within two years of assuming caregiving responsibilities, women’s sense of burden matched the initially lower burden of men. The burden level of the men involved in the study remained stable over the same two year period. Brody (1985) reported that the consequences of parental caregiving produces emotional strain that results from restrictions on time and freedom; isolation;
conflict from competing demands; difficulties setting priorities; interference with usual lifestyle, social and recreational activities.

Fittings and Rabins (1985) discussed earlier research conducted by Fittings that concluded men and women experienced comparable levels of burden and gained similar scores on measures of family environment, extent of social network, and psychological adjustment. Fittings determined that regardless of gender, younger caregivers experience higher levels of resentment and unhappiness than their elder counterparts. The author concluded from that research that chronological age and life stage of the caregiver may be significant variables in predicting caregiver strain.

These studies demonstrate the effect of the responsibilities of caregiving and other life responsibilities on working age caregivers. There are limitations to these studies. They do not address the circumstances of working age mates who provide care to spouses, where competing demands, as has been suggested, are even greater than those experienced by other family caregivers. The importance of caregiver reactions to
these caregiving and competing demands is considered next.

There is limited information in the literature about caregivers' decisions to withdraw from caregiving responsibilities except in the context of the decision to institutionalize the care recipient. A decision to transfer location of care to a nursing home is by no means comparable to the decision to terminate the caregiving relationship in other ways. These alternative means of discontinuing caregiving involvement may include withdrawal of physical or emotional support while remaining in the same household. More explicitly, such disengagement may result in abandonment or divorce. None the less, the following discussion about family decisions to transfer location of care to nursing facilities is presented so as to set a context in which to formulate those stresses and strains that are significant enough to precipitate a modification in the ongoing plan of care.

Doty (1986) reported that the decision to institutionalize an elderly family member is usually associated with that ill individual's worsening health. Doty related those factors to Smallegan's findings (1983;
that changes in the care recipient's health usually relate to frequent falls, general debility, confusion, fractures, stroke, incontinence and difficult behavior. Other factors that Doty determined as likely to influence the decision to institutionalize include primary caregivers' lack of personal time; care recipients' behavioral problems associated with senility; caregivers' inability to meet physical demands of caregiving and fatigue resulting from sleep interruption.

Morycz (1985) reported on his research about family caregivers' decisions to institutionalize their impaired elderly family members. He determined that the strain (a subjective experience) felt by the caregiver resulted in role exhaustion and was a more significant predictor of the desire to institutionalize than the objective measure of stress that the caregiver managed as a result of caregiving. Generally role exhaustion appeared to be the end point of role strain due to overload of responsibility, conflict with care recipient or other family members or because of constriction of social opportunities.
Availability of Additional Family Caregivers

The composition of the helping network that assists in providing care to infirmed or disabled family members of all generations has received a good deal of attention in the literature. Extensive discussions about networks of secondary support, that is the organization and involvement of those who in addition to the primary caregiver provide assistance, have not lead to a conclusion about how these systems usually operate or should optimally function (Cantor, 1985; Coward, 1987; Shanas, 1979; Stephens and Christianson, 1986). In their seminal works on the patterns of caregiving, Shanas (1979) described a substitution phenomena and Cantor (1985) documented a hierarchical pattern to caregiving. The work of these two investigators and subsequent research demonstrate that the preponderant pattern of caregiving includes one primary caregiver and limited consistent or occasional assistance with ongoing or intermittent aspects of care from secondary caregivers. There is limited agreement in the literature about how these secondary networks occur or operate. However, there is consistency among the reports that females fill the majority of these roles.
Availability of Formal Caregiving Assistance

The inclusion of formal services in the helping network is not the norm (Bass and Noelker, 1987; Hoch and Hemmens, 1987; Johnson and Catalano, 1983; Soldo, 1985; Stoller and Earl, 1983). It appears that agency assistance is most often introduced when care recipients have high levels of disability and involved consequent needs. In such circumstances such help is incorporated in the helping network to assist informal caregivers. Even in those circumstances of high needs and limited available informal support, the involvement of formal services in caregiving is limited. The use of such formal services typically occurs if there are adequate financial resources to privately pay for such care or at the other extreme economic need is so significant as to produce entitlement to government services. Another possible source of formal care assistance is from old age entitlement programs. Conclusions regarding the current frequency and recommended appropriate ways to incorporate formal care assistance to assume specific responsibilities into the informal care network awaits further investigation. The utilization of such services
in the MS population, given the extent of underinsurance, lack of qualifying "skilled" needs on the part of the MS patient, and financial constraints that exist in this group will begin to be described in the proposed study.

Summation

There are many factors which influence the manner of caregiving by one family member to another and the consequences of providing that assistance. Some of these factors have to do with many of the objective realities with which the family must deal in addition to the provision of care to the infirmed adult. These "objective realities" may include providing care to other family members, sustaining financial security, and protecting one's own health. Other factors have to do with intrapersonal feelings about the caregivers' own needs and place in the family. Still other issues may involve interpersonal relationships between the caregiver and care recipient or between the caregiver and other family members. All must be considered when working to understand the dynamics of family care. They will be considered in the proposed study.
The above literature review demonstrates the importance of several elements of individual and family dynamics on family caregiving involvement. The reviewed characteristics include the gender and age of the caregiver; the marital characteristics of the caregiver; the competing roles and responsibilities of those caregivers; the availability of family and formal sources of caregiving assistance; and spouse reaction to caregiving involvement. The studies presented in this review demonstrate the importance of these factors as they relate to caregiving involvement among aged spouse caregivers, adult children caregivers to aged parents, parents who aid adult children who have been disabled since childhood, and to a limited extent, the spouse caregivers of working age disabled adults. While indicative of the experience of many family caregivers, these studies do not reveal the experience of well spouses who must assist their mates in the management of a severe and unpredictable disease while balancing many additional responsibilities and adjusting to a dramatic change in their marriage and personal expectations. The proposed study will begin to address some of these gaps in the literature.
The present study adds to the literature in several ways. It investigates spouse caregivers who face the societal expectations that associated with the vow of "until death do us part" (Wasow, 1985). The study considers the relationship of marital satisfaction and caregiving involvement among working age couples.

Among respondents to this investigation only one of the spouses is available for caregiving. That spouse has no opportunity to negotiate responsibilities along gender lines. This provides an opportunity to study the reactions of caregivers who provide assistance that is inconsistent with traditional gender role behaviors and to explore the consequences of that process. Unlike other studies about working age couples who live with chronic disability, this study investigates a cohort of caregivers who assist significantly disabled spouses.

This study takes into consideration the many roles and responsibilities, in addition to assisting the MS patient, that the caregiving spouse maintains. The proposed study will address the circumstances of spouse caregivers who may well be the sole source of family income. The possible conflict of providing child care to young members of the household is also considered.
Also, it provides initial data on the secondary sources of caregiving assistance utilized by working age couples managing chronic disability.

In summary, this investigation of caregiving spouses to MS patients provides some unique insights about one of the most common sources of long term care among working age adults who are disabled.

**Research Hypotheses and Variable Definitions**

**QUESTION 1.** Who are the principal caregivers of married adults with MS (MS patients)?

**HYPOTHESIS 1a.** Among married people who are MS patients, spouses are the principal caregivers.

**HYPOTHESIS 1b.** Caregiving wives are more likely to be principal caregivers to their husbands who are MS patients than are caregiving husbands likely to be principal caregivers to their wives who are MS patients.

**HYPOTHESIS 1c.** Among married people who are MS patients, wives who are MS patients will receive
principal caregiving from formal care services in greater proportion than will husbands who are MS patients.

QUESTION 3. Controlling for the MS patient level of disability and the gender of the spouse caregiver, what is the relationship of the MS patient extent of cognitive disability, hours of assistance provided by the spouse caregiver to the MS patient, and selected characteristics of the marriage with the level of perceived burden experienced by the spouse caregiver?

HYPOTHESIS 3a. Controlling for the MS patient level of physical disability and the gender of the spouse caregiver, the greater the extent of MS patient cognitive impairment, the greater the level of perceived burden experienced by the spouse caregiver.

HYPOTHESIS 3b. Controlling for the MS patient level of physical disability and gender of the spouse caregiver, the greater the amount of assistance
provided by the spouse caregiver to the MS patient, the greater the level of perceived burden experienced by the spouse caregiver.

HYPOTHESIS 3c. Controlling for MS patient level of physical disability and gender of the spouse caregiver, the greater the number of competing role involvements of the spouse caregiver, the greater the level of perceived burden experienced by the spouse caregiver.

HYPOTHESIS 3d. Controlling for MS patient level of physical disability and gender of the spouse caregiver, the lower the marital satisfaction of the spouse caregiver, the greater the level of perceived burden experienced by the spouse caregiver.

HYPOTHESIS 3e. Controlling for MS patient level of physical disability and gender of the spouse caregiver, the fewer the number of years the couple has been married, the greater the level of perceived burden experienced by the spouse caregiver.
HYPOTHESIS 3f. Controlling for MS patient level of physical disability and gender of the spouse caregiver, the greater the number of children under the age of 13 in the household, the greater the level of perceived burden experienced by the spouse caregiver.

Conceptual and operational definitions of variables included in the above hypotheses follow.

PRINCIPAL CAREGIVER

CONCEPTUAL: The individual (spouse, other family member, friend or paid attendant) who provides the greatest number of hours of caregiving assistance to the MS-spouse in performance of activities of daily living.

OPERATIONAL: This variable was measured by self-report of the MS patient of the individual who has provided the greatest amount of assistance during the past month with the activities included in the expanded version of the ADL Self-Care Scale (Gulick, in press), a measure of daily activities devised especially for people with MS.
MS PATIENT (HUSBAND/WIFE)

CONCEPTUAL: A married or co-habiting individual who receives care for MS at the Cleveland Clinic Mellen Center and whose disability requires at minimum, bi-lateral assistance for walking.

OPERATIONAL: An individual identified on the Mellen Center for Multiple Sclerosis Treatment and Research data base as married or co-habiting, with clinically definite MS according to medical research and diagnostic criteria (Poser, Paty, Scheinberg, McDonald, Davis, Ebers, Johnson, Sibley, and Tourtellotte, 1983) who requires at minimum bi-lateral assistance for ambulation (Kurtzke, 1983).

SPOUSE CAREGIVER (HUSBAND/WIFE)

CONCEPTUAL: The individual who is identified by the MS patient as the marriage partner or life mate of the MS patient. Actual legal marital status is not a criteria.
OPERATIONAL: The individual who was identified by
the person with MS on the Demographic Profile as the
marriage partner or life mate.

FORMAL CARE PROVIDER

CONCEPTUAL: Any individual who while acting as an
independent agent or agency representative provides
homemaking or personal care services in return for
pay or room and board.
OPERATIONAL: Any individual reported by the person
with MS as reimbursed (exchanged monies or goods and
services such as room and board) for providing
assistance included in the expanded version of the
ADL Self-Care Scale (Gulick, in press).

MS PATIENT LEVEL OF PHYSICAL DISABILITY

CONCEPTUAL: The extent of lower extremity (legs)
disability and upper extremity (arms and hands)
disability experienced by the MS patient.
OPERATIONAL: The score obtained on the Modified
Expanded Disability Status Scale, a standard measure
of MS physical disability, based on interviewer
observation. This measure is the Expanded Disability Status Scale (EDSS) (Kurtzke, 1986),

MS PATIENT EXTENT OF COGNITIVE DISABILITY

CONCEPTUAL: The extent of disability to learn and remember new information or to recall previously learned material experienced by the person with MS which is produced by the disease.

OPERATIONAL: The score obtained on the Quantitative Mental Status Examination (Mahler, Davis and Benson, 1989). The measure was designed to assess cognitive dysfunction common among the MS population.

SPOUSE CAREGIVER COMPETING ROLE INVOLVEMENTS

CONCEPTUAL: The extent of spouse caregiver participation in role involvements that entail obligations to others.

OPERATIONAL: The total number of involvements on the Role Survey that were identified as "competing" in which the spouse caregiver indicated current participation.
SPouse CareGiver Hours Spent in Gainful Employment

Conceptual: The estimated number of hours that the spouse caregiver has spent in gainful employment during the last month.
Operational: The number of hours that the spouse caregiver reports on the Role Survey as having spent in gainful employment during the past month.

MS Patient - Spouse CareGiver Years of Marriage

Conceptual: The number of years during which the couple has been married or co-habitated as indicated by the spouse caregiver.
Operational: The response by the spouse caregiver on the Demographic Profile.

Number of Children Residing in the Household Under Age 13

Conceptual: The number of children, regardless of relationship to the spouse caregiver, who reside in the household.
Operational: The response by the non-MS spouse on the Demographic Profile.
SPOUSE CAREGIVER MARITAL SATISFACTION

CONCEPTUAL: The extent to which the spouse caregiver perceives agreement with the marriage partner about matters important to marriage and satisfaction with the relationship.

OPERATIONAL: The global score yielded on the Dyadic Adjustment Scale (Spanier, 1976) as reported by the spouse caregiver.

CAREGIVING ASSISTANCE PROVIDED TO MS PATIENT BY SPOUSE CAREGIVER

CONCEPTUAL: The estimated number of hours spent by the spouse caregiver in helping to manage the household and personal care needs of the MS patient during the past month.

OPERATIONAL: The number of hours reported by the spouse caregiver as spent in caregiving activities during the past month for the MS patient on the Caregiving Activity Survey.
LEVEL OF PERCEIVED BURDEN EXPERIENCED BY THE
SPouse CareGIVER

CONCEPTUAL: The amount of distress experienced by
the spouse caregiver that is associated with
activities of caregiving, interaction with the MS
patient or restrictions on personal time that result
from caregiving responsibility.
OPERATIONAL: The global score yielded on the
"Burden Interview" developed by Zarit (1989) as
reported by the spouse caregiver.
Methodology

Study Design

A cross-sectional survey was used to investigate the above stated hypotheses. As Warwick and Linninger (1975) explain that some of the major appropriate uses of survey research are to answer the questions "who does what", "how does something get accomplished", "What is the outcome". The proposed study hypotheses are within the range of these questions. The survey design was appropriate to the objectives of the research in that it produced the kinds of data needed to answer the study hypotheses. The use of this design is indicated as it is being used for a preliminary investigation of a previously undescribed segment of the caregiving population.

