WIVES' PERCEPTIONS OF SOCIAL SUPPORT
WHILE CARING FOR HUSBANDS WITH MULTIPLE SCLEROSIS

By
TONI CLARE STOVEL
B.Sc.N., The University of Victoria, 1981

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Department of Nursing

The University of British Columbia
1956 Main Mall
Vancouver, Canada
V6T 1Y3

Date Oct 12th 1988
ABSTRACT

WIVES' PERCEPTIONS OF SOCIAL SUPPORT
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This study was designed to gain an understanding of wives' perceptions of social support while living with and caring for husbands who have multiple sclerosis. In order to understand the experience from the perspective of the participants the qualitative method of phenomenology was chosen.

Data collection and data analysis occurred concurrently. Data were collected through unstructured interviews with each of the eight wives who participated. Each transcribed interview was analyzed separately and in relation to the other interviews. Emerging themes were validated and clarified by the participants in the second interview. Eventually an organizing framework emerged that revealed two central themes common to the wives' perceptions of social support.

The first central theme describes the wives caregiving experience which was the context for understanding the wives' perceptions of social support. Within this central theme three sub-themes are explored: the commitment of these wives in providing care to their husbands, their desire to have some distance from
caregiving, and ambivalence arising from the simultaneous and conflicting desires to provide care and to distance from caregiving.

The second central theme describes the nature of support as perceived by the wives. This theme builds upon the first theme and discusses three sub-themes: support for caregiving, support for distancing, and support for ambivalence. Support for caregiving discusses information, practical assistance, acknowledgement, and finances. Support for distancing discusses social activities, professional services, and anticipatory support. Support for ambivalence discusses the desire these wives have to be understood.

These findings are discussed in relation to the socialization of women into expressive and caring roles. Furthermore, the reasons why these wives had difficulty in accepting support are explored. The implications for nursing practice, education, and research are delineated in light of these findings.
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CHAPTER 1
INTRODUCTION TO THE STUDY

Introduction

Multiple sclerosis is usually a progressively disabling chronic illness in which people require assistance with daily activities. Due to the social and economic benefits of keeping people in their homes this assistance is often provided by family members. Within the family, those most likely to assume the role of caregiver are women (Brody, 1895; Shanas, 1979a; 1979b) and it is female spouses who experience the greatest degree of burden as caregivers (Cantor, 1983).

Caregiving is associated with physical and psycho-social symptoms of stress, anxiety, and burnout (Ekberg, 1986; Isaacs, 1971; Lindgren, 1985). As well, caregiving is associated with role conflict and role fatigue due to competing familial and occupational demands (Goldstein, Regnery and Wellin, 1981). This is particularly true of mid-life wives such as seen in families with multiple sclerosis.

Although caregiving can be a stressful situation, research shows that the burden of caregiving can be modified by available social support such as family visits, or practical assistance from family, friends, and
health professionals (Zarit and Zarit, 1982). However, it is not clear that all sources and types of support are equal. As well, the need for, and benefits of support lie primarily in the subjective perception of the caregiver. Even so, there is limited research available that explores the qualitative aspects of social support. It is therefore critical that health care providers gain an understanding of social support from the perspective of careproviders.

The chronic nature of multiple sclerosis, the number of women who provide family care, the apparent burden of caregiving, and the subjective nature of social support reflect the importance of exploring social support from the perspective of wives who provide care to husbands with multiple sclerosis. It is only through this understanding that nurses will be able to offer these caregivers support in a meaningful way.

Background To The Problem

Over the past thirty years Canadian health surveys have shown a dramatic rise in chronic illness (Peron and Strohmenger, 1985). In order to respond effectively to this trend, health professionals, such as nurses, must become aware of the multiple problems faced by individuals and families living with chronic illnesses. The most demanding problems include: managing regimens,
controlling symptoms, time management, preventing social isolation, adjusting to changes in disease trajectory, and normalizing life (Strauss, 1979). Strauss also points out that in handling these problems, families develop basic strategies that require financial, familial, and professional resources, as well as interactional and social skills in order to mobilize those resources. Therefore, the resources available to the family, such as formal and informal support, become crucial to the management of day-to-day living when coping with a chronic illness.

One chronic illness that requires resource management by both the individual and family members is multiple sclerosis. Multiple sclerosis is a disabling disease of the central nervous system. Onset occurs primarily between the ages of 20 to 40 and women are 40% more likely to be affected than men (Russell, 1985). The prevalence rate in Canada ranges from 21.2 to 111 per 100,000 while the rate in British Columbia is 93.3 per 100,000 (Sweeney, Sadovnick and Brandejs, 1986).

The symptomology of multiple sclerosis is varied. Some individuals experience little or no symptom progression from the time of onset. The majority, however, experience either continuous progressive deterioration, or periods of remittance and relapse with progressive deterioration. The symptoms of multiple
sclerosis may occur singly or in combination. Most commonly, symptoms include problems in vision, speech, coordination, sensation, use of extremities, and bowel and bladder control (Matson and Brooks, 1977). Other symptoms include conceptual impairment and loss of memory for recent events (Surridge, 1969), extreme fatigue (Kraft, Freal and Coryell, 1986), emotional euphoria and depression (Surridge, 1969; Whitlock and Siskind, 1980).

Due to the disabling and long term effects of the disease, it is understandable that families are greatly affected by the problems the disease imposes. At a time when families are raising children, planning careers and often carrying heavy financial responsibilities the onset of a disabling disease such as multiple sclerosis can be devastating.

In recent years there has been a growing interest in studying the caregiving role of family members. This has come about for several reasons. First, family caregivers have been a long neglected and invisible group, even though family provided care is a long established pattern (Soldo and Myllyluoma, 1983). Second, there are social benefits in maintaining the family unit and third, it is economically beneficial to society to maintain the chronically ill outside of formally established institutions. Finally, with the rise in chronic illness and shifts toward community based family-provided care it
is expected that more and more people will spend a part of their lives as caregivers (Cutler, 1985). In fact, Brody (1985) suggests that the caregiver role (particularly parent care) is becoming so common that it be considered a normal and predictable life course experience.

In response to the recent interest in the family caregiving role researchers have begun to study family-provided home care. A number of studies indicate that families are typically "the first line of defence against institutionalization" (Soldo and Myllyluoma, 1983) and willingly provide care until the burden is perceived to be too great (Chenoweth and Spencer, 1986; Colerick and George, 1986; Soldo and Myllyluoma, 1983). In a study by Isaacs (1971), one-third of the patients were placed in a geriatric institution primarily to relieve strain on family members: "strain of such severity as to constitute a threat to either the physical or mental health of relatives" (p.284).

The literature shows that the strain of caregiving is multidimensional. Caregiving is associated with physical and psychological symptoms of burnout, depression and loneliness (Ekberg, 1986), low levels of life satisfaction (Fengler and Goodrich, (1979), and social isolation and financial concerns (Chenoweth and Spencer, 1986). In addition, when caregivers are compared
to available norms they score substantially lower in social participation, affect balance, and life satisfaction (George and Gwyther, 1986).

Studies show there is usually one family member identified as the primary caregiver and due to persistent sex-role differences women are much more likely to assume this role (Brody, 1985; Shanas, 1979b; Soldo and Myllyluoma, 1983). In fact, 85% of caregivers are women, leading Sommers (1985) to state that "family" provided care is a euphemism for the "closest female relative" (p.10).

In addition to women being the predominant providers of home care, some research shows that women, compared to men, receive less support from family, friends, and health providers (Johnson, 1983; Polansky, 1982). For example, Polansky (1982) in a study of 80 caregivers found that 65% of the male caregivers received formal assistance compared to 42% of the female caregivers.

It is interesting to speculate why female caregivers receive less support than their male counterparts. Caregiving is often perceived as an extension of the traditional woman's role. Traditionally, women's primary and most valued social role has been to protect, nurture, and foster the growth of others, particularly family members (Adams, 1971). Therefore, it may be assumed that women are more skilled and willing to provide care than
men which may lead to fewer offers of assistance. It may also be that some women refuse assistance because they view offers of assistance as a judgement on their competence as wife or homemaker. It is erroneous however, to assume that the role of wife and homemaker is comparable to the role of caregiver. It is not until women are given the opportunity to tell their story that we will understand social support from the unique perspective of women in the caregiving role.

Although there is clear evidence that perceived social support promotes well-being and inhibits disease (Cobb, 1976; Caplan, 1964; Pilisuk and Froland, 1978; Shumaker and Brownell, 1984) there has been little research exploring support within the context of caregiving. There has been even less research exploring the subjective nature of social support. This is particularly important as it is the subjective perception of support rather than the frequency of support, that correlates with positive health outcomes for the caregiver (Zarit and Zarit, 1982).

At this time we know very little about women's perceptions of support while in the caregiving role. What we do know is that the caregiving role is often arduous and overwhelming in its demands, and that social support is linked to well-being. This suggests that women caregivers would likely benefit from social support. But
what type of support would be beneficial for women? What meaning do women give to social support? How does support fit into the context of caregiving? As health providers, nurses are the major source of formal support to families with chronically ill members. Therefore, it becomes imperative to understand social support from the perspective of the women themselves.

Problem Statement

Parallel to the increase in chronic illness is an increase in family provided home care. In recent years an abundant amount of research has become available on family caregiving, some of which focuses on women. However, the majority of this research is quantitative in nature and specifically addresses caregivers of the elderly. To date there is very little qualitative research on women as caregivers to the chronically ill, and no studies available on wives as caregivers to husbands with multiple sclerosis. Because available research indicates that caregiving is associated with physical and psychosocial burden, and evidence shows that this burden may be moderated by perceived availability of social support, it is important that caregiver perceptions of social support be explored. At present there is a lack of knowledge and understanding of social
Support as articulated by wives who provide care to husbands with multiple sclerosis.