Campbell and Stanley (1963) refer to such a methodology as a "data-analysis" design rather than as a quasi-experimental design. They note that despite serious limitations in the ability to provide evidence in support of causation, these methodologies do have their purposes.

"In data analysis designs, when high correlation occurs, the credibility of the hypothesis is strengthened in that it has survived a chance of
disconfirmation. In this sense, a ....
correlational approach can provide a
preliminary survey of hypotheses. Those which
survive can then be checked through .... experimental
manipulation." (p. 27).
In accordance with these guidelines, this study was
intended to provide a preliminary investigation of the
spouse caregivers who are married to MS patients. These
preliminary data can be used, in turn, to generate more
complex hypotheses that require more rigorous research
methodologies. The use of structured surveys,
questionnaires adapted from psychometrically tested
measures, and standardized scales facilitated the
accuracy of measurement of the interview.

There are recognized limitations to this
methodology. This especially relates to the validity of
the findings because of the potentially confounding
factors of history and self-selection of subject who
enter the protocol. Concern about sources of lack of
reliability due to unstandardized measures is
acknowledged. This issue is difficult to avoid given the
lack of prior systematic inquiry and theoretical
specification in this or other caregiving populations.
Study Population Selection

Study criteria for this investigation of the caregiving spouses and their mates who are MS patients treated at the Mellen Center were initially based on the characteristics of the MS patients. The general dissertation study criteria were as follows:

1. MS patient was registered on the Cleveland Clinic Mellen Center patient data base.

2. MS patient was assessed to have clinically definite or laboratory supported MS according to accepted medical diagnostic and research criteria (Poser, Paty, Scheinberg, McDonald, Davis, Ebers, Johnson, Sibley and Tourtellotte, 1983).

3. MS patient experienced moderate to severe impairment, defined operationally as EDSS >/ 6.5 (requires bilateral assistance to walk 100 feet on level ground) (Kurtzke, 1986).

4. For reasons of practicality, the spouse caregiver and MS patient resided of Cuyahoga or surrounding counties.

5. The spouse caregiver and MS patient concurred at the time they agreed to participate in the study that they are married or co-habiting.

4. Both spouses indicated willingness to participate in this study according to the Institutional Review Board accepted plan for obtaining informed consent.

The appropriateness of these persons for inclusion in the study protocol was not dependent on the legal status of the marriage. Neither was the extent of caregiving assistance provided by the caregiving spouse a
factor. Because of the limited number of potential study participants for the dissertation survey (n=74), no sample selection from the known population was made. The inclusion of the entire population of Mellen Center spouse caregivers for the study group was necessary in order to assure adequate statistical power for data analysis, i.e., 10 observations/subjects for each variable included in a regression analysis, (Cohen and Cohen, 1973). There were 74 couples identified as appropriate for the study protocol.

These spouse caregivers and their mates who are MS patients treated at the Mellen Center represent a subsample of a broader study of caregivers to persons with MS. The total sample for this larger study includes 77 caregivers and the MS patients who they assist. This total sample consists of three comparison groups: 15 spouse caregivers of MS patients and those MS patients treated at the Fargo, North Dakota MS clinic; 18 unmarried MS patients and their (non-spouse) caregivers who are treated at the Mellen Center for Multiple Sclerosis Treatment and Research Cleveland Clinic Foundation; and 44 spouse caregivers and their mates who are MS patients treated at the Mellen Center.
The selection of the subset of spouse caregivers and MS patients treated at the Mellen Center for the dissertation research was made for reasons of parsimony and statistical power. The detailed investigation of Mellen Center spouses was intended to restrict the range of hypotheses to be tested to the presumed most common source of care, spouses and to the larger of the two spouse subsets. In addition, this methodology was intended to limit possible sources of error that may result from regional differences that might influence caregiving involvement between spouses who live in Cleveland and those who live in North Dakota.

Data Collection

Data for this dissertation investigation were collected by trained interviewers skilled in psychosocial assessment as well as neuropsychological testing. Interviews were conducted in a location convenient for the respondent: in the home; at the clinic; or elsewhere.

The interviewer scheduled a meeting with both spouses. The interviewer began that meeting with a review the purpose of the study and obtained informed consent from both respondents by reading the statement of consent
and obtaining the verbal approval of the interviewees. The interviewer then assisted the spouse caregiver to a location out of hearing range from the location of the MS patient interview. The interviewer will provided the spouse caregiver with copies of the self-report forms and reviewed the instructions for those forms. The spouse caregiver completed those self-report forms while the interviewer met with the MS patient.

The interviewer then proceeded to interview the MS patient. Frequently visual impairment and poor hand strength or coordination limited the MS patient’s ability to complete self-report forms. For the sake of consistency, the interviewer read all of the self-report forms to the MS patient. Those interviews were conducted in private. Only the MS patient and the interviewer were present.

In those few cases where MS patient was physically unable to provide such information, informed consent was obtained from the MS patient and subsequent data collection about disease characteristics were obtained by report of the spouse caregiver and so noted. Two MS patients were so limited in ability to communicate either in writing or orally because of MS related deficits that
the MS patient interviews were deferred. In each of those cases the spouse caregiver interview was completed. Information about the MS patients care needs, helping network and background information were obtained from the spouse caregiver.

After finishing the MS interview, the interviewer met with the spouse caregiver. That second interview was also be conducted in private. The interviewer first responded to questions about the self-report forms and then allowed the spouse caregiver additional time to independently complete the forms. Any assistance that the interviewer provided in this regard was within the limits recommended by the authors of the instruments. After receiving the completed self-report instruments, the interviewer conducted the spouse caregiver Demographic Survey.

When the interviews were completed the interviewer met with both spouses, reviewed assurances of confidentiality, determined respondents' interest to receive results of the study, recommended the services of the Mellen Center clinical staff for any care needs that were identified during the interviews, and thanked the couple for their participation.
Instrumentation

Instruments for measurement of study variables, related available validity and reliability information, and data collection methods are described below. Copies of study instruments are attached. (See Appendix A, pp TBD)

DEMOGRAPHIC PROFILE. This questionnaire was constructed for the purposes of this study to collect background information in a structured manner about the MS patient and caregiving spouses interviewees.

Two study variable obtained from this questionnaire will be included in the hypothesis testing. They are years married and number of children under age 13 residing in the household.

This survey poses closed-ended questions that gained precise and quantifiable responses that assure comparability of data between interviewees. It was designed to yield responses appropriate for computer coding and statistical analysis. Items were drawn from review of the caregiving literature. The survey was administered individually to the spouse caregiver and to the MS patient by the interviewer.
The study variable *year married* is managed as a continuous level variable. The study variable *number of children in the household* is managed as an continuous level variable.

**ADL-SELF CARE SCALE.** The ADL-Self Care Scale, developed by Gulick (1987) is a measure of functional ability which was designed for people with MS and which has known psychometric properties.

The study variables *principal caregiver* and *formal care provider* were obtained from an accounting of who provides the assistance needed according to the Gulick ADL-self care scale.

The Gulick ADL Self-Care Scale is designed to assess the level of independent function experienced by persons with MS and constructed to determine who assists in meeting those care needs which persons with MS can not independently perform. The original 15 item Self-Care subscale and 12 item Help-From-Others subscale have established content validity based on review of the literature and item appropriateness validated by client service coordinators of the National Multiple Sclerosis Society. Construct validity was established by factor
analysis. Concurrent validity was found acceptable against the established measure of MS disability, the EDSS (Kurtzke, 1986). A reliability coefficient (internal consistency) of .96 was obtained for the total scale. Test-retest reliability over 2 to 4 weeks equaled .86, (Gulick, 1987).

The extension of the scale for purposes of the current study to identify sources of assistance was made in consultation and with approval of the scale author (Gulick, personal communication, Nov. 12, 1988). The modification involves the MS patient identifying the number of hours that several people, including spouse, other family members and professional care attendants, spend in assisting in those activities identified in the Help-From-Others subscale. This extension of the original scale has no known psychometric properties. These interview data were obtained by the interviewer from the MS patient.

The study variable principal caregiver was determined by identifying the one individual who provided the greatest number of hours of assistance to the MS patient during the previous month. It was managed as a nominal level variable.
The study variable *formal care provider* was identified in the same manner as the variable *principal care provider*. It was also managed as a nominal level variable.

**Ambulation Rating.** This measure is based on the ambulation index of the Extended Disability Status Scale (EDSS), the standard measure of physical disability in MS patients (IFMSS, 1985). The study variable *MS-patient level of physical disability* was quantified as the measure obtained on this rating.

Based on the professional observation of the client's ambulation ability and manual ability, this measure yields a single score between 1 and 10. Extensive validity and reliability testing of the EDSS have established the integrity of that measure (cf. LaRocca, Scheinberg and Slater, 1984) which has been used for more than 25 years by members of the medical profession.

Study interviewers were trained in the use of this scale by the Medical Director of the Mellen Center. Interrater agreement in the use of this measure between interviewers and each with the Medical Director was .87 and .9 respectively after this training.
This measure was taken by the interviewer during the MS patient interview. Assessment of current ambulation ability, rather than depending on the rating indicated on the patient data base, was done in order to assure that an accurate assessment of physical ability is available for analysis. EDSS scores stored on the clinical data base that were used to identify study participants may be several years old and, due to the progressive nature of the disease, inaccurate. The study variable MS patient level of physical disability was managed as a continuous level variable.

**QUANTITATIVE MENTAL STATUS EXAMINATION.** The Quantitative Mental Status Examination (QMSE) (Mahler, Davis, and Benson, 1989) is a screening instrument sensitive to the cognitive impairment common in MS. The study variable MS-spouse extent of cognitive disability was quantified as a measure of this instrument.

The QMSE assesses dysfunction in the areas of language, learning, orientation, memory, and visual/spatial perception. The maximum score for this measure is 100 points and a score less than 80 indicates significant cognitive dysfunction. A reliability coefficient of $r = .72$ was established for this measure.
(Mahler et al, 1989). Criterion validity was established by comparing normative and patient data and proved statistically significant (p < .05).

The interviewers who were trained by a neuropsychologist in the administration of this measure completed the QMSE with the MS-persons.

The study variable **MS-spouse extent of cognitive disability** was managed as a continuous level variable.

**SPOUSE CAREGIVER ROLE SURVEY.** This structured survey, constructed for the purposes of this study, includes questions about 12 roles in which spouse caregivers may participate. The study variable **MS caregiver role involvement** was calculated as the sum of the competing roles in which the spouse caregiver reports current involvement. The study variable **spouse caregiver hours spent in gainful employment** was calculated as the self-reported time currently spent in that role.

The spouse caregiver Role Survey is not a scale and has no known psychometric characteristics. However, there is no instrument available in the psychosocial literature known to this writer, who has discussed the matter with several clinical psychologists and sociologists, that
assesses typical individuals' role involvements, amounts of time spent in those involvements, and changes in involvements related to a specific event.

Items for this interview are drawn from the work of Super (1980). They have been reviewed and found appropriate for the study population by the Medical Director, Clinical Nurse Specialist, Occupational Therapist, and Psychologist at the Mellen Center. Although the survey addresses the number of role involvements, amount of time spent in them, and importance attached to each role currently and before MS, only the actual count of current conflicting role involvements was used in the present study. The non-MS spouse Role Survey was self administered.

The study variable *spouse caregiver competing role involvements* was managed as a continuous level variable. That variable, *non-MS spouse hours spent in gainful employment*, was managed as a continuous level variable.

**CAREGIVING ACTIVITY SURVEY.** This measure was adapted from the Philadelphia Geriatric Center Multi-level Assessment Instrument (MAI) (Lawton, Moss, Fulcomer, and Kleban, 1982). It is a self administered instrument designed to measure the functional capacity
of elders. One of this measure's subscales, the "Daily Living Rating Scale" (DLRS) is particularly useful in assessing impairment in ability to perform daily routines. Psychometric properties of the Lawton "Daily Living Rating Scale" and its subscales were established on a study sample (n=484) which demonstrated a reliability alpha=.93, retest reliability=.75. Validity measures included summary ratings r=.87, R=.87, and criterion group r=.54, (Lawton, Moss, Fulcomer and Kleban, 1982).

This subscale was modified for the purposes of the present study to ascertain the number of hours spent by the spouse caregiver in assistance to the MS patient. The study variable caregiving assistance provided to the MS patient by the spouse caregiver was calculated as the total number of hours of spouse caregiving assistance reported on this survey.

For the purposes of the present study, the items on the DLRS were reworded to gain spouse caregiver estimates of personal involvement/ratings in each of the following areas: number of hours spent in providing specific types of assistance (as described in the DLRS) to the MS patient during the last month; perceived importance of
that form of assistance to the well-being of the MS patient; and spouse caregiver involvement in that activity prior to the onset of MS patient disability. Only the number of hours spent in providing assistance was used in data analysis.

There is no reliability or validity information available for this revised measure. Neither is there an available scale to use for the intended purpose. Most of the caregiving studies described in the literature simply ask caregivers to estimate the time they spend in care provision. The Caregiving Activity Survey was devised to gain a higher degree of precision in this estimate. Because of the detail of activities included in the Lawton measure, it was selected for modification rather than the less detailed ADL Self-Care Scale by Gulick.

The Caregiving Activity Survey was self-administered by the spouse caregiver. The study variable caregiving assistance provided to the MS patient by the spouse caregiver was measured as a continuous variable.

**DYADIC ADJUSTMENT SCALE.** The Dyadic Adjustment Scale (Spanier, 1976) was used to assess spouse caregiver marital satisfaction. The study variable non-MS spouse
marital satisfaction was calculated as the global measure of this scale.