Purpose Of The Study

The purpose of this study is to explore and describe social support as perceived and experienced by women who live with and provide care to husbands with multiple sclerosis.

Definition Of Terms

1. Caregiver: A wife who is responsible for providing or coordinating daily activities while living with a husband who has multiple sclerosis.

2. Multiple Sclerosis: A chronic disease of the central nervous system, usually progressive in nature and characterized by either exacerbations and remissions or continuous progression. Symptoms occur singly or in combination and commonly include malfunction in vision, speech, coordination, sensation, use of extremities, and control of bowel and bladder (Hashimoto and Paty, 1986).

3. Social Support: An individual's perception of having his or her need for practical assistance, information, affection, esteem, understanding and acceptance fulfilled through actual or symbolic interaction with others.
Assumptions

The researcher assumes that social support has an impact on the experience of women living with and providing care to husbands with multiple sclerosis. It is also assumed that women are willing and able to talk openly and honestly, thereby giving an accurate account of their perception of reality.

Limitations

This study is limited by the characteristics of the participants in this study. That is, this study only examines the experience of social support in wives who: a) are of anglo-saxon background, b) live in or near Vancouver, c) are associated with the Multiple Sclerosis Society, and d) are married and living with husbands who have multiple sclerosis. In addition, the number of participants is limited due to the time constraints of a master's thesis. It is acknowledged that these limitations produce a sample that represents a select group of women and thus the findings may not have the depth and richness of a more comprehensive sample.

Summary

This chapter has provided the background for examining wives' perceptions of social support while living with and caring for husbands with multiple
sclerosis within the context of a nursing problem. The purpose of this study was presented as were the definition of terms, the assumptions, and the limitations. The following chapter will review the available research considered relevant to this study.
CHAPTER 2
SELECTED LITERATURE REVIEW

Introduction

Social support has received much attention in academic literature. Although the study of social support is plagued with conceptual problems, research into this phenomenon repeatedly shows that perceived support is associated with physical and psychological health and low levels of support are linked with high levels of stress. Clearly, the onset of a chronic disabling disease such as multiple sclerosis is a stressful event, and families, particularly women, are often the primary providers of care to ill family members. The provision of care is also perceived to be a burden and is associated with high levels of stress. However, there has been little research which examines perceptions of social support while caring for a family member with a chronic illness, and there was no research found that has examined wives' perceptions of social support while living with and caring for husbands who have multiple sclerosis.

The literature review is divided into two sections. The first section reviews the theoretical conceptualizations of social support, and addresses the major contributions towards understanding this phenomena. The second section reviews selected research that
examines informal social support provided to caregivers, formal support provided to caregivers, and the relationship between social support and the health of family caregivers.

Theoretical Conceptualizations of Social Support

Social support is an important concept in the realm of nursing practice. Not only does an assessment of social support have implications for nursing interventions, nurses are major providers of support to individuals and families dealing with illness. Consequently, there is an increased need for nurses to understand social support as a factor in health and illness. One of the difficulties is that the research on social support has been primarily atheoretical (Brownell and Shumaker, 1984) and as a result the concept of social support is not clearly defined. The purpose of this section is to provide an overview of the major contributions toward understanding this concept.

An early contributor to the study of social support was Gerald Caplan, a social psychiatrist. In 1964, Caplan presented a mental health model that focused on the role of significant others in maintaining the psychological and physical integrity of the individual over time. Caplan (1964) held that one's primary social group had
the power to positively (or negatively) influence the health outcomes for individual members.

Building upon this earlier work Caplan (1974) expanded this conceptualization of social support to include three elements in which the significant others: (a) help mobilize the individual's psychological resources in order to deal with emotional burdens; (b) share tasks; and (c) provide the individual with extra supplies of money, materials, tools, skills, and cognitive guidance to improve the individual's ability to handle the situation. Using this understanding, social support provided to wives of husbands with multiple sclerosis might include emotional or instrumental aid, or the provision of goods or information, all of which serve to improve the wives' ability to provide care to their husbands. Caplan (1974) claimed that "such support may be of a continuing nature or intermittent and short-term and may be utilized from time to time by the individual in the event of an acute need or crisis" (pp.5-6).

Departing from Caplan's belief that support includes instrumental aid (sharing tasks), Sidney Cobb (1976) identified support as consisting of three types of information. The first type of information leads the person to believe he or she is cared for and loved. This information is transmitted in intimate situations involving mutual trust whereby the person's needs for
affiliation and nurturance are satisfied. In social support literature this type of support is often called emotional support. The second type of information leads the person to believe he or she is valued and esteemed. This information is transmitted in social or work situations and reaffirms the person's sense of personal worth. In social support literature this type of support is often called esteem support. The third type of information leads the person to believe that he or she belongs to a network of communication and mutual obligation. This type of information leads people to know the other people in the network and provides information relevant to accessing goods, services, and resources.

Cobb has excluded instrumental aid as a component of support as he believes that the actual provision of goods and services may foster dependency, while information as he describes it tends to encourage independent behaviour. This conceptualization holds that although caregivers may have multiple tasks to perform, the provision of practical assistance will foster dependency and thus likely compromise the caregiver's self-esteem.

Weiss (1974) conceptualizes support as the quality of feeling sustained through the gratification of needs. Weiss investigated newly divorced people, and women who had recently moved to accommodate their husband's employment. What he discovered was that different types
of relationships provided different kinds of support. For example, the loss of intimate relationships resulted in the "loneliness of emotional isolation" (p.20) and could not be reconciled through friendships. The loss of friendships resulted in the "loneliness of social isolation" (p.20) even though the women were happily married. In applying these findings to caregiving situations the potential exists for a wife whose marital relationship has deteriorated due to the advance of multiple sclerosis, to experience "the loneliness of emotional isolation". In addition, the increasing demands of caregiving may lead to fewer opportunities for social contact thus resulting in "the loneliness of social isolation".

More recently, the idea of "two participants" has been added to the conceptualization of social support. Shumaker and Brownell (1984) define social support as "an exchange of resources between two individuals, perceived by the provider or the recipient to be intended to enhance the well-being of the recipient" (p.11). In this definition, the exchange of support may be positive, negative, or neutral (Shumaker and Brownell, 1984). This type of conceptualization is useful in understanding social support from the perspective of the wives of husbands with multiple sclerosis. What may be intended and perceived as helpful by the provider may not be
perceived similarly by the recipient. For example, is the support provided by health care professionals perceived by the caregiver, to be as useful as intended by the providers?

In the above conceptualization of social support reciprocity is the central theme. Shumaker and Brownell agree with Gouldner (1980) that a norm of reciprocity operates within our culture and that people usually return the benefits received from others. Greenberg (1980) contends that in receiving a benefit the recipient will experience an uncomfortable state of tension or indebtedness. To reduce this tension the recipient will reciprocate either directly or indirectly, or may even refuse the offered support.

In cases of chronic illness, where help is often needed over an extended time period, "the recipient's inability to reciprocate fully may become increasingly apparent and asking for help may become especially difficult" (Shumaker and Brownell, 1984, p.14). If reciprocity cannot be fulfilled, then relationships between the people involved may disintegrate. For example, caregiving wives may over time, be less able to reciprocate due to intensified caregiving demands. Thus, at a time when they most need support these women may find that their relationships have weakened and they
might even refuse help because they feel uncomfortable in their inability to reciprocate.

Although definitions of social support vary considerably, the underlying assumption of all investigations of this phenomena is that "supported people are physically and emotionally healthier than non-supported people" (Shumaker and Brownell, 1984, p.22). Many studies have provided evidence of the relationship between support and well-being, however, there is a lack of agreement about how social support promotes well-being.

Currently, two models attempt to explain how social support protects health and prevents disease. According to Robertson (1987), one model proposes that social support "has a direct effect on health and well-being and therefore, is beneficial on an on-going basis, regardless of whether or not a person is under stress" (p.191). The alternate model holds that support affects the well-being of an individual only when he or she is under stress. This model is called the "buffering model" because it assumes that support protects people "from the potentially pathogenic influence of stressful events" (p.191). In this model the perception of support increases the individual's ability to cope with the real or perceived stressor. In an extensive review of the research, Cohen and Wills (1985) concluded that there is
Social Support And Caregivers

Although the concepts of social support and caregivers have received substantial attention in the literature, few studies have explored social support from the perspective of the caregiver. Those studies that are available primarily focus on the support needs of elderly caregivers. Consequently, this literature review reflects social support as reported by elderly caregivers. Although not specific to the purpose of this study this body of literature is considered relevant due to the predominant focus on female and spousal perceptions of support which provide a basis for understanding mid-life wives' perceptions of support while caring for husbands with multiple sclerosis. Initially reviewed is the available research that examines informal social support provided to caregivers. Next, the formal support provided to caregivers is reviewed and finally, the relationship between social support and the well-being of caregivers is addressed.

Informal Social Support Available to Caregivers

A limited number of studies were found that explored informal social support available to caregivers. This
section reviews four studies that focus on caregivers' perceptions of social support received from family members and friends.