The Dyadic Adjustment Scale has been used for the similar purpose in at least one other spouse caregiver study (Simmons and Ball, 1984). It has undergone extensive validity and reliability testing. Three study-judges were employed to establish content validity. Criterion-related validity was significant (p < .001). Construct validity against the Lock-Wallace measure demonstrated a correlation of .86 (p < .001). Reliability was established with a Cronbach's alpha=.96. The 32 item measure yields a global score.

The Dyadic Adjustment Scale was self-administered by the spouse caregiver. The study variable spouse caregiver marital satisfaction was managed as a continuous variable.

**BURDEN INTERVIEW.** The Burden Interview (Zarit, 1989) is a measure that is commonly used in studies of family reactions to caregiving. The study variable level of perceived burden experienced by the spouse caregiver was calculated as the global measure of this scale.

The Burden Interview is a 22 item scale that identifies the extent to which a person experiences
various forms of distress as a result of caregiving responsibility. Internal reliability for the measure has been estimated using Cronbach’s alpha=.88 and .91 in two separate assessments (Zarit, 1989). Test-retest reliability is reported at .71. Validity has been estimated by correlating the total score with a single global rating of burden (r=.71) and by relating the total score with the Brief Symptom Inventory (Derogatis, 1986) (r=.41).

The Burden Interview was self-administered by the spouse caregiver. The study variable level of perceived burden experienced by the spouse caregiver was managed as a continuous level variable.
Results Section

Introduction

The following discussion presents findings about spouses of persons disabled by MS. These spouses represent a subsample of a more general study of caregivers to persons with MS. The total sample for this larger study includes 77 caregivers. This total sample consists of three comparison groups: 15 spouse caregivers of MS patients and those MS patients treated at the Fargo, North Dakota MS clinic; 18 unmarried MS patients and their (non-spouse) caregivers who are treated at the Mellen Center for Multiple Sclerosis Treatment and Research Cleveland Clinic Foundation; and 44 MS patients and their spouse caregivers treated at the Mellen Center.

It is the group of married MS patients and their spouse caregivers who constitute the dissertation study population.

A total of 108 MS patients entered on the Mellen Center data base were identified as appropriate for admission to the broader investigation and were invited with their caregivers and spouses to participate. Married MS patients and their spouse caregivers accounted
for 69% (n=74) of those 108 patients and caregivers invited to participate from the Mellen Center. There was a 57% overall acceptance rate for participation from that original group of 108. Of the 74 married MS patients and their spouse caregivers who were invited to be interviewed, 44 married MS patients and their caregivers (58%) agreed to participate. Of those 30 married MS patients who were not interviewed, 24 (80%) are women. The mean age of those married MS patients not interviewed is 51.5 years. Comparable age data is not available for those spouse caregivers who were not interviewed. Information about the couples who chose not to participate is available based on clinical knowledge of this population. Although it is not categorically the case, many of the non-respondents are known to be involved in especially stressed and sometimes abusive relationships as well as frequent hospital recidivists.

Reasons that interviews were declined among those 30 couples include: 10 MS patients (30%) indicated concern about possible negative consequences; 6 spouses caregivers declined interviews although their MS patient spouses were accepting of the interviews; 1 MS patient reported disappointment with the Mellen Center and
consequent disinterest to participate; 1 MS patient saw no likely personal benefit from participation; 1 MS patient indicated no need for caregiving assistance; 11 MS patients offered no reason for declining participation.

The results presented in the following sections include information obtained from those 44 married MS patients treated at the Mellen Center and their spouse caregivers who were included in the study. These results include descriptive statistics of the MS patients, descriptive statistics of their spouse caregivers, findings about caregiving involvement and formal hypothesis testing.

Description of Care Recipients

Demographic Data

The final study sample for the dissertation research includes 44 pairs of respondents who all indicate legal marriages. These couples include 23 women with MS (52.3%) and 21 men who have the diagnosis (47.7%). In the sample there are no couples in which both partners have been diagnosed as having MS. Thus the data set includes information about a proportionately larger
number of "caregiving husbands" than is commonly reported in the literature. However, this sample represents a smaller proportion of women with MS than would be expected since the disease effects women twice as frequently as it does men.

As is indicated in Table 1, these MS spouses have a mean age of 49.6 years. Their reported duration of current marriage is 24.2 years. A majority of the study subjects affected by MS are white (n=40, 90%) and the rest are black (n=4, 10%). The racial distribution within this study population under represents the anticipated .4 relative risk of American blacks to contract MS compared to whites.

**Education and Employment Status**

Table 1 also provides details of the educational background of the disabled spouse group. These MS spouses include 21 high school graduates (47.7%), 5 associate degree or trade school graduates (11.4%), 7 college graduates (15.9%), and 8 individuals with advanced degrees (18.1%). This level of education is slightly higher than the mean 12.1 years of education reported Cuyahoga County residents in the 1980 Census. Six members of this group are currently employed outside
### Table 1

**Selected Characteristics: MS Patients and Spouse Caregivers**

<table>
<thead>
<tr>
<th>Description</th>
<th>$\bar{X}$</th>
<th>S.D.</th>
<th>Range</th>
<th>N</th>
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<tr>
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<td>21</td>
<td>47.7</td>
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<tr>
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<td>23</td>
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<td></td>
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</tr>
<tr>
<td>Male</td>
<td>23</td>
<td>52.3</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>21</td>
<td>47.7</td>
<td></td>
<td></td>
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<tr>
<td><strong>MS Patient Age</strong></td>
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<td>11.04</td>
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<tr>
<td><strong>Years Married</strong></td>
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<td>12.01</td>
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<tr>
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<td>4</td>
<td>9.1</td>
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<td>White</td>
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<td>6</td>
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<tr>
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the home. Of these 6, all are men. One is a high school graduate and the other five have greater than high school education.

All MS-spouses benefit from some source of health insurance. The majority, 86.4%, have private insurance; 36.4% have medicare; one individual (2.3%) has received approval from his HMO for his rehabilitation services to be provided at the Mellen Center. These data do not indicate the extent to which underinsurance is a problem for this study group. The data do, however, suggest a higher rate of insurance coverage than is available to the general MS population (NMSS, 1988).

**Illness Characteristics**

The MS spouses have carried their neurological diagnosis for a mean of 13 years (S.D.=8.3) and have experienced difficulty with ambulating for a mean of 8.3 years (S.D. = 5.5).

Indicators of MS Spouse General Health Status are presented in Table 2. Indicators of their MS related disability are presented in Table 3. This table presents information about the ordinal ranking in decreasing order of disability. Possible rankings on this measure range from 1, no symptomatology of MS to 10, dead from
complications of the disease. Given the study criteria for this investigation, the possible range of scores is 6.5, walks with bi-lateral assistance, to 9.5, dependent for bed mobility. The actual range represented by the study sample is 6.5 to 8.5. More than 57% of these persons with MS are so physically disabled that they are non-ambulatory and always require assistance to transfer from one surface to another. Consequently, this 57% of the MS spouses are dependent for toileting, bathing, and getting in and out of bed. The level of cognitive disability among this study group is profound.

Forty percent of the MS spouses were hospitalized during the preceding year. A similar proportion, (40%) had skilled nursing needs that at least temporarily qualified them for insurance reimbursed home health agency visits during the preceding year. Subsequent data will establish that this home health agency involvement is neither enduring or intense enough to constitute major caregiving involvement.
## General Health Indicators: MS Patients and Spouse Caregivers

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<th>Description</th>
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<th>Spouse Caregiver</th>
<th>Number of Limiting Conditions</th>
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<th>%</th>
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<td>100</td>
<td></td>
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<td></td>
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</tr>
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<td></td>
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<td>0</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>MS Patient Hospitalization</td>
<td>No</td>
<td>27</td>
<td>61.4</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Yes</td>
<td>17</td>
<td>38.6</td>
<td></td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Caregiver Hospitalization</td>
<td>No</td>
<td>41</td>
<td>86.4</td>
<td></td>
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<td></td>
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</tr>
<tr>
<td></td>
<td>Yes</td>
<td>3</td>
<td>13.6</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Caregiver Outpatient Mental Health</td>
<td>No</td>
<td>39</td>
<td>88.6</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>5</td>
<td>11.4</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Table 3

**Disease Status Indicators: MS Patient**

**M. S. Physical Disability: Modified Ambulation Index**

<table>
<thead>
<tr>
<th>Description</th>
<th>Score</th>
<th>N</th>
<th>&amp;</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walks with bilateral assistance</td>
<td>6.5</td>
<td>9</td>
<td>20.4</td>
</tr>
<tr>
<td>Able to independently transfer</td>
<td>7.0</td>
<td>16</td>
<td>36.4</td>
</tr>
<tr>
<td>Independent in an electric chair</td>
<td>7.5</td>
<td>8</td>
<td>18.2</td>
</tr>
<tr>
<td>Independent in eating &amp; grooming</td>
<td>8.0</td>
<td>6</td>
<td>13.6</td>
</tr>
<tr>
<td>Dependent for bed mobility</td>
<td>8.5</td>
<td>5</td>
<td>11.4</td>
</tr>
</tbody>
</table>

**M. S. Cognitive Disability: SDMT**

<table>
<thead>
<tr>
<th>Description</th>
<th>X</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>32.5</td>
<td>13.5</td>
<td>0-58</td>
</tr>
</tbody>
</table>
Spouses Caregivers

Demographic Data

Characteristics of the non-MS spouses are presented in Table 1. Twenty three of the spouse caregivers (52%) are husbands to women who have MS and 21 (48%) are wives whose husbands are disabled by the condition. It is worth reiterating that this sample represents a larger proportion of caregiving males than is commonly reported in the literature.

On average, these spouses are 50 years of age and have been in the current marriage for 25 years. Of the 43 respondents who provided information about educational background, 24 (55.8%) are high school graduates, one (2.3%) did not graduate high school and 18 (41.9%) received a degree beyond high school. This level of education is greater than that reported for Cuyahoga County residents in the 1980 census.

Thirty nine members of the study group of spouse caregivers are white (89%), 4 are black (9%), and one is middle eastern (2%).

Employment Status

The majority of these spouses (n=29, 68%) are employed outside the home. The largest proportion of the
working spouses (32%) are employed in professional or management positions. These working spouses include 70% (n=16) of all caregiving husbands and 62% (n=13) of all caregiving wives. Among the 15 (32%) spouses who are not currently employed outside the home, all have had some previous work experience. The mean year in which they stopped working was 1983. Although there is not a statistically significant relationship, this work discontinuation generally two years after the onset of MS patient disability. Among those who are not employed, reported reasons for current unemployed status are as follows: by choice (n=5, 33%); MS related concerns (n=5, 33%); age related retirement (n=2, 14%); disability retirement related to the condition of the spouse caregiver (n=3, 20%).

All spouse caregivers have health insurance benefits. The data does not indicate the adequacy of this coverage.

Physical Health Status

Indicators of the health status of the spouse caregivers is presented in Table 2. The health status of this study population is comparable to that of spouse caregivers to persons with MS who live in Canada. The
Canadian research, conducted by Niskala and Dewis (1989) revealed that 58% of the caregivers had some limiting condition. This Canadian data is the only available information about the health status of spouse caregivers of this age group. Fifty two percent of the caregivers in the present study experience such limitations. A majority of caregivers from both study groups had been seen by a physician during the previous year (80% in Canada, 71% at Mellen). Niskala and Dewis suggest that this level of physical health status is comparable to the general population.

**Mental Health Status**

As is indicated on Table 4, global scores on the Brief Symptom Inventory indicate that both caregiving husbands and caregiving wives experience emotional distress that is one standard deviation above the norm for the general population. Another indicator of the emotional well-being of these spouse caregivers is their indicated satisfaction with their marriage. This measure is assessed using the Dyadic Adjustment Scale. The theoretical question regarding this scale as representative of individual adjustment to the relationship rather than adjustment of the dyad as a
<table>
<thead>
<tr>
<th>Description</th>
<th>X</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brief Symptom Inventory (BSI)</td>
<td>.5</td>
<td>.4</td>
<td>.0 - 1.7</td>
</tr>
<tr>
<td>Dyadic Adjustment (Marital Satisfaction) (DAS)</td>
<td>102.1</td>
<td>19.0</td>
<td>59 - 138</td>
</tr>
<tr>
<td>Zarit Caregiver Subjective Burden (CSB)</td>
<td>36.0</td>
<td>14.2</td>
<td>6 - 99</td>
</tr>
</tbody>
</table>
functioning group remain unanswered. Consequently, gender adjusted scores are not considered. This measure is calibrated so that lower scores indicate lower marital satisfaction. Scores on the Dyadic Adjustment Scale indicate that the caregiving spouses have only slightly lower scores than those reported in the general population, mean=114.8, S.D.=17.8.

Another relevant measure of the emotional health of the caregiving spouses is the reported sense of burden that they experience because of their caregiving responsibilities. This dimension is measured by the Zarit Burden Interview. Norms for this measure have not been computed, but Zarit offers estimates for ranges of burden represented by his scale. He states that scores between 21 and 40 indicate mild to moderate burden. According to these estimates, the study group experiences a moderate level of burden, mean=36, S.D.=14.2.

**Role Involvements**

Table 5 presents information about role involvements for the spouse caregivers. This table presents information about the median number of hours individuals report spending in these roles because the data do not represent a normal distribution within the population as
Table 5

Role Involvements for Non-MS Spouses

<table>
<thead>
<tr>
<th>Description</th>
<th>&amp;*</th>
<th>Hrs.**</th>
<th>&amp;*</th>
<th>Hrs.**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Positive (N=3)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse</td>
<td>97.7</td>
<td>60</td>
<td>75.0</td>
<td>60.0</td>
</tr>
<tr>
<td>Leisure</td>
<td>79.5</td>
<td>21</td>
<td>70.5</td>
<td>11</td>
</tr>
<tr>
<td>Citizen</td>
<td>54.5</td>
<td>8</td>
<td>31.8</td>
<td>5</td>
</tr>
<tr>
<td>Competing (N=9)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>70.5</td>
<td>110</td>
<td>52.0</td>
<td>200</td>
</tr>
<tr>
<td>Caregiver</td>
<td>11.4</td>
<td>6</td>
<td>18.2</td>
<td>4</td>
</tr>
<tr>
<td>Worker</td>
<td>77.3</td>
<td>180</td>
<td>55.9</td>
<td>180</td>
</tr>
<tr>
<td>Homemaker</td>
<td>63.6</td>
<td>48</td>
<td>81.8</td>
<td>68</td>
</tr>
<tr>
<td>Student</td>
<td>6.8</td>
<td>20</td>
<td>9.1</td>
<td>24</td>
</tr>
<tr>
<td>Patient</td>
<td>4.5</td>
<td>2</td>
<td>22.7</td>
<td>8</td>
</tr>
<tr>
<td>Child</td>
<td>22.7</td>
<td>40</td>
<td>20.5</td>
<td>30</td>
</tr>
<tr>
<td>Babysitter</td>
<td>9.1</td>
<td>14</td>
<td>11.4</td>
<td>5</td>
</tr>
<tr>
<td>Caregiver to Spouse</td>
<td>22.7</td>
<td>10</td>
<td>84.1</td>
<td>60</td>
</tr>
</tbody>
</table>

* Percent of total population
** Median number of hours spent in role by those reporting involvement
indicated by the large standard deviations calculated for the means of these hours. The roles are presented in two nominal categories "positive roles" and "competing roles". As categorized, the nominal category "positive roles" includes: "spouse", "leisurite" and "citizen". They are so designated because of the positive wording and implication of voluntary involvement used to describe them. The nominal category "competing roles" includes: "parent"; "caregiver" (to someone other than the MS patient); "worker"; "homemaker"; "student"; "patient"; "child"; "babysitter"; "caregiver to MS patient". In the current literature only the roles "worker", "parent" and "caregiver" are usually included when discussing competing roles (Brody, 1985; Moritz, 1985; Soldo and Myllyluoma, 1983; Stone, Cafferata and Sangl, 1987; Stoller, 1987). The additional six roles are included in this competing category because, consistent with the work of Morycz and Zarit, they indicate involvement in activities that include responsibilities to others that may produce role conflict. The role "patient" is included in this category because it indicates a debility that may interfere with caregiving availability. This assumption is supported by the work of Niskala and Dewis
(1989) and Stone, Cafferata and Sangl (1987). It is the number of current "competing" role involvements was included in formal hypothesis testing.

The following discussion of changes in role involvements is based on the spouse caregivers’ recollections of role involvements at a time before MS disability compared to current involvements. This ranking of change is based on a 5-point scale that ranges from "much less" to "much more". This data do not allow for testing the significance of change in the spouse caregiver participation in these roles. Involvement in the three "positive" roles changes with the onset of disability. There is a decline from before MS disability to present time in the proportion of spouse caregivers who consider themselves engaged in the roles of "spouse", "leisurite" and "citizen". Also important to consider is the amount of time that those who remain active in these roles devote to those "positive" activities. There is a decline in the number of hours spent as "leisurite" and "citizen" among caregiving spouses who remain active in these roles. There is a decline in the number of caregiving spouses who consider themselves to participate in the positive role "spouse" (i.e., involved in
activities of an ongoing intimate and sharing relationship, including but not limited to sexual relations). However, those who consider themselves to be engaged in that role maintain a consistent level of involvement (60 hours) compared to those who were "spouses" before the onset of MS disability.

The change in "competing role" involvements is more complex. There is an increase in both the proportion of the population and amount of time spent in four of the competing roles; "patient", "student", "homemaker", and "caregiver to spouse". Although there is an increase in the proportion of respondents who report involvement as "caregiver" (to someone other than the MS patient) and "babysitter" there is a decrease in the amount of time spent in these roles. Although fewer spouses are involved as a "parent" (a likely reflection of the maturing of the family since onset of MS disability), those who are involved are more active in that role than previous to onset of MS disability.

Involvement in Caregiving

Table 6 provides information about three different categories of assistance that spouse caregivers provide to their disabled mates. The first of these categories,
<table>
<thead>
<tr>
<th>Description</th>
<th>Total (hours)</th>
<th>Women (hours)</th>
<th>Men (hours)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>X</td>
<td>S.D.</td>
<td>Median</td>
</tr>
<tr>
<td>Routine Homemaking</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grocery Shopping</td>
<td>9.9</td>
<td>9.5</td>
<td>8.0</td>
</tr>
<tr>
<td>Housework</td>
<td>48.5</td>
<td>108.8</td>
<td>20.0</td>
</tr>
<tr>
<td>Handiwork</td>
<td>8.2</td>
<td>13.4</td>
<td>4.0</td>
</tr>
<tr>
<td>Laundry</td>
<td>13.9</td>
<td>15.6</td>
<td>9.5</td>
</tr>
<tr>
<td>Finances</td>
<td>6.1</td>
<td>7.0</td>
<td>4.0</td>
</tr>
<tr>
<td>Subtotal</td>
<td>45.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MS Spouse ADL</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using the phone</td>
<td>3.9</td>
<td>12.5</td>
<td>1.0</td>
</tr>
<tr>
<td>Traveling away from home</td>
<td>35.2</td>
<td>109.4</td>
<td>10.0</td>
</tr>
<tr>
<td>Mobility inside the home</td>
<td>9.8</td>
<td>16.8</td>
<td>2.5</td>
</tr>
<tr>
<td>Correspondence</td>
<td>2.1</td>
<td>4.0</td>
<td>1.0</td>
</tr>
<tr>
<td>Subtotal</td>
<td>13.5</td>
<td></td>
<td></td>
</tr>
<tr>
<td>MS Spouse Personnel</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication</td>
<td>5.4</td>
<td>17.4</td>
<td>2.0</td>
</tr>
<tr>
<td>Eating</td>
<td>13.9</td>
<td>16.1</td>
<td>7.0</td>
</tr>
<tr>
<td>Dressing</td>
<td>10.3</td>
<td>11.0</td>
<td>7.5</td>
</tr>
<tr>
<td>Grooming</td>
<td>6.6</td>
<td>8.5</td>
<td>2.5</td>
</tr>
<tr>
<td>Bathing</td>
<td>6.7</td>
<td>8.1</td>
<td>4.0</td>
</tr>
<tr>
<td>Toileting</td>
<td>10.2</td>
<td>17.1</td>
<td>4.0</td>
</tr>
<tr>
<td>Bed Transfer</td>
<td>4.9</td>
<td>7.0</td>
<td>2.5</td>
</tr>
<tr>
<td>Subtotal</td>
<td>88.5</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Routine Homemaking, includes the following activities: grocery shopping; house work; handiwork; laundry; and finances. The second category, MS Patient Activities of Daily Living, includes: using the phone; traveling away from home; getting around inside the home; managing personal correspondence. The third of these categories, MS Patient Personal Care Activities, encompasses: taking medication; eating meals; dressing; grooming; bathing; toileting; and getting in and out of bed.

Because the data do not represent a normal distribution within the population, the median number of hours spent in these activities is discussed. The sum of the median hours reported spent in each of the categories indicates that spouse caregivers spend 45.5 hours in routine home making during the previous month. This is the amount of time devoted to maintaining the household but is not directly related to managing MS related disability. Calculation of the median number of hours devoted to MS patient activities of daily living and personal care activities describes the time spent in meeting care needs that would not exist except for MS. A total of 45 hours each month is given to this kind of care. In combination, these three kinds of
responsibilities represent more than a half time job. As is indicated in Table 7 which details data obtained from the activities of caregiving survey, this part-time job represents a reported increased amount of time spent in these activities since the onset of MS disability. The greatest increase in type of caregiving as recollected by the spouse caregivers is devoted to the category "MS patient personal care", the next bigger increase is in "routine homemaking". It is the "MS patient ADL" need for "assistance traveling away from home" that produced the largest increase in any single activity. There are not statistically significant differences in the amount of time that caregiving husbands and wives spend in these various activities. This lack of statistical significance may be due in part to the non-normal distribution of the data.
Table 7

**MS Spouse Change in Caregiving Involvement**

<table>
<thead>
<tr>
<th>Description</th>
<th>X</th>
<th>S.D.</th>
<th>Median</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Routine Homemaking</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grocery Shopping</td>
<td>4.1</td>
<td>1.3</td>
<td>4.0</td>
</tr>
<tr>
<td>Housework</td>
<td>4.2</td>
<td>.9</td>
<td>4.0</td>
</tr>
<tr>
<td>Handiwork</td>
<td>3.8</td>
<td>1.2</td>
<td>4.0</td>
</tr>
<tr>
<td>Laundry</td>
<td>4.0</td>
<td>1.6</td>
<td>4.0</td>
</tr>
<tr>
<td>Finances</td>
<td>3.6</td>
<td>1.2</td>
<td>4.0</td>
</tr>
<tr>
<td><strong>MS Spouse ADL</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Using the phone</td>
<td>2.9</td>
<td>1.7</td>
<td>3.0</td>
</tr>
<tr>
<td>Traveling away from home</td>
<td>4.2</td>
<td>1.4</td>
<td>5.0</td>
</tr>
<tr>
<td>Mobility inside home</td>
<td>3.9</td>
<td>1.5</td>
<td>4.5</td>
</tr>
<tr>
<td>Correspondence</td>
<td>3.2</td>
<td>1.6</td>
<td>3.0</td>
</tr>
<tr>
<td><strong>MS Spouse Personal Care</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Medication</td>
<td>3.8</td>
<td>1.4</td>
<td>4.0</td>
</tr>
<tr>
<td>Eating</td>
<td>4.0</td>
<td>1.4</td>
<td>4.5</td>
</tr>
<tr>
<td>Dressing</td>
<td>4.0</td>
<td>1.4</td>
<td>4.5</td>
</tr>
<tr>
<td>Grooming</td>
<td>3.8</td>
<td>1.5</td>
<td>4.0</td>
</tr>
<tr>
<td>Bathing</td>
<td>3.7</td>
<td>1.7</td>
<td>4.0</td>
</tr>
<tr>
<td>Toileting</td>
<td>3.8</td>
<td>1.7</td>
<td>4.5</td>
</tr>
<tr>
<td>Bed transfer</td>
<td>4.0</td>
<td>1.5</td>
<td>4.5</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>3.8</td>
<td>.7</td>
<td>3.7</td>
</tr>
</tbody>
</table>

* 1= much less  
  2= less  
  3= same  
  4= more  
  5= much more
Characteristics of the Household. Nineteen of the couples (43.2%) have no other residents in their households. Children, age 13 years and younger, reside in 25% (n=11) of the study households. Twelve couples (27.3%) have one other person in the household and another 12 couples (27.3%) live in households that include 4 to 6 permanent members. One husband has recently taken temporary residence at his place of employment because of domestic difficulties. Although he counts himself a household of one this spouse indicates commitment to the marriage and considers himself to be a prominent caregiver to his wife.

The mean income for households represented in the study, $35,671 annually (S.D.=17,481), is greater than indicated in the 1980 census for either Cuyahoga County ($21,387), or the U.S. ($20,306). Information regarding household income was not provided by 6 respondents (14%) of the study population.

The primary source of household income both before the onset of MS disability and currently results from earned wages. There is increased dependence on illness and age related income since the onset of MS disability. Although General Relief and Supplemental Security Income
were presented as potential sources of income, no respondents depended on these entitlement programs either before or since MS disability.

Reliability Testing

_quantitative mental status examination (QMSE)._ A complication in assessing cognitive function of the MS patient was encountered during this research. The Quantitative Mental Status Examination (QMSE), the proposed measure of this variable, includes 9 subscores that are intended to capture distinct aspects of cognition. These subscales are summed for a total QMSE score. Two subjects are impaired to an extent that they are unable to respond to verbal commands. One other subject, because of his MS, has neither the capacity for speech nor ability to produce written material. Although he appeared to be of functional cognitive ability to the study interviewer this subject was unable to participate in cognitive testing. These three individuals were eliminated from further analysis of the relation of cognition to other study variables.

In addition to those three who are unable to complete any aspect of this testing, 11 members of the
study population were unable to complete two of the QMSE subscales. These subscales, Visual Construction and Language Ability, require visual acuity sufficient to read bold print and hand writing ability sufficient to produce 4 word sentences. Because the QMSE, a relatively new cognitive test battery, has not been previously applied to a significantly disabled population this difficulty in testing a profoundly physically impaired population had not been anticipated. Rather than use this incomplete data, a second measure of cognitive functioning was substituted for the hypothesis testing.

This second measure of cognitive ability, the Symbol Digit Modality Test (SDMT) (Smith, 1973) was included in the study protocol to replicate reliability testing with the QMSE. It was successfully completed with 41 of the subjects. Comparison of the SDMT scores of those who were able to complete the QMSE and those who were not able to complete that measure reveals a statistically significant difference between the two sets of subjects (p<.05). This analysis supports the finding that those unable to complete the entire QMSE are more demented than those who have the physical capacity to perform all subscales of the QMSE. The SDMT has been
substituted as the measure of cognitive disability in all subsequent analysis.

The measure of reliability established in the literature for the Dyadic Adjustment Scale is Cronbach’s alpha=.96. The responses to the same scale demonstrated a Cronbach’s alpha = .88 in the current study.

The measure of reliability established in the literature for the Zarit Burden Scale is Cronbach’s alpha=.88 and .91. The responses to the same scale demonstrated a Cronbach’s alpha = .91 in the current study. The correlation between the Zarit Burden Score and the Brief Symptom Inventory, used as a measure of validity in the literature, was r=.41. The same two measures in the current study demonstrated a correlation, r=.60.