One study that offers insight into family-provided support to caregivers is by Scott, Roberto, and Hutton (1986). Scott and associates examined the instrumental, social-emotional, and perceived adequacy of support provided by families to 23 primary caregivers of Alzheimer's patients. Of the caregivers, 20 were spouses and three were daughters with a total of 15 female caregivers. The mean age of all caregivers was 64.4 years. In addition, there were 21 other family members included in the interviews. Ratings of all types of instrumental assistance, such as financial help, physical care of the patient, and providing information, were derived by summing the number of different types of help. Social-emotional support, coded as low, moderate, or high, was rated on two dimensions consisting of the degree of positive affect and the degree of negative affect. Adequacy of total support (instrumental and social-emotional) was coded as "more than enough support", "enough support", and "not enough support".

The findings of this study show that the major tasks of caregiving were the responsibility of the primary caregiver. There was negligible financial assistance and only three of the 21 family members assisted with
accompanying the patient to and from doctor appointments, while only seven family members assisted with domestic help such as cleaning or cooking. Moreover, few family members (n=5) visited the caregiver or patient and few (n=5) assisted with the physical tasks of caregiving. The most frequent type of assistance included providing respite care such as staying with the patient or taking the patient out (n=11), and providing information or advice (n=9). The types of assistance most appreciated by caregivers were home visits and having someone stay with the patient so that the caregiver could take a trip, rest, run errands, or get out of the house for social activities. These findings show that although caregivers appreciate specific types of assistance, family members provide little in the way of instrumental support.

Fifteen of the 23 caregivers indicated a cohesive style of caregiving in which there was high positive social-emotional support from family members. These caregivers expressed few family problems related to care of the patient. This may be due, however, to the finding that the primary caregiver received little assistance with actual patient care, thus decreasing the probability for conflict. The remaining caregivers (n=8) reported a combination of positive and negative levels of social-emotional support. The kinds of problems reported included lack of visits from family members,
disagreements over the type of care required, and disagreements over the patient's functioning capacity.

Finally, caregivers were rated on their perceived satisfaction with the amount of total instrumental and social-emotional support received. One-third (n=8) of the caregivers received more than enough support, 11 received enough support, and four received less than adequate support. This last category mentioned infrequent visits by family members, lack of situational understanding, and lack of assistance with housework or respite care as some of the areas where support was lacking. Overall, the majority of caregivers were satisfied with the support they received.

Although the findings of this study cannot be generalized due to the limitation of sample size, it is interesting to speculate why caregivers in this study are generally satisfied with the minimal amount of support they receive. Perhaps the answer lies in our societal expectations of the marital dyad in which the promise of "for better or worse" allows spousal caregivers to expand their expectations of marriage according to their current circumstances. If the partners have been a primary source of support for each other through their married years, it may be they expect to continue this during a long term illness without assistance from family or friends. Perhaps it is difficult for some spouses to acknowledge
the need for assistance if it is seen to reflect on their sense of competence as careprovider. A final reason these caregivers were satisfied could be that they were elderly, and compared to mid-life caregivers, were likely to be "free of competing demands that would tend to increase caregiver dissatisfaction" (Hess and Soldo, 1985, p.81).

Satisfaction and dissatisfaction with caregiving was explored in a qualitative study of 47 caregivers by Marcus and Jaeger (1982) who found that certain aspects of support contributed to the degree of satisfaction with the caregiving role. When asked the question "What makes a day easy/difficult?", four themes emerged. Caregivers reported that being relieved from the routine of caregiving made life easier, visitors eased their burden, caregiving was easier when the carereceiver was not sick, and being tied to the house was difficult to tolerate. In response to the question "Of all the things you do for your relative what gives you the most satisfaction, the most pleasure?", the most frequent responses (n=20) were: coping, getting results, receiving recognition, "to know I am doing a good job". These responses were followed by: seeing improvement in the carereceiver, distractions from caregiving, companionship, "that I still have somebody to talk to", and finally "nothing gives me pleasure". The results of this research show the importance of both
instrumental and emotional support as perceived by the caregivers themselves. In addition, it also seems that satisfaction gained from providing good care likely heightens the caregiver's self-esteem.

Repeated research shows that spouses, when available, willingly assume the responsibility of primary caregiver (Cantor, 1983; Johnson, 1983; Shanas, 1979b). Cantor (1975; 1980) describes the hierarchical nature of support in which friends and neighbors assist only when family members are not available and that within the family there is one person, usually female, who assumes primary responsibility. Eggert and associates (1977) found that in severe chronic conditions family supports become eroded over time. Presumably then, a wife caring for a husband with a debilitating illness such as multiple sclerosis, will not only assume major caregiving responsibilities but may find that support is only available when she is unable to fulfill the role herself. This next study compares support available to spousal caregivers versus other-family-member caregivers.

In an exploratory study, Johnson (1983) investigated social support in dyadic family relations, using a sample of 167 families of post-hospitalized elderly persons. Not surprisingly, among those patients who were married (45%), the spouse (66% female) was identified as the major caregiver. Thirty-nine percent of the primary
caregivers were off-spring (59% female) and 16% of the primary caregivers were other relatives.

Consistent with Cantor's findings Johnson found that family members are available as caregivers in serial order. Shanas (1979a) conceptualizes this as the "principle of substitution" whereby if one individual is unable to help, another will step in. In this study, married patients, whose spouse was almost always the major caregiver, received much less support from the off-spring than in situations where the patient was widowed. In families where a spouse was present the children were less available as a source of support for either the caregiver or receiver. Johnson also noted that the more personalized care, such as housekeeping, shopping and personal hygiene of the patient, were rarely performed by an off-spring when a spousal caregiver was present. The areas in which off-spring did assist their caregiving parent was with shopping and chauffeuring. Even when off-spring were the major caregivers the frequency of their support to the disabled parent was less than when a spouse was caregiver. In addition, off-spring, typical of mid-life caregivers, were more likely to describe ambivalence and conflict in their role and reported more competing demands stemming from other commitments.

Further to the Johnson study, in which there was limited instrumental support available to spousal
caregivers, Fitting, Rabins, Lucas and Eastham (1986) found a high degree of emotional support provided to spousal caregivers. All 54 caregivers in their study spoke with a friend or family member at least once a week and the majority spoke with someone on a daily basis. Seventy-three percent of spousal caregivers reported having an adult child as a confidant and 80% had at least one child with whom they had a reciprocal relationship. A relationship was defined as reciprocal if the confidant was reported to discuss his or her problems with the respondent. Eighty-five percent of the male and female spousal caregivers identified a reciprocal relationship with at least one confidant. Further, 96% of the husband caregivers and 100% of the female caregivers had at least one confidante with whom they discussed their problems.

Interestingly, 16.7%, mainly male caregivers, reported an improvement in their spousal relationship since the onset of the dementing illness, while 42.6%, mainly female caregivers, reported a deterioration in their relationship. This might suggest that wife caregivers receive less spousal support than husband caregivers.

This section has addressed informal social support provided to family caregivers. The available research shows that spousal caregivers, most frequently female, receive less support from family and friends than other
caregiver categories. The studies presented show that primary caregivers receive limited instrumental support but are generally satisfied with the emotional support received. The following section addresses formal support received by caregivers.

**Formal Social Support Available to Caregivers**

Given the limited amount of instrumental support wife caregivers receive from family and friends, and the expressed desire for relief from caregiving responsibilities, it is important to explore the role of health care professionals in the provision of formal support to primary caregivers. It is interesting to note the paucity of available research in this area, and consequently the following five studies provide limited insight into formal services available to caregivers.

In addition to examining informal supports, Johnson (1983), studied the use of formal supports by caregivers. In a study of 167 families she found that the use of all formal supports was lower among spousal caregivers than non-spousal caregivers. In fact, formal supports were used by only 13% of spousal caregivers, 26% by offspring caregivers, and 40% by "other relative" caregivers. She suggests that spousal caregivers use less formal supports because of the North American family system. "Husbands and wives are expected not only to
fulfill one's instrumental needs but also to provide social and emotional satisfaction" (p.382). Therefore, it should not be surprising that spousal caregivers expect continuity of these marital expectations when facing chronic illness, and consequently seek and use less formal support than off-spring or other-family-member caregivers.

In analyzing the marital dyad, Johnson (1983) found that husband caregivers were more likely to seek formal services than wife caregivers. Moreover, husband caregivers received more support from other family members. Johnson suggests this is a predictable finding given the lower participation by males in domestic functions in general. As well, husband caregivers experienced significantly less strain, possibly a result of receiving more support from family, relatives and formal services. It should be noted that in addition to not defining "formal supports", Johnson did not attempt to discover the caregivers' perception of satisfaction with received assistance. Thus the usefulness of these findings is limited.

Congruent with Johnson's findings, Polansky (1982), in a study of 80 elderly caregivers, concluded that most caregivers performed strenuous nursing tasks unaided and that fewer than half received formal home services. In addition, she found that 65% of the male caregivers
(husbands and sons) received formal health services whereas only 42% of the female caregivers (wives and daughters) had such help. Furthermore, 44% of the male caregivers received services more than three days a week, whereas only 13% of the females had help that frequently. She attributed this in part to health personnel being less willing to offer assistance when the caregiver is female. Again, the caregivers' perception of satisfaction with formal supports was not addressed.

In contrast, Marcus and Jaeger (1982), in a Canadian study of 47 elderly caregivers, found that male and female caregivers received proportionately the same level of formal services and that all but two caregivers received some form of formal assistance. This difference may be a reflection of the Canadian system of universal health care: this might be particularly relevant for mid-life wives whose husbands are no longer able to contribute financially. When formal health care does not drain finances, women might be more receptive to accepting these services.