Hypothesis Testing

Hypotheses 1a-1c

The first set of hypotheses considers those persons who are the principal source of caregiving assistance to married persons with MS. Results of the statistical tests for these formal hypotheses follow.
HYPOTHESIS 1a. Among married people with MS, spouses are the principal caregivers.

FINDING: The present research supports the primacy of spouses as primary caregivers to married persons with MS. Spouses are demonstrated to be the principal care givers among 35 (79.9%) of the study group.

Many individuals are reported to provide secondary assistance to support the spouses who are primary caregivers. The most common source of secondary assistance reported by care recipients is children who live in the household (n=14). The majority of these children are of school age and are as likely to be sons as daughters. There are several adult children who reportedly continue to live in the parental household and provide secondary caregiving assistance. Other sources of secondary assistance in order of reported frequency include: paid attendants (n=6), parents (n=4), siblings or other relatives (n=3), friends (n=2) and for those who are employed, co-workers (n=2).

HYPOTHESIS 1b. Wife caregivers are more likely to be principal caregivers to their husbands with MS than husband caregivers are to their wives who have MS.
FINDING: Wives are the primary caregivers for 95% for disabled males. Husbands are the primary caregivers for 65% for disable females. Using the test of significance for differences between 2 proportions (Blalock, 1972) this represents a statistical difference (p<.01) between wives and husbands as principal caregivers. The 8 female MS patients whose husbands are not indicated to be primary caregivers, receive primary assistance from: formal care providers (n=3); children (n=3) and parents (n=2). The one male MS patient who does not receive primary caregiving assistance from his wife reports that he obtains the majority of his assistance from a co-worker at his place of employment.

HYPOTHESIS 1c. Among married people with MS, wives with MS will receive principal caregiving from formal care services in greater proportion than will husbands with MS.

FINDING: In no case was a husband with MS reported to receive principal caregiving from formal care services. Among wives with MS, 13% (n=3) reported receiving principal caregiving from formal care services. Although
these results are in the predicted direction, they do not reach statistical significance.

Formal attendants are secondary caregivers in 5 other cases. In total, 18% of the couples utilize some formal caregiving assistance. The services of the formal caregivers are paid for with out-of-pocket funds in each instance those services are utilized.

**Hypotheses 2a-2d**

The second set of hypotheses addresses factors that influence the number of hours that spouses spend in caregiving to their mates disabled by MS. A review of the correlation matrix of all variables included in these hypotheses, Table 8, demonstrates moderate to no correlations among the variables, thereby eliminating concern about multicollinearity among the independent variables. There are, in fact, no statistically significant correlations between any of these variables. Each of these hypotheses specifies that the variables MS spouse level of physical disability and gender of the spouse caregiver are intervening variables. These two variables are entered in the regression equation in one block. A general comment about the effect of the two intervening variables "MS patient level of physical
### Table 8

**Correlation Matrix**

**Caregiving Hours and Independent Variables**

<table>
<thead>
<tr>
<th>Correlations:</th>
<th>Caregiver Hrs/Mo Spent Caregiving</th>
<th>MS Patient Physical Disability</th>
<th>Caregiver Gender</th>
<th>Caregiver Cognitive Disability</th>
<th>Caregiver Competing Roles</th>
<th>Caregiver Hrs Employed Outside Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Caregiver Hrs/Mo Spent Caregiving</td>
<td>--</td>
<td>.34</td>
<td>--</td>
<td>.10</td>
<td>--</td>
<td>.08</td>
</tr>
<tr>
<td>MS Patient Physical Disability</td>
<td>.34</td>
<td>--</td>
<td>--</td>
<td>.10</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Caregiver Gender</td>
<td>.10</td>
<td>.20</td>
<td>.01</td>
<td>.24</td>
<td>.26</td>
<td>.08</td>
</tr>
<tr>
<td>MS Patient Cognitive Disability</td>
<td>.10</td>
<td>.20</td>
<td>.01</td>
<td>.24</td>
<td>.26</td>
<td>.08</td>
</tr>
<tr>
<td>Caregiver Competing Roles</td>
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<td>.03</td>
<td>.18</td>
<td>.08</td>
<td>.20</td>
<td>.08</td>
</tr>
<tr>
<td>Caregiver Hours Employed Outside Home</td>
<td>.07</td>
<td>.25</td>
<td>.07</td>
<td>.18</td>
<td>.20</td>
<td>.08</td>
</tr>
<tr>
<td>Total Caregiver Dyadic Adjustment</td>
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<td>.16</td>
<td>-.21</td>
<td>-.24</td>
<td>-.33</td>
<td>-.20</td>
</tr>
</tbody>
</table>

**Minimum pairwise N of cases:** 38

**2-tailed signif:** * - .01  ** - .001
Table 9  
**Multiple Regression Results for Factors Influencing Total Hours Spent in Caregiving**

<table>
<thead>
<tr>
<th>Predictor Variable</th>
<th>$\beta^2$</th>
<th>df</th>
<th>$F$</th>
<th>Beta</th>
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<tbody>
<tr>
<td>BLOCK 1</td>
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<tr>
<td>Ms Physical Disability</td>
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<td>.41</td>
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<tr>
<td>Caregiver Gender</td>
<td></td>
<td></td>
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<td>-.08</td>
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<tr>
<td>BLOCK 2</td>
<td>.21</td>
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<td>3.2*</td>
<td>.27</td>
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<tr>
<td>MS Cognitive Disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BLOCK 1</td>
<td>.12</td>
<td>2/41</td>
<td>2.8</td>
<td>.34</td>
</tr>
<tr>
<td>Ms Physical Disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Gender</td>
<td></td>
<td></td>
<td></td>
<td>-.04</td>
</tr>
<tr>
<td>BLOCK 2</td>
<td>.12</td>
<td>3/40</td>
<td>1.8</td>
<td>.00</td>
</tr>
<tr>
<td>Caregiver Competing</td>
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<td></td>
</tr>
<tr>
<td>BLOCK 1</td>
<td>.13</td>
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<td>2.9</td>
<td>.35</td>
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<tr>
<td>Ms Physical Disability</td>
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<td>Caregiver Gender</td>
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<td>BLOCK 1</td>
<td>.14</td>
<td>2/24</td>
<td>1.9</td>
<td>.32</td>
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<tr>
<td>Ms Physical Disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Gender</td>
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<td></td>
<td></td>
<td>.30</td>
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<tr>
<td>BLOCK 2</td>
<td>.42</td>
<td>3/23</td>
<td>5.53**</td>
<td>.54</td>
</tr>
<tr>
<td>Caregiver Hours Employed</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>BLOCK 1</td>
<td>.12</td>
<td>2/41</td>
<td>2.8</td>
<td>.32</td>
</tr>
<tr>
<td>Ms Physical Disability</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Gender</td>
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<td></td>
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<td>-.01</td>
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<td>3/40</td>
<td>2.06</td>
<td>.13</td>
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<tr>
<td>Caregiver Dyadic Adjustment</td>
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<td></td>
</tr>
</tbody>
</table>

*: $p \leq .05$  
**: $p \leq .01$  

1. After controlling for "MS - spouse level of physical burden "and" gender of non-MS spouse
disability" and "gender of the spouse caregiver" on this set of hypotheses is made before analyzing the individual regressions. As in indicated in Table 9, regression analysis Betas demonstrates that in each of these hypotheses the level of physical disability has a relatively high influence on the total number of caregiving hours provided. Using the same data, spouse caregiver gender offers a relatively low explained variance.

HYPOTHESIS 2a. Controlling for MS patient level of physical disability and the gender of the spouse caregiver, the greater the cognitive impairment of the MS patient, the greater the number of hours of caregiving assistance provided by the spouse caregiver to the MS patient.

FINDING: The addition of the level of cognitive disability to the equation increases the explained variance beyond that produced by the physical disability score alone. The total equation results include $R^2 = .21$, $F = 3.18$, $p < .05$. The level of cognitive disability increases the amount of explained variance in the number of caregiving hours provided in the predicted direction
although it does not demonstrate statistical significance, \( p = .09 \). Because the size of the sample is small the significance of this association is considered suggestive of the hypothesized relationship. Of the three variable included in this regression, the level of cognitive disability offers the relatively second strongest explanation of variance, Beta=.27.

HYPOTHESIS 2b. Controlling for the MS patient level of physical disability and gender of the spouse caregiver, the greater the number of competing role involvements of the spouse caregiver, the fewer the number of hours of caregiving assistance provided by the spouse caregiver to the spouse with MS.

FINDING: The addition of the number of competing roles in which the spouse caregiver participates to the equation does not increase the explained variance beyond that produced by the level of physical disability alone. Rather, the addition of this variable increases the error variance beyond that measured when the physical disability score and gender of the well spouse are entered into the equation. The total equation results include \( R^2 = .12 \), \( F=1.79 \) and was not significant. The
number of competing roles in which the spouse caregiver participates has virtually no impact on the explained variance of the number of hours that the spouse spends in providing caregiving assistance. Although the variable number of competing roles in which the spouse caregiver participates offers the relatively second strongest explanation of variance, Beta=.02, in this equation, it virtually amounts to zero.

HYPOTHESIS 2c. Controlling for the MS patient level of physical disability and the gender of the spouse caregiver, the greater the number of hours spent in gainful employment by the spouse caregiver, the fewer the number of hours of caregiving assistance provided by the spouse caregiver to the MS patient. FINDING: This hypothesis, as stated, includes all spouse caregivers, regardless of their employment outside the home. Those currently not employed outside the home are calculated to have 0 hours of paid employment. Using this strategy, the number of hours spent in gainful employment has no relation to the number of caregiving hours provided when the variables MS patient level of physical disability and the gender of the spouse
caregiver are statistically controlled. The total equation results include $R^2 = .17$, $F = 2.51$, $p = .07$. The number of hours spent in employment outside the home effects the number of caregiving hours provided in the predicted direction although it does not demonstrate statistical significance.

A secondary analysis of this hypothesis that includes only those spouses involved in some level of gainful employment outside the home ($n=27$) is indicated. This secondary analysis establishes a very different set of relationships than those found in the original equation. With the inclusion of the variables MS patient level of physical disability and gender of the spouse caregiver in the first block of this equation, $R^2 = .14$. In the second block of the two-step regression, the inclusion of the variable hours spent in gainful employment increases the explained variance, $R^2 = .42$. The overall equation is statistically significant, $F = 5.53$, $p < .01$. This revised equation greatly increases the explained variance. The influence of the individual variables on the explained variance in this revised equation is notable. There is a statistically significant association between the number of hours the
spouse caregiver spends in gainful employment and the number of hours that spouse spends in providing caregiving assistance to the spouse, p<.001. This relationship is in the opposite to predicted direction. The greater the number of hours these working spouses spend in gainful employment the greater the number of hours that they also spend in providing caregiving assistance. Additional review of study data is necessary to generate hypotheses to explain this finding. A possible explanation of this phenomena is that among couples in the lower socioeconomic groups, the caregiving spouses must work longer hours in order to support the family and are also unable to pay for assistance or have other family members to help out. A competing explanation is that those who work outside the home benefit from better emotional health than those who are home more and have more energy for caregiving. Additional research to investigate these explanations would be of benefit.

HYPOTHESIS 2d. Controlling for the MS patient level of physical disability and gender of the spouse caregiver, the lower the marital satisfaction experienced by the
spouse caregiver, the fewer the number of hours of
caregiving assistance provided by the spouse caregiver to
the MS patient.

FINDING: This 3 step regression does not yield
significant results $R^2 = .13$, $F = 2.06$, $p = .12$. Only the
level of physical disability is a significant variable in
the equation, $p < .05$.

**Hypotheses 3a-3f**

The third set of hypotheses addresses factors that
influence the burden associated with caregiving
experienced by spouse caregivers. In these regressions
it is the gender of the spouse caregiver, rather than the
level of physical disability of the spouse caregiver,
that is more likely to influence the dependent variable.
A correlation matrix of all variables included in these
hypotheses, Table 10, demonstrates limited correlations
among the variables. This eliminates concern about
multicolinearity among the independent variable. The
only significant relationship in this matrix is that
exists between wife caregivers and longer durations of
marriage. However, this relationship does not appear to
other relationships in the study. Table 11 summarizes
the results of this series of regressions.
Table 10

Correlation Matrix

<table>
<thead>
<tr>
<th>Burden Score and Independent Variables</th>
<th>Caregiver Subjective Burden</th>
<th>MS Patient Physical Disability</th>
<th>Caregiver Cognitive Disability</th>
<th>Patient Caregiving Hrs/Mo</th>
<th>Caregiver Competing Roles</th>
<th>Caregiver Dyadic Adjustment</th>
<th>Years Married</th>
<th>Children In Household</th>
</tr>
</thead>
<tbody>
<tr>
<td>Correlations:</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Caregiver Subjective Burden</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>MS Patient Physical Disability</td>
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<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Caregiver Gender</td>
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<td>.20</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>MS Patient Cognitive Disability</td>
<td>-.03</td>
<td>-.24</td>
<td>.26</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Caregiver Hrs/Mo Spent Caregiving</td>
<td>.18</td>
<td>34</td>
<td>-.10</td>
<td>-.01</td>
<td>--</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Caregiver Competing Roles</td>
<td>.27</td>
<td>.03</td>
<td>.18</td>
<td>.08</td>
<td>-.00</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Caregiver Dyadic Adjustment</td>
<td>-.59 **</td>
<td>.16</td>
<td>-.21</td>
<td>-.24</td>
<td>.18</td>
<td>-.33</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>Years Married</td>
<td>-.34</td>
<td>.38</td>
<td>-.48 **</td>
<td>-.12</td>
<td>-.25</td>
<td>-.32</td>
<td>.33</td>
<td>--</td>
</tr>
<tr>
<td>Children In Household</td>
<td>.18</td>
<td>.05</td>
<td>.08</td>
<td>-.04</td>
<td>-.03</td>
<td>.24</td>
<td>-.33</td>
<td>-.22</td>
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</tbody>
</table>