In discussing the availability of formal support services to caregivers, the research findings of Archbold (1980) are worth noting. Archbold used a focused interview approach with six families who had an elderly parent one or more years post-stroke. Typically, a female mid-life offspring was the primary caregiver. Archbold
reported that all families agreed that not enough home services had been provided when their post-stroke parent was discharged from the rehabilitation hospital. As well, no professional assessment had been undertaken to evaluate the family's ability to cope physically, emotionally, or financially with the recovering patient. All families reported they were unprepared and that they "did not remember any health professional discussing the issues related to the care-giving situation" (p.81).

In conjunction with the general lack of formal support services, the families experienced a loss of contact with the health care system. Once the family was judged as managing adequately, services were discontinued. This left the family physician (who was not involved with the treatment and therefore less able to provide the needed information) as the only health care professional involved with the family. The result was that families felt stranded and were left with no direct line to those most familiar with their problems. This experience is corroborated by Hayter (1982) and Waso (1985), who found that families were often frustrated and distrustful of the health care system. Caregivers in these two studies reported that once a diagnosis was made, physicians tended to withdraw their services, leaving the caregiver with feelings of hopelessness and limited guidelines for performing their role.
In a Canadian study, Robertson and Reisner (1982) interviewed 26 primary caregivers of persons with dementia. All but one of the caregivers were female, 11 were spouses, 8 were daughters. The average age of the caregivers was 60.5 years. The caregivers' knowledge and utilization of home support services was assessed, as was their expressed need for these services. Although women caring for husbands with multiple sclerosis do not have to deal with the same memory and behavioral deteriorations as seen with dementia, the gender of the sample and the Canadian context closely fit the parameters of this thesis.

More than one-half (n=17) of the caregivers expressed the need for community relief services such as day care, holiday and weekend relief. Approximately the same number (n=14) were aware of these services. Despite this, these services were being utilized by only four of the women. The authors suggest that this may reflect a lack of accessibility of these services, or that the existing services do not meet the perceived needs of the caregivers.

Most of the caregivers who expressed a need for home nursing (n=14), meals-on-wheels (n=5), or social work services (n=11) were in fact receiving these services. However, only one-half of the caregivers who expressed the need for homemaking services (n=14) were actually
receiving those services. This was an unexpected finding as these services are readily available. The authors speculate that cost may have been acting as a deterrent.

In summary, this research shows there is limited understanding of formal health support services provided to caregivers. Although the findings are mixed, wives generally receive fewer formal supports than husbands. However, the available research has not adequately addressed the caregivers' perceptions of these services and we know little about the perceived satisfaction with formal services available to caregivers.

Social Support and the Health of Caregivers

Although the link between social support and physical and mental health has been well established through research, there is surprisingly little research that has examined the health outcomes of social support provided to caregivers. Considering that the ability of the caregiver to provide care is a crucial factor in maintaining a disabled person at home, it becomes crucial to understand the impact of social support on the health of the caregiver. Those studies that have explored social support and its relation to health will now be reviewed.

In a study of the well-being (physical health, mental health, financial resources, social participation) of 510 predominantly female caregivers, George and
Gwyther (1986) found statistically significant (.01) relationships between all four dimensions of well-being and perceived social support. "Caregivers who do not need more social support report higher well-being than those who desire more assistance from their friends and kin" (p.258). On the strength of these and other findings the authors suggest that it is the characteristics of the caregiving situation and the resources available to the caregiver, rather than the condition of the patient, that most directly affect caregiver well-being.

Consistent with this finding Fengler and Goodrich (1979), in a study of wives as caregivers (n=15), found that wives with high levels of life satisfaction reported greater satisfaction with the amount of expressive and instrumental support received by family and friends. In addition, the support of friends, sympathizers, children, or relatives differentiated those wives in the high life satisfaction group from those in the low life satisfaction group.

Not only is support associated with caregiver well-being but one study has correlated it to levels of burden. Scott and associates (1986) found that caregivers who were rated as not receiving enough support reported greater burden than those who were rated as receiving adequate support. Interestingly however, those caregivers that were rated as receiving more than enough support
reported similar amounts of burden to those not receiving enough support. The authors suggest that these caregivers may be receiving increased support from family primarily because they were most at risk for dysfunction.

These research findings must be viewed with caution. Zarit and Zarit (1982) point out that even though some research correlates social support with burden we must not make the "inferential leap" that more social support leads to less burden. They go on to say that most of this research has not clearly defined what support is and, as noted in the previous two sections, it is the frequency of contacts from family, friends, and health providers that is commonly used as the measurement of support. This ignores the subjective nature of support. In addition, frequency as a measurement does not address the potential for support to be positively or negatively valued. Clearly, in order to provide suitable and useful social support to wives providing care to husbands with multiple sclerosis, social support must be understood from the subjective perspective of the wives themselves.

Summary

This chapter presented the literature in two sections. The first section discussed the major contributions towards understanding the phenomena of social support. The diversity of conceptual definitions
of social support was provided, which in turn, reflects the difficulties in understanding this complex concept. Consequently, research into social support has been unable to clearly identify how support acts to promote health and prevent illness. The second section examined the limited research available that has explored the type, source, and adequacy of both formal and informal support available to caregivers. As well, the health outcomes of support provided to caregivers was addressed. The following chapter describes the methodology used in this research which explores wives' perceptions of social support.
CHAPTER THREE
METHODODOLOGY

Introduction

Phenomenology was the method chosen for this study. Qualitative methods, such as phenomenology, are used when there is little known about a phenomenon and attempt to "describe the human experience as it is lived" (Omery, 1983, p.50). As there is limited knowledge available concerning caregivers' perceptions of support, this methodology provided a mechanism for gaining such an understanding. This chapter describes the methodology used for this study. Five major areas will be discussed: the phenomenological perspective, the selection of participants, data collection, data analysis, and ethical considerations.

Phenomenological Perspective

Presently there are two major approaches to research: the quantitative method and the qualitative method. The quantitative method attempts to understand phenomena by reducing a phenomenon to select variables which are then observed and analyzed to determine statistical probabilities and relationships (Duffy, 1985). Alternatively, the qualitative method seeks to understand phenomena that are not well understood, by
studying the whole of a phenomenon within its natural environment (Knaack, 1984). The purpose of this method is to deepen the understanding of the phenomenon under investigation by discovering how persons interpret and give meaning to situations (Rist, 1979).

Phenomenology, the qualitative method used in this study, is both a philosophy and a methodology. As a philosophy, phenomenology is based on the belief that our world is social in nature and is a constant flow of interactions between and among people, events, and objects. In addition, events and objects are important only through the meaning people attach to them. A further belief holds that reality is a subjective experience and each person has his or her own reality of a situation (Oiler, 1981). Therefore, it is the meaning a woman attaches to her support systems that is important, and that meaning will vary from woman to woman; each woman's experience is unique because each woman has her own reality.

It is out of the philosophy of phenomenology that the method is derived. Phenomenology as a method seeks to explain the nature of human phenomena (Knaack, 1984). It seeks to understand "the cognitive subjective perspective of the person who has the experience and the effect that perspective has on the...behavior of that individual" (Omery, 1983, p.50). It is a search for meaning without
any preconceptions about what that meaning might be. Therefore, the researcher must set aside any beliefs about what the experience means and work towards understanding the experience from the individual's perspective. In this way, predetermined expectations or categories are not applied to the experience; rather, the meaning emerges from the accounts of the individuals involved.

Selection of Participants

Criteria for Selection

Six criteria were used in selecting women for this study.

1. Participants were twenty years of age or over.
2. Participants were verbally fluent in English.
3. Participants lived in or near Vancouver.
4. Participants lived at home with a spouse who was diagnosed with multiple sclerosis.
5. The spouse with multiple sclerosis was in a state of remission.
6. The spouse with multiple sclerosis was dealing with no other acute or chronic illnesses that required medical attention.

Selection Procedure

Participants for this study were located through the Multiple Sclerosis Society of Vancouver. The nursing
staff at the Multiple Sclerosis Society compiled a list of nineteen women who met the specified criteria. The staff of the Multiple Sclerosis Society wrote an initial letter of contact which accompanied a letter from the researcher (see Appendix A) outlining the study and explaining the involvement of participants. Interested women were asked to contact the researcher by telephone. It was also indicated that the researcher would contact each woman ten days after the letters were posted.

Three people contacted the researcher by phone. One gentleman called to say that his wife was ill with cancer and would not be able to participate. Another woman indicated she was interested in participating but did not meet the criteria for the study as her husband had recently been institutionalized. The third woman who contacted the researcher met the criteria and was included in the study.

The researcher phoned the remaining 16 women. One woman declined to participate and two women agreed to participate only if the researcher needed more participants for the study. In addition, one woman agreed to participate but would not be available for a second interview due to winter holidays. Two other women did not meet the criteria for the study. The researcher was unable to contact three of the women. The remaining seven
women met the criteria and agreed to participate, for a total of eight women who participated in this study.

**Characteristics of Participants**

The women who participated in this study ranged in age from 38 to 61 years, with a mean age of 47.5 years. The women were married an average of 21 years. Four women were employed outside the home; two full-time and two part-time. The remaining women worked in the home as homemakers. The two women who worked full-time had assistance in the home. Although no women expressed serious financial concerns, four expressed concern for future financial abilities. Six of the families had children living at home ranging in age from 5-25 years.