Minimum pairwise N of cases: 41
2-tailed Signif: ** - .001
Table 11

Multiple Regression Results for Factors Influencing
**Mrs. Spouse Subjective Burden**

<table>
<thead>
<tr>
<th>Predictor</th>
<th>R^2</th>
<th>df</th>
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<th>p-value</th>
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<tr>
<td><strong>BLOCK 1</strong></td>
<td></td>
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<tr>
<td><strong>Mrs. Physical Disability</strong></td>
<td>.07</td>
<td>4/37</td>
<td>1.32</td>
<td>.08</td>
</tr>
<tr>
<td>Caregiver Gender</td>
<td></td>
<td></td>
<td></td>
<td>.32</td>
</tr>
<tr>
<td><strong>BLOCK 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mrs. Physical Disability</strong></td>
<td>.13</td>
<td>1/26</td>
<td>1.76</td>
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<tr>
<td><strong>Cognitive Disability</strong></td>
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<tr>
<td><strong>BLOCK 1</strong></td>
<td></td>
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<tr>
<td><strong>Mrs. Physical Disability</strong></td>
<td>.02</td>
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<td>.42</td>
<td>.44</td>
</tr>
<tr>
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<td></td>
<td></td>
<td>.05</td>
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<tr>
<td><strong>BLOCK 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Caregiver Hrs/Mo Caregiving</strong></td>
<td>.05</td>
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<td>.70</td>
<td>.18</td>
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<tr>
<td><strong>BLOCK 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mrs. Physical Disability</strong></td>
<td>.02</td>
<td>2/41</td>
<td>.42</td>
<td>.04</td>
</tr>
<tr>
<td>Caregiver Gender</td>
<td></td>
<td></td>
<td></td>
<td>.05</td>
</tr>
<tr>
<td><strong>BLOCK 2</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Caregiver Competing Roles</strong></td>
<td>.08</td>
<td>3/40</td>
<td>1.21</td>
<td>.26</td>
</tr>
<tr>
<td><strong>BLOCK 1</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Mrs. Physical Disability</strong></td>
<td>.02</td>
<td>2/41</td>
<td>.42</td>
<td>.05</td>
</tr>
<tr>
<td>Caregiver Gender</td>
<td></td>
<td></td>
<td></td>
<td>.02</td>
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<tr>
<td><strong>BLOCK 2</strong></td>
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<tr>
<td><strong>Caregiver Psychiatric Adjustm</strong></td>
<td>.36</td>
<td>3/40</td>
<td>7.5**</td>
<td>.52</td>
</tr>
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<tr>
<td><strong>Mrs. Physical Disability</strong></td>
<td>.02</td>
<td>2/41</td>
<td>.42</td>
<td>.00</td>
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<td>Caregiver Gender</td>
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<td><strong>BLOCK 2</strong></td>
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<tr>
<td>Years Married</td>
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<td>3/40</td>
<td>1.21</td>
<td>.19</td>
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<td>.03</td>
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<tr>
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<tr>
<td>Children Under 13 in Household</td>
<td>.05</td>
<td>1/40</td>
<td>.70</td>
<td>.16</td>
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</table>

** Note: df = degrees of freedom. **p < .01

1 After controlling for "Mrs. Spouse level of physical burden" and gender of non-Mrs. spouse. **
HYPOTHESIS 3a. Controlling for the MS patient level of physical disability and the gender of the spouse caregiver, the greater the extent of MS patient cognitive impairment, the greater the level of perceived burden experience by the spouse caregiver.

FINDING: The regression that includes these variables does not show a statistically significant influence of cognitive impairment on the amount of perceived burden, $R^2 = .13$, $F=1.76$, $p=.17$. Of the three variable included in this regression, the level of cognitive impairment of the MS spouse offers relatively the second strongest explanation of variance in the perceived burden of the spouses caregivers $\text{Beta}=-.26$.

HYPOTHESIS 3b. Controlling for the MS patient level of physical disability and gender of the spouse caregiver, the greater the amount of caregiving assistance provided by the spouse caregiver to the MS patient, the greater the level of perceived burden experienced by the spouse caregiver.

FINDING: The regression that includes these variables does not indicate a statistically significant influence of caregiving hours on the amount of perceived burden
experienced by the spouse caregiver when the variables MS patient level of physical disability and the gender of the spouse caregiver are statistically controlled, $R^2=.05$, $F=.70$, $p=.55$. Of the three variable included in this regression, the number of hours spent in caregiving by the spouse caregiver offers relatively strongest explanation of variance, Beta=-.18. This finding is in the opposite to predicted direction but is consistent with the finding that the greater the number of hours spent in gainful employment, the greater the number of hours spent in caregiving.

HYPOTHESIS 3c. Controlling for MS patient level of physical disability and gender of the spouse caregiver, the greater the number of competing role involvements of the spouse caregiver, the greater the level of perceived burden experience by the spouse caregiver.

FINDING: The regression that includes these variables does not indicate a statistically significant influence of number of competing roles in which the spouse caregiver participates on the amount of perceived burden, $R^2=.08$, $F=1.21$, $p=.32$. Of the three variable included in
this regression, the number of competing roles offers the relatively strongest explanation of variance, Beta=.26.

HYPOTHESIS 3d. Controlling for MS patient level of physical disability and gender of the spouse caregiver, the lower the marital satisfaction of the spouse caregiver, the greater the level of perceived burden experience by the spouse caregiver.

FINDING: The hypothesis is strongly supported. With the inclusion of the variables MS patient level of physical disability and gender of the spouse caregiver in the first block of this equation, \( R^2 = .02 \). In the second block of the two-step regression, the inclusion of the variable marital satisfaction increases the explained variance, \( R^2 = .41 \). The overall equation is statistically significant, \( F = 7.35, p < .001 \). Of the three variable included in this regression, the level of marital satisfaction offers relatively the strongest explanation of variance, Beta= -.60. Considering the association of each of the independent variables with the dependent variable, neither the level of physical disability, nor the gender of the spouse caregiver, demonstrate a significant statistical association. There is a
statistically significant inverse association between the level of marital satisfaction and level of perceived burden. That is, lower levels of marital satisfaction are associated with higher levels of burden, $t = -4.6$, $p < .001$.

HYPOTHESIS 3e. Controlling for MS patient level of physical disability and gender of the spouse caregiver, the fewer the number of years the couple has been married, the greater the level of perceived burden experienced by the spouse caregiver.

FINDING: The two-step regression does not demonstrate statistical significance, $R^2 = .13$, $F = 1.91$, $p = .14$. Of the three variable included in this regression, the level of cognitive impairment of the MS patient offers relatively the strongest explanation of variance, Beta = -.39. Considering the strength of the relationships of each of the dependent variables with the independent variable, neither the level of physical disability ($p = .57$) nor gender of spouse caregiver ($p = .85$) has a linear relationship with the level of burden. However, there is a statistically inverse relation between the number of years the couple has been married and the level of burden.
experience by the spouse caregiver (p<.05). That is, the fewer the years that the couple has been married, the greater the burden experienced by the spouse caregiver.

HYPOTHESIS 3f. Controlling for MS patient level of physical disability and gender of the spouse caregiver, the greater the number of children under the age of 13 in the household, the greater the level of perceived burden experienced by the spouse caregiver.

FINDING: The two-step regression does not demonstrate statistical significance, $R^2=.05$, F=71, p=.55. Of the three variables included in the regression, the number of children under the age of 13 in the household offers relatively the strongest explanation of variance, Beta=.18.
Discussion

Summary

This study was constructed to gain information about a caregiving population that has not been well described in the literature, working age spouses of persons with MS. Factors associated with availability or willingness to participate in spouse caregiving have not been described among those married to people with MS. There is, however, a significant literature about caregiving to elders and adult children that can influence the current study. Review of that literature about informal caregivers indicates that certain factors influence involvement in, and reaction to, caregiving. Research indicates that such factors include demographic characteristics, the type of illness experienced by the disabled spouse, sources of support to assist in caregiving, quality of the relationship between the caregiver and care recipient, as well as additional responsibilities and personal interests the caregiver maintains in addition to caregiving.

Results of this study about a category of caregivers who have not been well described in the psychosocial literature include:

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* a description of relevant characteristics of spouse caregivers whose mates are MS patients
* a review of those individuals who assistance the caregiving spouse in meeting the needs of MS patients
* a report of some of the crucial ways that spouse caregivers managing care needs of their mates who are MS patients household routines
* an examination of the correlations between caregiving spouse characteristics and involvement in caregiving
* an analysis of the correlation between spouse caregiver characteristics and spouse caregiver emotional reaction to caregiving involvement.

The spouse caregivers included in this survey are all actively involved in caregiving to their spouses disabled by MS. They spend a mean of 59 hours a month in various aspects of care provision. This involvement is comparable to the time commitment of caregivers to the frail elderly (Stone, 1987; The Travelers Companies, 1985). In general, their physical health is comparable to others of their age who are not involved in caregiving. They experience a slightly higher level of
overall emotional distress than is common to the normative population (Derogatis, 1986), but experience a level of marital satisfaction that is, on average, within the limits of the general population (Spanier, 1976).

These caregiving spouses represent a relatively even distribution of women and men who are on average 50 years of age. A large majority of the caregiving spouses are employed outside the home. They have been in their current marriages for a mean of 24 years and have been dealing with MS related disability for a mean of 13 years. A majority of the respondents are white. This racial distribution is not characteristic of the disease incidence but is representative of the patient population of the medical facility utilized to obtain the sample. The participants are residents of urban and suburban communities who benefit from educational backgrounds and current household incomes that are above the norm for the area.

The spouses to whom they provide care experience significant physical and cognitive disability, compared to the general MS population, (National Multiple Sclerosis Society, unpublished data).
Although the caregiving spouses do provide the vast majority of care that their disabled mates receive, there are additional sources of assistance. Most commonly this assistance comes from the children of these couples. The majority of these caregiving offspring are of school age. This represents a different utilization of secondary caregivers compared to categories of other persons in need of chronic care (Cantor, 1985; Shanas, 1979; Stephens and Christianson, 1986). However, as is typical with others who manage chronic illness (Bass and Noelker, 1987; Hock and Hemmens, 1987; Soldo, 1985), there is limited utilization of formal sources of caregiving assistance. The formal services are used most commonly by families whose wives are disabled by MS. Those formal services that are used are paid for out of pocket. Caregiving spouse respondents spend the time they devote to activities of caregiving, in descending order, performing homemaking activities, assisting with MS patient personal care activities, and, finally, helping with activities of daily living. Men and women spend comparable amounts of time in the helping activities. This finding is different than that noted in most other studies that investigated gender differences in
caregiving (Bass and Noelker, 1987; Brody, 1985; Hirst, 1985; Stoller, 1983). Spouses of both genders report comparable increases in the amount of time devoted to all three categories of caregiving activities since the onset of MS disability. This is similar to the caregiving patterns of aged couples (Stone, 1983).

The variables that were hypothesized to influence the amount of time that caregiving spouses spend in assistance to their disabled mates include: level of physical disability of the MS patient; gender of the spouse caregiver; level of cognitive disability of the MS patient; number of competing roles in which the spouse caregiver participates; number of hours spent in gainful employment by the caregiving spouse; and the level dyadic adjustment experienced by the caregiving spouses. Of these hypothesized factors, the levels of physical and cognitive disability as well as the number of hours that those who are employed do spend working affect the amount of time that spouses devote to caregiving assistance. This latter finding is of surprise, however, because the relationship is in the opposite to predicted direction. That is the greater the number of hours that the spouse caregiver works, the greater the number of hours that
spouse devotes to caregiving. Possible alternative explanations for this relationship have been discussed and need to be explored. The gender of the spouse caregiver and the level of dyadic adjustment do not affect caregiving provided in the sample surveyed. These dynamics are different than those caregivers of comparable age and varying levels of marital distress who provide parent care at different levels of intensity (Cicerelli, 1983). It appears that the caregiving spouses in the present study have made a commitment to their care responsibilities that perhaps extends beyond the traditional expectations of a marriage.

The variables that were hypothesized to influence the amount of burden that the caregiving spouses experience because of their caregiving include: level of physical disability of the MS patient; gender of the spouse caregiver; level of cognitive disability of the MS patient; number of hours that the spouse caregiver devotes to caregiving; number of competing roles in which the spouse caregiver participates; number of years the couple have been married; and number of children under the age of 13 years who reside in the home. Of these, only the level of dyadic adjustment and number of years
the couple have been married influence the level of burden experienced by the spouse caregiving spouse. As predicted, based on the work of Olson, McCubbin, Barnes, and Larsen (1983), these variables are both inversely related to the level of subjective burden. The greater the number of years married, the lower the burden. The lower the level of dyadic adjustment, the greater the burden. It should be noted that many of the non-significant relationships were in the predicted direction and several approached statistical significance. Possibly, the sample size was simply too small to gain statistically significant explained variances among the variables included in the regression equations.

Conclusions

This study sample of caregiving spouses is composed of men and women who are for the most part, of middle age, enduring marriages, good education and comfortable financial means. They are a group of spouse caregivers who "have made it" in dealing with the disability and its consequences within the marriage on average for more than a decade. Their spouses are objectively in need of significant amounts of care. The spouse caregivers are indeed the "mainstays" for meeting care needs. There are
few differences between men and women in how much spouse caregiving they provide. These data are consistent with several aspects of the literature review. Hirst (1985) identified a trend among men of younger age, compared to the elder men who held more traditional values, to assist in the care of their disabled children. It is possible that the similarity between women and men in their caregiving involvement indicate a similarity in the way that the two groups of working professional choose to reconcile their dual commitments (Brody, 1985).

The data indicate that caregiving wives are more likely to experience a sense of subjective burden than are caregiving husbands in reaction to that involvement. Perhaps, just as there have been different normative standards set for the two genders for Brief Symptom Inventory, the Zarit Burden Interview should have similar gender based norms established.

As evidenced by the regression analysis, physical and cognitive MS impairments are two of the strongest predictors of the objective stress of hours spent in caregiving by the spouse caregivers. It is interesting to note that the number of work hours, a variable that is perhaps less possible to modify because of the need of
income and benefits, does influence the number of hours spent in caregiving. The number of competing role involvements, a variable that is more easy to modify so as to accommodate caregiving demands, does not influence the number of hours spent in caregiving. Based on the direct relation between number of hours spent in gainful employment and number of hours spent in caregiving, it appears that those spouses involved in gainful employment outside the home feel an even stronger responsibility for meeting spouse care needs than those who are not so employed. This may represent an extension for spouses of both genders of the "super mom" syndrome that many working women face.

By far, the regression that includes "level of physical disability", "gender of the spouse caregiver" and "hours spent in gainful employment" explains the greatest amount of variance in the number of hours spent in caregiving for those who work. For all those surveyed the regression that includes "level of physical disability", "gender of the spouse caregiver" and "level of cognitive dysfunction" explains the greatest amount of variance in the number of hours spent by all caregivers. However, these proposed relationships do not provide a
statistically or theoretically adequate explanation of the factors that are associated with the hours spent in caregiving. Again, this lack of statistical significance may be related to the relatively small sample size. The possibility that some caregiving spouses are committed to the marriage and caregiving responsibilities because of religious or societal expectations but develop close relationships with others that compensates for the diminished marital relationship.

As noted, the spouse caregivers in this study are committed to their marriages and to their caregiving involvement. Many commented that MS has become just one aspect of their family lives and that they simply "do what has to be done". Based on available data it is not possible to determine the source of this commitment. Identification of factors that foster this commitment would increase the understanding of motivating factors for this population. Given the strength of the relationship of working and caregiving, different aspects of the work environment and career orientation should be investigated. It is possible that for some spouses, employment offers a beneficial and socially sanctioned respite opportunity that would not be otherwise
available. Knowledge of this population, based on clinical experience, indicates that spouse caregivers who benefit from flexible work environments as well as empathetic employers and co-workers consider those associations to be a major source of support.

The objective burden of caregiving is not associated with the subjective reaction to that circumstance. The level of physical disability of the MS-spouse has only a weak association with the subjective reaction by the spouse caregiver to that circumstance. The effects of the cognitive disability, number of competing role involvements, and number of children under the age of 13 residing in the household do have relatively stronger explanatory power. Additional investigation of the consequences of MS patient cognitive impairment may reveal that it is not as behaviorally disruptive as the cognitive changes associated with Alzheimer Disease patients. It is possible that this dementia does not produce the same behavioral sequelae and is therefore less emotionally burdensome. Although the impact of competing roles on the reaction to caregiving is not significant, it does offer relatively stronger explanatory power compared to other factors that have
been demonstrated to influence subjective burden in other caregiving populations. It is possible that with additional refinements to this role survey, its use may yield more significant results. Because of the age of the study sample and their relatively mature families, it is possible that the impact of children on the emotional reactions could not be adequately assessed. Conversely, given the active involvement of children in caregiving it is possible that the presence of these offspring in the household poses more of an emotional asset than a liability.

It is the quality of the relationship, as evidenced by dyadic adjustment, and years in the marriage that are associated with the experience of burden. It seems that these spouses who are relatively far along in their marriages demonstrate adjustments similar to their aged counterparts (Zarit, 1986). The strong relationship between dyadic adjustment and subjective experience of emotional burden provides an indication that the MS-related caregiving and marital relationship become closely intertwined. The second relationship of note is the inverse association between the duration of the marriage and level of burden. Although the objective
impact of the disease certainly does not lessen with passing years, the subjective response to the disability does. This finding may be an artifact of the fact that typical marriages improve during middle age because life stresses gradually resolve.

Although they are the primary caregivers, spouse caregivers do have assistance in meeting care needs. More than half of those spouse caregivers interviewed have such caregiving support. This help comes most often from family members, usually school age children, who shared the household. The use of formal services is not common for either meeting housekeeping responsibilities or direct care needs. This is rather surprising even given that lack of entitlement to federal and community sources of assistance. Since these families have relatively good financial resources, the purchase of formal care services would be anticipated to be utilized more frequently than is the case. Reasons for this limited use of formal care services warrants additional investigation to determine if such involvement might lessen the emotional burden on the caregiving spouse. The utilization of formal health care services, if only on an intermittent basis for teaching purposes, may
reduce the medical complications experienced by the MS patient. Finally, the use of such services could have an even more significant impact on those couples who did not participate in this investigation and who are believed to be more emotionally troubled by the caregiving.

**Limitations**

This investigation provides insight about the circumstances of a select group of respondents who are committed to their marriages, have comfortable financial resources, and sources of assistance in meeting caregiving responsibility. This is a small, homogeneous, and self-selected study group although it is adequate for addressing the hypothesized relationships. This data will be useful for formulating future investigations but will not be directly generalizable.

Although many of the hypothesized relationships examined in this study were in the predicted direction, they did not reach statistical significance. A larger study sample may have produced stronger relationships.

Those interviewed come from similar geographic, socioeconomic and ethnic backgrounds. It is therefore
difficult to generalize these findings to couples who do not share these characteristics.

Based on available data, all couples from the Mellen Center data base who were invited to participate do have similar geographic, socioeconomic and ethnic backgrounds. Still, nearly one third of the married couples invited to participate in the study declined to be interviewed. The dynamics of the couples who were not interviewed may be very different than those who were surveyed in regards to available resources, amounts of caregiving provided, and emotional reactions to that involvement. It may be surmised that those couples who agreed to be interviewed consider their circumstances and relationships satisfactory enough to reveal such personal information to interviewers. Likewise, those who are less willing to be interviewed may face more negative dynamics or circumstances.

The cross-sectional nature of the study design also poses limitations. It is not possible to ascertain the different stages of adjustment these couples traversed before reaching their current functioning. Neither does this study provide information about the dynamics of once married couples who are now divorced. Additional
research is needed in order to describe the "natural history" of spouse caregiving and its consequences.

In addition to the limitations produced by the small sample size and cross-sectional nature of the study, there are also some weaknesses in the instrumentation used to obtain the data. Few of the survey questionnaires have known psychometric values. However, all the surveys include items suggested by a well developed literature and represent an improvement on open-ended interviews that have been used in other, similar, studies. In addition, two of the surveys, "Activities of Caregiving" and "ADL Self-Care Scale" represent rather minor modifications of instruments that have been subjected to the rigors of psychometric assessment. Measures used to assess attitudinal variables do have known psychometric properties and the behavioral variables have strong face validity. Many of the behavioral measures are dependent on respondent recall over a one month period of time. This recall may be influenced by poor recollection as well as by emotional factors associated with those behaviors. However, the quality of these data are comparable to that
obtained in similar research about other groups of caregivers.

Despite these limitations, this research does have implications for increased understanding of the psychosocial dynamics of informal caregiving.

**Implications For Practice**

Because the involvement of spouses is assumed to be so crucial to the care of persons with MS, it is important for health care providers to understand the availability and capacity of these spouse caregivers to provide care to their spouses who are MS patients. Study results indicate that it is important to devote as much attention to caregiving husbands as to caregiving wives because of the similarities in both the care they provide and their reactions to that caregiving.

Concern about the adequacy of care in terms of time available to provide the needed assistance is of special importance among those caregiving spouses who work.

Although there is not a direct relationship between the objective provision of care and the subjective reaction to that caregiving, the data does indicate that there are negative impacts on the health of the
caregiving spouses. It is important to support health conscious behavior among these spouse caregivers, especially in regards to the physical demands of their caregiving. Instruction about transfer techniques, recommendations about appropriate equipment, as well as about environmental accommodations can be particularly important.

The data do not indicate causality in the relation between marital satisfaction and caregiving burden but the association is a strong one. Interventions directed to supporting a positive marital relationship may be one of the best modalities available for alleviating burden.

Given the limited information gained about the use of formal sources of assistance in this population, it is difficult to make practice recommendations about this source of caregiving assistance.

Children of persons with MS are apparently actively involved in the provision of care to their disabled parents. Little is known about the consequences to these children because of their caregiving involvement. Despite the lack of empirical or theoretical knowledge about this group of schoolage caregivers, it is important to turn our practice attention to them.
These data reveal that caregiving is not strictly in the realm of otherwise non-employed persons who have "time available" to take on this responsibility. These women and men are active members of the work force who represent of potentially strong special interest group. Information gained from this study does advance the understanding of caregiving available in the psychosocial literature. These contributions include information about a relatively poorly described group of caregivers, working age adults. Also of significance is the information gained about the similarity of involvement in caregiving between husbands and wives. The study provides insight about emotional reactions to caregiving involvements and the accommodations spouses have made in their role involvements in order to provide caregiving. This information can be helpful in increasing the understanding of caregivers for other working age chronic disability groups such as families managing rheumatoid arthritis, head injury or AIDS.

Implications For Research

This research reveals many similarities between the present sample and other caregiving populations. It also reveals differences that warrant additional
investigation. Longitudinal studies will reveal the natural history of these marriages and how the care needs are met during different phases of the illness and marriage. These future studies should attempt to gain information about couples who are stressed, possibly to the point of neglectful or abusive relationships. Samples of subsequent study should be extended to include a more heterogeneous population of spouse caregivers.

Future studies should investigate factors that motivate spouses to remain committed to the marriage and determine what characteristics of work life influence caregiving. A longitudinal study would increase understanding of the interplay of the relationship between dyadic adjustment and caregiving burden. It would also provide an opportunity to examine the characteristics of those marriages or caregiving arrangements that end and factors that contribute to those dissolutions.

Other investigations are also indicated based on the findings of this study. These should examine factors that contribute to the low utilization of formal care services and the interest in and barriers to such utilization. It is also recommended that a separate
avenue of investigation be undertaken that addresses the children who provide care to their parents, the impact that this behavior has on concurrent emotional and academic development as well as on future emotional well-being. The consequences to these caregiving children potentially have very far reaching effects.

The findings of this research clearly establish that the management of the consequences of MS is truly a family affair. In order to offer comprehensive health management, policy recommendations and research directions, it is essential to consider the impact of this illness on the caregivers as well as those disabled by the disease.
BIBLIOGRAPHY


APPENDIX A
DEMOCRATIC PROFILE

Study Identification Number

Date of Interview

Location of Interview

Gender of Interviewee Male Female

1. What is your relationship to the person with M.S.? self spouse parent child other relative paid attendant other (specify)

2. Please tell me the year in which the M.S. was diagnosed?

3. Tell me the year when the M.S. most recently made assistance with walking necessary.

4. Now I'd like to know the name, age, and relationship to you of all members of your household. Begin by counting yourself.

<table>
<thead>
<tr>
<th>Name</th>
<th>Age</th>
<th>Relationship</th>
<th>M.S. Person</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>

M.S. Person does not share household with EC.

5. Which one of these people is the person who has M.S.? (Interviewer, make "X" by M.S. person or by "does not share household" as appropriate).

6. Just to make sure that I have this count right, am I correct that you have ___ permanent members of your household.

Write count ___

7. And you have ___ children who are 13 years of age or younger who are permanent members of your household.

Write count ___
Study Identification Number: _________________________________

Date: _________________________________

The next 10 questions give me some background information about you.

5. What is your race?
   - White
   - Black
   - Asian
   - Hispanic
   - Native American
   - Other

6. What is your date of birth?

7. What is your current marital status?
   - Single
   - Married
   - Co-habiting
   - Widowed
   - Divorced

   If married:
   7a. How long have you been in this marriage?

8. Have you ever been married before?
   - Yes
   - No

   If yes,
   8a. How many times?

9. How many years of education have you received?

10. What is the highest academic degree that you have received?
    - High School
    - Trade/Associate Degree
    - BA/BS
    - MA/MS
    - Ph.D./M.D./etc.

11. Are you currently employed outside the home?
    - Yes
    - No

   If "Yes": SKIP 12; GO to 14.
   If "No": GO to 12.

12. If you are not presently working outside the home, what was the last year you worked outside the home. If you have never been employed outside the home, just tell me "never".

   __________
Study Identification Number: ________________________________

Date: ____________________________________________

12. If you are not working outside the home, why is that? (Read choice, mark one):
   by choice
   Can't find work
   Age retirement
   Disabled
   Other (specify)
   ____________________

14. What is your current occupation? ________________________________

15. How long have you been at this occupation? ____________________

16. Would you say that you view your occupation as a JOB or as a CAREER?
   Job
   Career
   ____________________

17. Have you experienced a change in the number of hours that you work outside the home since the onset of M.S. disability?
   Yes
   No
   ____________________

   If "Yes": GO to 18.
   If "No": SKIP 16, 17, 20; GO to 21.