The diagnosis of multiple sclerosis was made between one and fifteen years ago. As a direct result of the diagnosis and ensuing disabilities, all but one husband were retired. This husband worked 3-4 hours a day and was able to control the hours he worked. Three husbands had retired within the last eight months. The four remaining husbands retired anywhere from five to eleven years ago. One husband was bed-ridden, five were mobile with the use of a wheelchair or three wheel motorized scooter, and two husbands were independently mobile with some balance difficulties.
Data Collection

Data were collected through in-depth interviews ranging in length from one to four hours. Each woman was interviewed twice with approximately six to eight weeks between the first and second interviews. With the exception of the two women who worked full-time and who preferred to be interviewed at their place of employment, all interviews were conducted in the participants' homes. This provided a comfortable and confidential location for the interview. As well, it provided an opportunity to observe environmental and familial factors pertinent to living with husbands who have multiple sclerosis. Although the women were interviewed alone and in confidence, there were opportunities to speak with five of the husbands.

The interviews were unstructured and although initial questions originated from an interview guide (see Appendix B), subsequent questions evolved out of the accounts provided by the participants. The questions were broadly stated and there was minimal control over the direction the interview took. As well there was no attempt to problem-solve or counsel the participants although this was difficult in the first interviews due to the researcher's greater familiarity with the role of clinician rather than researcher. Initial questions were broadly stated such as "Tell me what it is like living
with a husband who has multiple sclerosis" and,"What are the things or people that make your day easy/difficult?". This type of question allowed each woman to take the interview in any direction that was meaningful to her. To encourage further exploration of a topic, statements were used such as "Tell me more about that". It was a constant challenge not to lead the participant by introducing new ideas or questions based on preconceptions about what the experience might be like. It is only when the researcher is able to recognize her biases and put them to the side or bracket them that she is able to see the experience from the individual's perspective (Oiler, 1981).

Once the first interviews were completed and the researcher began to have a sense of the overall experience, the second interviews were begun. The second interviews were used to collect further data, and to clarify and validate emerging themes. Thus the second interviews helped to refine and alter early conceptualizations so that the analysis reflected as closely as possible the women's perceptions of social support while living with husbands who have multiple sclerosis.

Each interview was audio-taped and subsequently transcribed to facilitate the analysis. At the end of each interview field notes were recorded which included observations of the mood, affect, and behaviors of the
participant. The researcher also noted her own behaviors as a way of determining the influence she had on the interview. In addition, the field notes included any discussion that occurred subsequent to the audio-tape being turned off. Valuable information was often gleaned as the researcher was leaving the women's homes. The observations, field notes, and transcribed recordings all became part of the data that was subsequently analyzed.

Data Analysis

In keeping with phenomenology, constant comparative analysis was used in which data collection and data analysis occurred concurrently (Omery, 1983). In addition, the women's accounts were analyzed using Giorgi's (1975) framework.

Following each interview the audio-tape was transcribed. This process of transcribing fostered greater familiarity with the data and thus facilitated data analysis. Following transcription, the researcher read the transcript over while simultaneously listening to the audio-tape in order to obtain a sense of the whole. The transcript was then read slowly and more thoroughly identifying meaning units or categories of complete thoughts expressed by the participant. These meaning units were reflected upon and themes were identified. At this stage the researcher began to take
the findings that were in the language of the participant and abstract them into the language of nursing. For example, a segment of data in which a woman spoke about the tasks of caring for her husband was abstracted into the theme of "the role of caregiving".

Using these steps in data analysis each interview was examined separately and in relation to the other interviews. The field notes were also reviewed and compared for recurring themes. Emerging themes were validated and clarified by the participants in subsequent interviews. Thus the themes were subjected to an ongoing process of refinement which permitted the researcher to be true to the lived experience as described by the participants. By moving back and forth between the data and the central themes the researcher began to "synthesize the insights into a descriptive structure of the meaning of that experience" (Omery, 1983, p.58). Eventually an organizing framework emerged that reflected these women's perceptions of support while living with and caring for husbands who have multiple sclerosis.

Ethical Considerations

Approval for this study was obtained from the University of British Columbia Screening Committee for Research Involving Human Subjects. The rights of
participants were protected through adhering to the standards set by the Screening Committee for Research.

Participation was voluntary and a written consent (see Appendix C) was obtained from each participant prior to conducting the initial interview. Three to four weeks before the initial interview participants received a written description of the study along with an explanation of the expectations and rights of the participants. At the time of, and prior to, each interview the researcher reminded the participants of their right to withdraw from the study at any time. They were also reminded of their right to decline answering any questions and to request erasure of any portion of the tape without prejudice. Participants were also informed that their choice of whether or not to participate would in no way jeopardize any health care being received by themselves or their family members.

Confidentiality was ensured. The names of those who chose to participate were not revealed to anyone, including the referring agency. The audio-tapes, transcripts and fieldnotes were coded and stored in an unexposed area. Names and identifying information were removed from all written material. Access to the audio-tapes and transcripts were limited to the researcher, and the two members of the thesis committee. Upon completion of all written work in relation to this study the audio-
tapes and computer-disks will be erased and the transcripts will be destroyed.

The right of participants to receive information was also respected. One woman requested and received the name of a resource person to contact for financial information. Two other women were provided information pamphlets identifying offices, buildings and recreational facilities that are wheelchair-accessible. Another woman requested information on the impact of parent chronic illness on the child. Another woman, whose husband had been diagnosed one year previously, sought clarification and validation of exercise and diet regimens suitable for persons with multiple sclerosis. This information was provided subsequent to the taped interview. Finally, each woman who participated in the study, and one man whose wife was unable to participate, requested a summary of the findings which will be provided upon completion of this study.

Summary

This chapter outlined the methodology used in this study. The selection of participants, the data collection and data analysis were identified. As well, the ethical considerations were discussed. The following chapter will describe the accounts of women's perceptions of support while caring for husbands who have multiple sclerosis.
CHAPTER 4  
WIVES' ACCOUNTS

Introduction

This chapter discusses the findings of this research study. The accounts of eight wives were analyzed to gain an understanding of how these wives perceived social support while living with and caring for husbands with multiple sclerosis. Through the analysis of these accounts two central themes emerged. The discussion of these two themes reflects the unique stories of the eight wives who participated in this study and is not intended to reflect women in general.

The first theme explores the caregiving experience as described by these wives. When these women were asked about social support they consistently discussed their perceptions of support within the context of their caregiving experience. Therefore, the understanding of social support became embedded within the caregiving experience. Within this central theme three sub-themes emerged. These were a) committing to caregiving, b) distancing from caregiving, and c) living with ambivalence. These sub-themes provided the basis for the second central theme, the nature of support.

The second central theme describes the nature of support as perceived by the wives. Again, three sub-
themes emerged in relation to this second theme: a) support for caregiving, b) support for distancing, and c) support for ambivalence. These central themes and sub-themes form the organizing framework for the findings of this study and are illustrated in Figure 1, on the following page. These themes will now be addressed.

The Wives' Caregiving Experience

Each wife in this study identified a profound commitment to provide care to her husband, identified as "committing to caregiving". This commitment yielded many new responsibilities which, at times, were perceived to be overwhelming and burdensome resulting in a desire for distance from the demands of caregiving, identified as "distancing from caregiving". The simultaneous commitment to caregiving and the desire to distance from caregiving catalyzed feelings of guilt, identified as "living with ambivalence". In order to understand the role of caregiving in which social support is perceived each of these three sub-themes will now be addressed in greater depth.

Committing to Caregiving

The wives in this study were deeply committed to providing care to their husbands. This commitment was reflected in their numerous caregiving responsibilities.
WIVES' PERCEPTIONS OF SOCIAL SUPPORT
WHILE CARING FOR HUSBANDS WITH MULTIPLE SCLEROSIS

THE CAREGIVING EXPERIENCE

COMMITTING to CAREGIVING (enmeshment) leads to DISTANCING from CAREGIVING leads to LIVING with AMBIVALENCE (guilt)

leads to recommitment to caregiving

THE NATURE OF SUPPORT

SUPPORT for CAREGIVING
a. Information
b. Practical Assistance
c. Acknowledgement
d. Finances

SUPPORT for DISTANCING
a. Social Activities
b. Professional Services
c. Anticipatory Support

SUPPORT for AMBIVALENCE
a. Being Understood

Figure 1. Wives' Perceptions of Social Support While Caring for Husbands with Multiple Sclerosis
The origins of this commitment were the wives' commitment to their marriages, their lack of distinction between the role of wife and caregiver, and the empathy they felt toward their husbands. These aspects of commitment will now be discussed.

The commitment to caregiving was reflected in the ways in which caregiving was provided by these wives. Above and beyond the usual household tasks of laundry, shopping, meal preparation, and cleaning, wives assisted their husbands with tasks such as cutting food into edible pieces, assisting with walking up and down stairs, transferring to and from wheelchair, dressing and undressing, and daily hygiene such as in-dwelling catheter care. These tasks required a great deal of time, attention, and planning on the part of the wife. The pervasiveness of this caregiving was expressed in one woman's statement:

W. = Wife
R. = Researcher

W.6 I'd have to be home when he'd come home to help him from the car to the house and help him go to the bathroom and get up again to get changed and dressed and get him back to the kitchen. So that would be an hour before -- you never knew when supper was going to be, everything just sort of stops when he used to come home, no matter what you were doing you had to stop everything you were doing to help him [crying].

In addition:

W.3 When [husband] was sick I would sleep in this chair by his bedside and then if he moved or anything I was there, but I would never go to bed
for maybe a week, maybe two weeks.

These statements reflect the commitment wives made to caregiving and the resultant demands caregiving places on them.

In addition to the direct physical care mentioned above, a number of wives assumed responsibility for arranging health care appointments and accompanying their husbands to see the family doctor, neurologist, urologist, physiotherapist, and any other necessary health persons. Some wives also accompanied their husbands to multiple sclerosis self-help groups, swimming activities and other related activities and conferences.

Another aspect of their caregiving was the anticipation of their husbands' needs. A number of wives spoke of slowly introducing their husbands to the use of walkers, wheelchairs and other home accessories. For example:

W.6 I'm thinking about changing the bathroom to put lifts in and put higher toilet seats in and stuff like that. But he's not ready [to accept] that so I'm slowly introducing that to him by showing him brochures and things.

Anticipating the husband's needs was not limited to the introduction of home accessories. A number of wives spoke of their role in protecting their husbands' physical and psychological integrity. One woman, in discussing the difference between living with her husband
before and subsequent to the diagnosis of multiple sclerosis, stated:

W.2 I'm much more protective, like I have to be careful of his ego and not help when he doesn't want help. But I'm, like I'm more apt to take his arm or to help him up the steps. And maybe he needs it and maybe he doesn't, but I'll be watching things like that.

This constant anticipation of the husband's needs included safety factors such as clearing pathways for walking or moving the wheelchair, or leaving lights on in rooms so that the husband wasn't manoeuvring himself in the dark. The outcome of this commitment to caregiving is that women placed their husbands' needs before their own. This is concisely stated in the following:

W.6 So you're always thinking ahead, always making sure that everything is fine for him and then whatever is left over is for me.

For the wives, caregiving also extended into the social arena. As the husband became more disabled there was less time spent socializing with friends. On one hand, it became burdensome for wives to repeatedly transfer their husbands from wheelchair to car and to pack the wheelchair in the trunk; several wives spoke about how exhausting and time consuming this process was. On the other hand, some husbands, because of the illness, became less motivated or able to go out and socialize with their friends. Consequently, women also assumed the role of best friend and primary social companion to their husbands. As one woman stated:
W.4 He relies solely on me; I have to entertain him, you know, take him somewhere or that sort of thing, and I think that's the hardest part.

In addition to the difficulties experienced in getting out of the home for social activities there were fewer friends who visited the husband in the home. This partially reflected changing interests and abilities but it also reflected the discomfort some people have with illness itself:

W.3 Usually people won't even come and sit by the bedside and talk, you know, illness makes them uncomfortable, you know, and that's what happened with all the friends.

In responding to people's discomfort with the illness a number of wives extended their caregiving responsibilities to include protecting other people so that they were more comfortable with the disability. For example:

W.2 Our role is often to make people comfortable with it [multiple sclerosis] rather than them supporting us.... helping them to know how to talk about it.

This extended role of comforting other people with the illness provided these wives with a means of reciprocating support and a number of women identified that helping other people was a source of self-esteem.

Their commitment to caregiving led the wives to assume many of the tasks and responsibilities that had been the husband's prior to the illness. These included home maintenance, repairs, and yardwork. As well, due to
the emotional and intellectual effects of multiple sclerosis, many husbands no longer shared in family decision-making. Consequently, these wives became the primary decision-makers for the family. As one woman stated:

"And that makes a big difference, You can't have the conversations you used to. Being assertive is your shoulders now. You can't discuss "Should we do this? Can we afford that? Shall we let the kids do this?"

The responsibility wives felt as primary decision-makers was perceived to be a burden. Many of the wives spoke of how difficult it was in no longer sharing decisions with their husbands, as well as assuming responsibility for decisions they were previously not involved with, such as financial matters.

The above accounts addressed the commitment to caregiving, reflected in the multiple responsibilities the wives willingly assumed as part of their caregiving. Related to this are the reasons these wives became so committed to providing care at home to their husbands.

Due to the usually slow progressive nature of multiple sclerosis many of the wives assumed caregiving responsibilities gradually, adding new tasks onto their existing responsibilities as wife and mother. Thus, a number of these wives identified that the role of caregiving was simply an extension of their caring role within the family. As such, caregiving per se was not
something they separated as different from other responsibilities. It was simply something they did. This next account shows the gradual evolution of caregiving:

W.4 It just flows. I mean, you just grow into it. You don't think about it. I mean, it's like somebody drowning, you just dive in and save them, you know. You don't think about it.

Given the often insidious nature of assuming caregiving responsibilities it becomes understandable that the role of caregiving is often not differentiated from the role of wife. As one woman stated:

W.2 I don't see it as any different than [being with] someone who is well. My role as a wife is to support my husband, with whatever he is doing, whatever he's got to deal with. The M.S. means he deals with different things than he might have to deal with otherwise.

The lack of differentiation between roles was augmented by their interpretation of their marriage vows. When asked about their commitment to caregiving many of these wives responded by talking about the vows "for better or worse" and "in sickness and health", vows that carried a profound commitment. A number of these wives stated their marriage vows meant commitment to whatever events, within reason, transpired during the marriage. As a result caring for their husbands became an extension of their role of wife. As one woman stated:

W.6 I just feel that, you know, I guess you take the vow "for better or worse" and you just go with it, and if that's what it is and that's how it turns out that's where you do it. That's what you're doing. (Pause) And I just expect that out of myself, you know, I really don't have too much
patience with people that would leave, you know.

This commitment to marriage and the lack of distinction between roles of wife and caregiver further explains the commitment these wives have to providing care to their husbands.

For the women in this study the commitment to caregiving also stemmed from the empathy they felt towards their husbands. All of them expressed an understanding of what their husbands were experiencing. This understanding was so pervasive that many of these women described their emotions as paralleling their husbands'. One woman succinctly reflected this in saying:

W.2 When he's sad I'm sad ... my emotions track with his pretty much; if he's down then I'm going to try to be up, but I'm going to feel bad inside until he's back up again.

The degree of emotional energy expended in empathizing can be envisioned in the account of one woman who described what it was like for her when her husband independently transferred from the couch to the wheelchair:

W.6 While he's trying to get up you're trying to get up too. He tries, and he tries and then, you know, you're almost going with him, and then finally when he gets up, you know, you just relax.

This ability to feel what their husbands feel was extended to include the husband's symptomology. For example, one woman whose husband was recently diagnosed
experienced the difficulty her husband had in walking.

She expressed the following:

W.1 I don't notice anything different actually... except his walking, and I know he says his legs are awfully heavy, and he's weaving and I'm weaving, and I [nervous laughter] don't know what I'm going to do. But I have such a close sympathy with him that I'm feeling that I, I can feel what he's going through.

These extraordinary descriptions of empathy reflect the wives' perceptions of their ability to get inside their husbands' experiences of multiple sclerosis. These subjective experiences served to heighten their commitment to caregiving. By placing themselves in their husbands' situations these women felt a stronger need to provide the kind of care they envisioned for themselves, should they be in similar circumstances. For example, in asking one woman if her decision to keep her bedridden husband at home was something she did for her husband or for herself she answered:

W.3 Oh no, it's to make his [life easier] 'cause you know, I kept thinking, well, I would want somebody to look after me. I don't want to be in a position like this, and this is what kept me going. That's what kept me going. ... He needed to be home, he wants to be with his family. Yeah. ... I think the important part was that I wanted to do it for him because I thought, I don't want anybody to abandon me if I was sick, and this is what it was about, you know.

For these wives the golden rule "do unto others as you would have them do unto you", was a cornerstone in their commitment to caregiving.
In concluding this sub-theme, the wives in this study were strongly committed to caring for their husbands at home. The lack of distinction between their roles of wife and caregiver, their commitment to marriage, and their ability to empathize so strongly, led these women to assume multiple caregiving responsibilities. These caregiving responsibilities were both time-consuming and emotionally draining. All told, it becomes understandable that wives also desired some distance from the caregiving experience. As one woman said, "Where am I in all this?". The following section addresses this desire for distance.

**Distancing From Caregiving**

For the wives in this study the desire to distance varied according to the amount of daily time spent with their husbands and the degree of involvement in caregiving activities. The more time spent with the husband and the greater the involvement with caregiving the greater the desire to distance.

Most of the wives identified a desire for personal space that stemmed from the increased amount of time husbands spent at home. Due to the effects of multiple sclerosis all but one husband were retired. As well, these husbands were less able to participate in the kinds of activities they once used to, consequently, many
husbands spent much of their time at home. For the wives, particularly for those who didn't work full time, this meant a readjustment of their space. No longer was home the wife's semi-exclusive territory. As husbands became more disabled and spent increasing amounts of time at home, opportunities decreased for the wives to have personal space or private time in their own home. This is reflected in the following:

W.1 He's here all day long. We're together constantly. I don't like it at all. I feel I need my privacy and he needs his.... I can hardly cope with him having his illness. I don't want my space taken away from me, cause he's sort of coming in a little bit closer.

For many of these wives personal space meant having time at home alone. This following account reflects this desire:

W.8 I had to have him out of the house. Like I couldn't cope on a daily basis. I had to have some free time in the house without him around.

For these wives the desire for distance was not only distance from the actual time spent with the husband, but also included distance from the illness experience and related caregiving responsibilities. Several of the wives became so enmeshed that they needed to remind themselves that it was their husbands' illness and not their own. This next account is an example of the degree to which living with a chronic illness invaded one woman's life:

W.5 Illness is something like a growth. It keeps getting bigger and bigger and if you let it, it will take over. It's taken over. But it won't. It
won't consume me. I won't let it! No matter what!

The consuming nature of the illness experience provoked a desire to distance themselves from caregiving. This need was so great that one woman described the following process of "tuning out":

R. You said in the last interview that both you and your husband are drawn into the illness. Is being removed from the illness important?

W.2 Yes. Yes, 'cause I can tune out. You have to. I can't change it eh? But I do feel for [husband]. I can hardly take it, but I have to; there is nothing I can do about it. There is nothing anyone can do about the disease.