18. If you have experienced a change in the number of hours that you work outside the home since the onset of M.S. disability, in what year did that change occur?
   Year
   ____________________

19. What kind of change in the number of hours that you work outside the home have you experienced?
   Stopped working entirely
   Decreased # of hours
   Increased # of hours
   Started working
   ____________________

20. What would you say is the reason for this change?
   ____________________
Identify: Identification Number: ___________________________

Date: ___________________________

21. Before M.S. disability, what was the primary source of your household income? (Read choices)
   - Your earned income
   - Spouse's earned income
   - Other family's earned income
   - Social Security Disability
   - Employer paid disability
   - Supplemental Security Income
   - General Relief
   - Social Security Retirement
   - Employer paid retirement

22. Currently, what is the primary source of your household income? (Read choices)
   - Your earned income
   - Spouse's earned income
   - Other family's earned income
   - Social Security Disability
   - Employer paid disability
   - Supplemental Security Income
   - General Relief
   - Social Security Retirement
   - Employer paid employment

23. What is your current yearly household income?: ___________________________

24. Do you yourself have any health problems or limiting conditions? Yes ___ No ___

25a. If yes, please tell me what they are: ___________________________

25. What type of insurance do you have:
   - Private ___ Medicare ___
   - Medicaid ___ HMO ___
   - Other ___ D/H ___

26. During the past year, have you yourself used your insurance for any of the following outpatient visits:
   a. doctor/nurse _____, number of visits _____
   b. occupational therapist _____, number of visits _____
   c. physical therapist _____, number of visits _____
   d. psychiatrist _____, number of visits _____
   e. psychologist _____, number of visits _____
Study Identification Number: _____________________________

Date: ____________________________________________

27. Can you estimate the proportion of your medical expenses that your health insurance covered for these services?

28. Have you ever delayed or decided not to get outpatient health care because of concern for the amount your insurance will pay?
   Yes ____ No ____

29. During the past year, have you used this insurance for any of the following home health visits?:
   a. nurse___, ______ number of visits ___
   b. home health aid___, ______ number of visits ___
   c. occupational therapy___, ______ number of visits ___
   d. physical therapy___, ______ number of visits ___

30. Can you estimate the proportion of your medical expenses that your health insurance covered for these services?

31. Have you ever delayed or decided not to get home health care because of concern for the amount your insurance will pay?
   Yes ____ No ____

32. During the past year have you been hospitalized? Yes ____ No ____ For how many days?

33. Can you estimate the proportion of your medical expenses that your health insurance covered for these services?

34. Have you ever delayed or decided not to get hospital care because of concern for the amount your insurance will pay?
   Yes ____ No ____

This ends the care recipient demographic profile. Proceed to the next interview questionnaire.

For all caregivers, proceed to Question 35.
Study Identification Number: __________________________

Date: __________________________________________

THE FOLLOWING QUESTIONS ARE FOR CAREGIVERS ONLY.

31. How long have you been giving care specifically for M.S.? _________

36. Do you live in the same household as the person with M.S.? 
   Yes _____ No _____

37. How long have you been living with this person? 

38. In thinking about the person who provides the greatest number of hours of assistance to (the M.S. Person), who would you say that is? 
   Note name & relationship 

39. Under what, if any, circumstances would you step aside from your caregiving involvement? 

40. What outcome (e.g. nursing home placement, divorce, adult child moves in and takes over, etc.) would you foresee? 

41. What in your opinion would be the ideal caregiving situation? 

42. What have you found yourself doing that you would have never thought possible before M.S. became a problem? 

43. M.S. is often described as taking a heavy toll on relationships. Is there anything in particular that you find difficult to deal with? 

44. What rewards are there for you in your present role as caretaker? 

THIS ENDS THE NON-SPouse CAREGIVER DEMOGRAPHIC PROFILE. FOR NON-SPouse CAREGIVERS, THE INTERVIEW IS COMPLETE.

FOR ALL SPouse CAREGIVERS, PROCEED TO QUESTION 45.
RELATIONSHIP BETWEEN CARE RECIPIENT AND SPOUSE

45. Think of a time before M.S. and describe your relationship
with your husband/life.

46. What is your relationship like now?

47. In what ways has your relationship changed?

48. What would you change if you could?

49. What are the activities that you can no longer do with your spouse
but would like to?

DMM/Kob

6/22/89
ROLE SURVEY

INTRODUCTION

As we go through our daily routines, we take on a number of roles which help give meaning to our lives. Each role is made up of sets of activities that we carry out with particular people within specified situations. Some roles are very important to us, while others require little time and effort. Sometimes we take on new roles as when we become parents for the first time, sometimes we drop roles that no longer fit into our lifestyles and schedules, for example when we graduate from school and are no longer students.

We would like to learn about the different roles that you have assumed and how your roles are affected by the presence of Multiple Sclerosis in your household. This questionnaire includes twelve roles that other people have said that they frequently play (you can probably think of others). We would like to find out which roles you currently hold and how you may have changed roles compared to a time before M.S. became disabling to your loved one.

INSTRUCTIONS

For each of the twelve roles there are 3 questions about your involvement in that role before M.S. and 3 questions about your involvement in that role currently.

First go through the list and answer all the questions about your role involvements before M.S. Then go back to the top of the current role involvements that is within the last 12 months.

Question A Please read each role description then decide if that role fits you. Mark yes for each role that applies to your situation (most people will have several roles).

Question B For each role that is a "yes", estimate the number of hours per month you are engaged in that role.

Question C For each "yes" role rate how important or meaningful that role is to you and your well being. Rate the importance somewhere between 1. little importance and 5 very important. (1 = somewhat important; 2 = moderately important; 3 = important).

Remember, first answer all the questions about PERIOD PRIOR, then answer the questions about your CURRENT role involvements.
<table>
<thead>
<tr>
<th>ROLE SURVEY</th>
<th>BEFORE M.S.</th>
<th>CURRENTLY</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. SPouse: married person; activities involved in an ongoing intimate, sharing relationship, including ongoing sexual relationship and cohabitation.</td>
<td>a: yes/no</td>
<td>yes/nc</td>
</tr>
<tr>
<td></td>
<td>b:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>c:</td>
<td></td>
</tr>
<tr>
<td>2. PARENT: has children in household natural or adoptive; activities related to raising children and providing for their welfare and supervision (e.g. feeding, clothing, providing financial support, driving them to school and community events; etc.).</td>
<td>a: yes/no</td>
<td>yes/no</td>
</tr>
<tr>
<td></td>
<td>b:</td>
<td></td>
</tr>
<tr>
<td></td>
<td>c:</td>
<td></td>
</tr>
<tr>
<td>3. CAREGIVER to other adult family member: engaged in activities related to nursing and medical care, providing comfort and help with grooming and self-care of adult family member other than spouse (e.g. aging or disabled parent).</td>
<td>a: yes/no</td>
<td>yes/nc</td>
</tr>
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<td>b:</td>
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<td></td>
<td>c:</td>
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<tr>
<td>4. WORKER: one who is engaged in paid employment, usually outside the home, in an effort to &quot;earn a living.&quot;</td>
<td>a: yes/no</td>
<td>yes/no</td>
</tr>
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<td></td>
<td>b:</td>
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<td></td>
<td>c:</td>
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<tr>
<td>5. HOMEOWNER: one who is engaged in activities of managing and operating a household (e.g. cooking, cleaning, shopping).</td>
<td>a: yes/no</td>
<td>yes/no</td>
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<td>b:</td>
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<td>6. STUDENT: enrolled in formal education classes for a grade, full or part-time, including class and preparation time (e.g. high school student, trade/technical school student).</td>
<td>a: yes/no</td>
<td>yes/nc</td>
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<td>b:</td>
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<tr>
<td>7. LEISURE: seeing one's self as engaged in recreational pursuits and other personal fulfillment activities, including sports, music and arts (e.g. cycling, hiking, stamp collecting, ballet, etc.). Idle study, reading for pleasure.</td>
<td>a: yes/no</td>
<td>yes/nc</td>
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</tbody>
</table>
STUDY IDENTIFICATION NUMBER: ________________________________

DATE: ________________________________

Before M.S. 
Currently

8. CITIZEN: activities of community involvement that is not primary employment; includes ward political activities, local PTA, attendance at council meetings, sitting on advisory boards, volunteer social services, etc.

   a) yes/no
   b) _______
   c) _______

9. PATIENT: one has a medical or other health condition such that one has to spend time going to doctors, taking medications, eating special diets or limiting activities (e.g., diabetes, heart disease, arthritis, mental/behavioral problems).

   a) yes/no
   b) _______
   c) _______

10. CHILD: one still depends on one's parents for financial support and decision making to some degree or is a minor in the household.

    a) yes/no
    b) _______
    c) _______

11. BABYSITTER: engaged in providing temporary care and supervision of other's children (e.g., grandchildren, nieces).

    a) yes/no
    b) _______
    c) _______

12. CAREGIVER: in spouse with M.S.: engaged in activities related to nursing and medical care, providing comfort and care, with grooming and self-care of one's spouse.

    a) yes/no
    b) _______
    c) _______
PLEAS NOTE

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University Microfilms International
CAREGIVING ACTIVITY SURVEY

INTRODUCTION: People who have multiple sclerosis need help with a wide variety of self-care tasks and activities of daily living. This is especially common after the point when they need help walking or are confined to a wheelchair. We would like to know how much you help with or perform a number of common tasks or activities as you care for your family member or friend who has M.S. in his/her home. For each activity listed below try to think about the proportion of assistance that you give, the amount of time involved, the importance of each activity, and whether there has been an increase or decrease in your efforts when compared to a time before the disability from M.S.

INSTRUCTIONS: Here are 18 common activities to consider. Please read each activity then mark each of the four lines that follow each activity. These questions relate to your involvement in the household of your family member or friend who has M.S. We know that this may or may not be your household as well. Mark "none" for any activity that does not apply to your situation or is unknown. Please follow these four steps:

1. On line "a", mark the amount of assistance you give ranging from 1 (no assistance) to 5 (do the task entirely on my own without help from patient).

2. On line "b", fill in the amount of time you spend in the caregiving activity by estimating the number of hours per month involved.

3. On line "c", rate the importance of the activity for the patient's well-being and mark the scale: 1 (little importance) to 5 (very important).

4. On line "d", compare your involvement in the activity currently to before M.S. became disabling and mark the amount of change on the scale: 1 (much less) to 3 (about the same) to 5 (much more) involved.
STUDY IDENTIFICATION NUMBER: ________________________________

DATE: ________________________________

CAREGIVING ACTIVITIES

1. Help the person with M.S. use the telephone (look up phone numbers, dial phone, etc).
   a. Assistance given: 1. none 2. some 3. moderate amount 4. a great deal 5. do it all myself
   b. Time spent: ____________ hrs/month
   c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
   d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more

2. Help the person with M.S. travel away from home, visit friends, meet appointments (need to accompany him or her, assist with getting in and out of vehicle, building elevators, etc).
   a. Assistance given: 1. none 2. some 3. moderate amount 4. a great deal 5. do it all myself
   b. Time spent: ____________ hrs/month
   c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
   d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more

3. Do grocery shopping for the household of the person with M.S.
   a. Assistance given: 1. none 2. some 3. moderate amount 4. a great deal 5. do it all myself
   b. Time spent: ____________ hrs/month
   c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
   d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more

4. Do housework in the home of the person with M.S.
   a. Assistance given: 1. none 2. some 3. moderate amount 4. a great deal 5. do it all myself
   b. Time spent: ____________ hrs/month
   c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
   d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more
5. Do handyman work around the house of the M.S. patient (e.g., simple household repairs, replacing broken window panes, painting, etc.)?
   a. Assistance given: 1. none 2. some 3. moderate 4. a great deal 5. do it all myself
   b. Time spent: hrs/month
   c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
   d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more

6. Do you do any laundry?
   a. Assistance given: 1. none 2. some 3. moderate 4. a great deal 5. do it all myself
   b. Time spent: hrs/month
   c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
   d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more

7. Help take medication (e.g., remind, mix, pour, administer)?
   a. Assistance given: 1. none 2. some 3. moderate 4. a great deal 5. do it all myself
   b. Time spent: hrs/month
   c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
   d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more

8. Do you help manage finances for the household?
   a. Assistance given: 1. none 2. some 3. moderate 4. a great deal 5. do it all myself
   b. Time spent: hrs/month
   c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
   d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more
9. Help the person with M.S. with personal correspondence (e.g., writing/sending letters, birthday cards, ordering things through the mail)?
   a. Assistance given: 1. none 2. some 3. moderate amount 4. a great deal 5. do it all myself
   b. Time spent: hrs/month
   c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
   d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more

10. Help the person with M.S. with meals (cut food, position glass, feed?)
    a. Assistance given: 1. none 2. some 3. moderate amount 4. a great deal 5. do it all myself
    b. Time spent: hrs/month
    c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
    d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more

11. Help the person with M.S. dress and undress?
    a. Assistance given: 1. none 2. some 3. moderate amount 4. a great deal 5. do it all myself
    b. Time spent: hrs/month
    c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
    d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more

12. Help the person with M.S. with personal grooming (e.g., comb hair, shave, apply make-up, brush teeth)?
    a. Assistance given: 1. none 2. some 3. moderate amount 4. a great deal 5. do it all myself
    b. Time spent: hrs/month
    c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
    d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more
STUDY IDENTIFICATION NUMBER: ____________________________

DATE: ____________________________

13. Help care recipient get around inside house at apartment (assist standing, walking)?
   a. Assistance given: 1. none 2. some 3. moderate amount 4. a great deal 5. do it all myself
   b. Time spent: ______ hrs/month
   c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
   d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more

14. Help care recipient with bath or shower, or give sponge bath or bed bath?
   a. Assistance given: 1. none 2. some 3. moderate amount 4. a great deal 5. do it all myself
   b. Time spent: ______ hrs/month
   c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
   d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more

15. Help care recipient with toileting (go to the bathroom and assisting on and off the toilet, changing catheter, administer suppositories and enemas)?
   a. Assistance given: 1. none 2. some 3. moderate amount 4. a great deal 5. do it all myself
   b. Time spent: ______ hrs/month
   c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
   d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more
16. Help care recipient get in and out of the bed?
   a. Assistance given: 1. none 2. some 3. moderate amount 4. a great deal 5. do it all myself  
   b. Time spent: ______ hrs/month
   c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
   d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more

17. Provide emotional support to care recipient in dealing with M.S. (e.g. act as a confidant, help your spouse express and explore feelings about having M.S.) and help care recipient cope on a day to day basis?
   a. Assistance given: 1. none 2. some 3. moderate amount 4. a great deal 5. do it all myself
   b. Time spent: ______ hrs/month
   c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
   d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more

18. Help manage care recipient's M.S. treatment (e.g. making appointments, helping patient understand treatments, coordinate social agency and home care services, arrange for alternate care from family members, run interference with institutional bureaucracies)?
   a. Assistance given: 1. none 2. some 3. moderate amount 4. a great deal 5. do it all myself
   b. Time spent: ______ hrs/month
   c. Well being: 1. little importance 2. somewhat important 3. moderately important 4. important 5. very important
   d. Change in involvement: 1. much less 2. less 3. about the same 4. more 5. much more