R. How does that affect you?

W.2 It makes me worry. I'm a chronic worrier... But I've learned how to worry without worrying.

R. How do you do that?

W.2 I just blank out. I just blank right out... But then I had to stop that actually, because I was a little worried that I would tune out and maybe not come back, if you know what I mean, like not come back to reality again.

This description reflects the extent to which some women experienced the need to distance. Other women expressed this need less intensely yet with just as much conviction. For example, another woman spoke simply of getting away by herself:

W.4 I get scared sometimes, you know. I sometimes feel like I'd like to get away by myself and just think about myself. You know, you're always sort of thinking about somebody else.

Many of the wives in this study experienced a desire to distance themselves during periods when their
husbands' moods were difficult to manage. Several women spoke of "getting out of his way", or "going out to the garden", or "taking a walk around the block". As one woman stated:

W.1 I used to go along with his moods...now I find I have given too much and I want to just back away.

This desire for distance from the husband's moods was so strong that some women willingly assumed other responsibilities to get away. The next account reflects how one wife creatively managed to distance herself from the effects of the illness by baby-sitting two small children in her home:

W.7 It's a lot more work granted but I've always liked children. And it's a break. It's not just listening to [husband] complain. It's someone to talk to... They make me laugh.

The process of adapting to and immersing oneself into the caregiving role led to less recognition of personal needs. The wives didn't always have a clear realization of their need to distance and awareness often occurred subsequent to an event that resulted in distance from caregiving responsibilities. For example, one wife who took some time off work due to work-related stress subsequently discovered that much of the stress was related to her caregiving role:

W.2 I was off work for stress and I thought it was all work but I found out I was caught in a wedge at work and I was caught in a wedge at home. And getting time off helped me to see that...All I needed was just to be alone in my bedroom and to get everyone to leave me alone.
Sometimes this awareness occurred subsequent to receiving respite care. For example, one woman identified that being alone was the best part of respite care:

W.3 Just being alone, yeah, just being alone! ... Just to feel the freedom.... And I've realized that there is life after M.S. because now I'm just getting to the point where I don't have to worry about getting home to see what's going on.

Another wife described the fun she had when she took a holiday with some of her women friends:

W.4 This is when you really realize how sort of hemmed-in you are, is when you go away and you don't have to think about anybody but yourself.

In concluding this sub-theme, the wives in this study experienced the desire to distance from the caregiving experience. This included distance from both the husband and from the illness itself. As husbands spent increasing amounts of time at home the wives experienced a desire for time away from their husbands and more time at home alone for themselves. As they became enmeshed in caregiving, a desire to distance from the illness resulted. When faced with simultaneous needs to provide care and to distance from caregiving it is understandable that these wives experienced ambivalence.

**Living With Ambivalence**

This sub-theme addresses the feelings of ambivalence that the wives in this study underwent. Ambivalence is defined as simultaneous conflicting feelings (Webster,
1979). In this study, the conflicting feelings arose from the wives' commitment to provide care to their husbands and the simultaneous desire to distance themselves from caregiving.

The outcome of these simultaneous feelings was ambivalence, usually described indirectly by the wives. In fact, most women expressed their ambivalence through describing their guilt. Because of their commitment to caregiving, wives felt guilty when they distanced themselves, while at the same time they felt justified in leading a normal active life that included personal outside activities and interests. This emotional volleying between what they wanted to do for their husbands and what they wanted to do for themselves created ambivalence. These ambivalent feelings were so strong that one woman, on a rare occasion of attending a social outing alone, expressed discomfort that she had been enjoying herself out of the home while a homemaker was caring for her bed-ridden husband. Many of these wives identified similar feelings but were unable to clearly articulate their ambivalence. The following account expresses the nebulousness of these feelings:

W.1 It's just a kind of helplessness...I don't know what it is, I can't even name it...Kind of like a hunger; like something I want to do and just can't do, and it could be anything I guess, could be helping [husband] or could be furthering my education, or whatever. Just stymied.
Although this woman was unable to label herself as ambivalent, her statement shows her feelings of wanting to provide support to her husband while at the same time wanting to fulfill her own needs for personal growth.

Although several wives in this study did participate in personal activities such as playing sports, shopping, and socializing, these women were not comfortable leaving the house when their husbands were at home. This ambivalence stemmed from contrasting their own abilities to participate in leisure activities with their husbands' abilities to do the same. Consequently, these wives attempted to accomplish their personal activities at times when their husbands were otherwise occupied. Even so, wives expressed a constant awareness of the amount of time spent away from home and were very careful not to extend their absences longer than necessary. This vigilance and related guilt are expressed in the following account:

W.7 Guilt is one of the number one things you have to deal with... You feel guilty no matter what you do. If you go [grocery shopping] and he's not with you, you feel guilty. If you take him with you he waits in the car and you feel guilty... The doctor was telling me I should walk at least an hour a day. If I do I feel guilty. And I have nothing to feel guilty about, and then just the thought that I'm out and he's in the house (pause, lowered voice) makes you feel guilty.

Not only did women feel guilty when leaving their husbands at home alone, they also required to have "legitimate" reasons such as grocery shopping or
medically-prescribed exercise to do so. Even then, the feelings of guilt were present.

One of the major reasons women experienced guilt in taking time away from home was the concern that their husbands would be at home alone, doing nothing. This was unquestionably identified by one woman who was contemplating an overnight outing with friends:

W.4 Well, you know, I don't like to leave him, for instance, because he doesn't do anything.... I just don't like the thought that he'd sit here all by himself. I mean, the kids will be off doing their thing. They wouldn't sit with him to entertain him, and he wouldn't phone anybody, so he'd sit here all by himself...And you do feel, you know, that if he can't do it, why should you. And then on the other hand I go: why shouldn't I?

Clearly, for these wives, the commitment to caregiving involved keeping the husband occupied and entertained. When wives were "out" and husbands were home unoccupied, this was felt as an abdication, however briefly, of the role of wife and caregiver and led to guilt. At the same time these wives recognized their need to have some independence and to live as normal a life as possible.

This desire to live a normal and active life in a reciprocal relationship led one woman to contemplate separation. The ambivalence this woman experienced was exacerbated by her husband's illness and is described in the following:

W.8 I'm not saying the breakdown of a marriage is an easy thing, it's got to be difficult for
everybody, but I see this [multiple sclerosis] as an added factor that makes it so much harder to cope with... My God, the guilt. What's going to happen to [husband] if I leave him?... I mean, on one hand I see every person being responsible for their own self, for their own feelings, for their own emotions, for their own situation. I mean, our life should be what we make it to be. I mean, we've all got control over what we do—illness, for example, is a factor that you have no control over—so it's very hard for me to say [good-by], you're responsible for you and I'm responsible for me. But then I think if I was married to a healthy man and the marriage wasn't working, I think I would leave. But for [husband] I can't do that. I find it very difficult to say "be responsible for yourself". He is responsible for himself, he's not responsible for the disease which is a definite factor in the marriage right now.

A final aspect of this sub-theme is the recommitment to caregiving. The push and pull surrounding the wives' desire to have a normal active life and at the same time provide support to their husbands, resulted in feelings of ambivalence. When these wives did take time for their own activities they experienced enormous guilt, which they alleviated by recommitting themselves to the caregiving experience. Even though some women recognized that in recommitting themselves they sacrificed some of their own needs, the alleviation of guilt, and their sense of responsibility as wife and caregiver warranted this sacrifice.

In summary, this section has addressed the central theme of the caregiving experience. The wives in this study made a profound commitment to provide care to their husbands. As these women became enmeshed in the
caregiving experience they began to desire distance from caregiving. The simultaneous feelings of wanting to provide care and wanting distance from caregiving resulted in ambivalence. When these women did take time away from caregiving they experienced guilt and to alleviate the guilt they recommitted themselves to the caregiving experience. These aspects of caregiving provide the foundation for the following central theme: the nature of support.

The Nature Of Support

This central theme describes the nature of support as perceived by the wives in this study. This theme is built around the three sub-themes discussed in the previous section because these wives' perceptions of support are grounded in the context of providing care to husbands with multiple sclerosis. Three sub-themes are discussed in this section: a) support for caregiving, b) support for distancing and, c) support for ambivalence. Support for caregiving discusses four types of support these wives found helpful with their caregiving responsibilities. Support for distancing discusses three types of support that facilitate distancing from the caregiving experience. Support for ambivalence discusses one type of support that these women identified as important for them while living with ambivalence.
Support For Caregiving

Each of the wives in this study identified that support for caregiving was important. The degree to which they viewed support as necessary varied according to the level of the husband's dependancy on his wife for physical and emotional care. This was contingent on the husband's ability to tend to his own needs such as arranging appointments, checking out available resources, and attending to daily activities and functions. Simply stated, the more dependent the husband was, the more caregiving the wife did; the more caregiving the wife did, the more support she thought was necessary. There were four major types of support that emerged from the wives' accounts: information, practical assistance, acknowledgement, and finances. Each of these will now be addressed.

A. Information as Support

Information about the disease, disease management, and resources available helped wives in their role as caregivers. Information served to decrease the uncertainty of dealing with a chronic illness. It also assisted wives in decision-making for disease management and, in addition, provided wives with the knowledge to enact their role as information providers to other people. These women initially sought information through
the formal health care system and expanded their information sources to include a wide variety of personal social resources. These aspects of information will now be discussed.

The diagnosis of a chronic illness such as multiple sclerosis brings with it an uncertain future. This is succinctly stated in one wife's statement:

W.5 They told us all there is to tell. There is nothing else to tell us. That's the hardest part, is trying to live with not knowing what's going to be tomorrow. Maybe things will keep going like this forever. They might get a lot worse.

This uncertainty was initially dealt with by gathering information about the disease and what to expect. The majority of the wives received this information from the Multiple Sclerosis Society and most found it very helpful. Not only did this information serve to educate wives and their families about the disease, but it also assisted them in preparing for the uncertainties of the disease process. Having information about the potential course of the disease provided some sense of predictability. This allowed wives to anticipate future possibilities and to plan for potential caregiving responsibilities. In being able to anticipate the possible course of the disease the wife gained a sense of control over an uncertain future. This next account reflects the security information gave to one woman:

W.6 By planning ahead and being able to anticipate ummm knowing and actually reading up on
husband's illness and knowing where he's going to, I sort of felt I'm not surprised when things happen.

Information also provided wives with knowledge about multiple sclerosis that they could pass on to other family members in their new role as information providers. Information that assisted wives in this role is reflected in the following:

W.5 And we phoned the MS Society and they sent out a package this high. And we came home and told the kids. The littlest guy he cried for about two weeks...But in this package came this book for kids. We sat down and read it with [son] and then he could understand. That sometimes daddy is not going to be so good and then other times he is going to be great.

This type of information not only assisted wives in their caregiving role but also promoted confidence in their role as mothers.

Once an understanding of the disease itself was gained, many wives sought information regarding disease management. In the early stages of the disease little is required in the way of disease management and most wives found it particularly helpful to be given information from health professionals that encouraged the family to manage the disease by continuing with their present lifestyle:

W.2 Our specialist said to forget you've got it. Don't join any societies, don't read any articles, don't do anything. Just operate normally.

R. Was that helpful?

W.2 I think it was, he told [husband] to listen to his
body and if you're tired rest, don't push yourself... So that's what we did.

This information provided wives with the security of knowing they could make decisions about family activities without exacerbating the progress of the disease. At the same time the wives and their husbands were able to adjust slowly to the idea of living with a chronic illness.

As the disease progressed the most valued type of information was practical information. Information about specific available resources was particularly useful and the more specific the information the more accessible the resource became. Regardless of whether the wife or the husband collected this information, the more specific the information the more likely it facilitated the caregiving role of the wife. The usefulness of practical information is reflected in the following:

W.4 They gave practical information. They asked him about his driving and about his wheelchairs and this sort of thing and what's available and to go there and be fitted for one, rather than just down to some medical supply place and buy one.

R. And when he gets the information, does it help you?

W.4 Well yes, because I know he's driving safer for instance. And the bathroom situation, the grips and that sort of thing. You know, we were told to put a chair in the shower and that sort of thing. A lot of things that do help day-to-day living a little easier.

Although all women identified practical information as important, not all women were satisfied with what they
received. For example, this next account reflects the
disappointment experienced by one woman when the need for
information was not met:

W.6 I thought I was going to get a lot of help when I
asked [health professional] to come out to the
house. But she says I think we should get him in
rehab, and you will learn it all there... But I
was disappointed because when he went to rehab. I
thought I was going to get a lot of information as
to how to deal with MS patients in the home. They
talked about it but it never materialized.

It would appear that health professionals did
attempt to provide the necessary information but unless
it was very specific and unless there was follow-up to
ensure the wife received and understood the information,
it was not perceived as very helpful. Without this, wives
became discouraged and began to seek information
elsewhere:

W.6 So that's when I really decided that I'm going to
try to learn as much as I can and where I can and
just ask people.... It's surprising how much
information you get from just the general public
just talking and asking questions and stuff.

Most wives in this study identified a wide variety
of sources for information such as networking with people
in the community, reading articles, magazines and books,
and listening to the media. Wives used this information
for decision-making in the area of disease management.
For example, one woman who used this system of networking
began implementing diet modifications:

W.1 I have been watching his diet, I'm starting to try
different things that I am reading about and
looking for chemicals and additives.
The above accounts reflect the value of information for these women in their role as caregivers. Information assisted wives in preparing for the uncertainties of living with multiple sclerosis and allowed them to make decisions regarding disease management. It was also fundamental in providing wives with the knowledge to be information givers to other people. The value placed on having access to information is also witnessed in the learning process whereby these wives, over time, expanded their sources of information.

B. Practical Assistance as Support

Practical assistance from family members and health care workers helped the wives in this study by lessening their involvement in caregiving tasks.

Family members became the first line of assistance for these wives. Many had sons or daughters living at home who offered periodic assistance. Some children offered direct assistance by helping with the dishes, cleaning, lawn work, and other household chores. Some children also offered aid to their fathers such as assisting with wheelchair transfers, clothing changes, and social activities. These types of assistance directly supported the wife by reducing her involvement in such tasks. The wives clearly identified that support for their husband was support for them, and that any
assistance provided to the husband had a direct effect on how the wife felt supported. As well, by receiving support from their children, these wives felt less isolated in their role as caregiver: when caregiving responsibilities were shared the emotional burden of carrying total responsibility was temporarily relieved. This next account shows how one daughter provided support by being instrumental in convincing her father to use walking aids when that became necessary:

W.4 She's the one that got the cane going, and got him to buy the [three wheel scooter]. I mean, I couldn't do it. She's very good with him.

Many of the wives were reluctant to depend too much on their children for assistance. Some identified that they would have appreciated more assistance but that their children led very busy lives and were not always available. Some felt that regular and predictable assistance from children was an imposition. Several wives identified that it was important that their children have normal and happy lives and it was therefore unreasonable to expect children to become too involved in activities that the wives identified as their responsibility. This next account reflects one woman's concerns about her daughter's assistance with home activities during a period when the wife was sick:

W.6 [Daughter] was doing all the cooking. She was 12 years old and doing the cooking and cleaning. She was acting like a mother; it was really tough on her, and ...[crying]...It's not fair to expect
that of her.

Practical assistance from extended family members was also received and perceived as extremely helpful. For example, one brother assisted the wife with minor home repairs, another brother and sister were available to sit with children when the wife attended medical appointments with her husband. Other family members socialized with the husband providing time for the wife to complete other responsibilities. Although this assistance was perceived as extremely helpful, the wives were reluctant to request such assistance too often. The wives felt these family members had families of their own and they did not want to impose unless necessary, or unless the assistance was offered rather than requested.

This concern about requesting or accepting help was creatively managed by one wife who arranged a reciprocal arrangement with her widowed mother. In return for living in the home, the mother contributed to many household tasks. The degree to which this facilitated the caregiving role of the wife is unmistakably expressed in the following account:

W.2 On top of trying to do a good job and be a good wife and a half decent mother there's all these things that you just have to keep going in the household and Mom really steps in. I've tried to think what would happen if I didn't have that because what would happen is [husband] would do some of them...and he would be sicker I'm sure he would because anything stressful and he winds up worse.
For most wives in this study, accepting help was difficult. They did not perceive themselves as needy and were very clear that, although their caregiving role was at times demanding, it was no different than the experience of a single parent and they felt quite capable of managing their responsibilities. Moreover they viewed these caregiving tasks as their personal responsibility. Although these wives stated they would request assistance when needed, they would do so only if that assistance did not undermine this image of themselves or their families. The following account depicts how one woman perceived practical assistance from her mother as pity:

W.6 If she'd just phone and come visit and relieve me of some time...But I wouldn't even think about her...My parents, they'd just,— it would be pity. It wouldn't work....They'd feel sorry. They got the bad mistake of feeling sorry and you can't feel sorry, you have to understand.

Those wives with few family resources for practical assistance usually turned to the health care system to provide homemaker service. Although they had anticipated homemaker assistance to be beneficial, most of the wives were ultimately disappointed. Several spoke of the amount of red tape they had to encountered before service was provided. Once service was provided, several wives spoke about the difficulty finding a qualified homemaker. These wives suggested that homemakers didn't understand the specific needs of people with multiple sclerosis, were impatient with the husband, and intolerant of his speech
and movement difficulties. It was commonly perceived that homemakers provided instrumental care, but without warmth or concern for the husband's social or emotional needs. One wife identified that when the physical care was completed, the homemaker watched television. Those wives who had received homemaker service also expressed concern about the rules limiting the level of homemaker assistance. As one woman stated:

W.3 This is what really bugged me about the homemaker service with their stringent rules. They're [homemaker] only allowed to vacuum once a month, do the laundry once a week, or something like this, crikey! It is just awful...And they're not trained to look after bed-ridden people...You have to go through half a dozen before you can find one that is suitable.

These rules restrict the type, amount, and frequency of homeservices provided. Therefore, these wives could not count on homemakers to assist with household and caregiving tasks as needed. In fact, the agency and homemaker determine what tasks will be undertaken and consequently, some of the wife's control over decision-making is removed. As a result, the wives in this study did not receive the more comprehensive assistance that they identified as necessary or helpful. This lack of needed support is identified in the following account by one woman who expressed much frustration and anger towards the health care system:

W.3 Over the years I've literally saved the government hundreds of thousands of dollars by keeping him out of the hospital. Too bad lady, that's your
stupid fault, you could have put him in hospital.

Not only were these wives disappointed with the service provided, but some had difficulty obtaining any service at all. Given the difficulty some wives had in accepting support, and that most only requested help when truly necessary, to refuse this assistance served to negate the wife and reinforce their perceptions that they "should" be able to manage on their own. One wife, who requested homemaker service for a specified time period following her surgery, was refused:

W.6 I phoned to see if I could get someone to look after my house. And they said "No because you don't qualify". I says "What do you mean"? "Well it's your husband that's the one that's handicapped and if it was for him we could do it but we can't do it for you cause you're not handicapped."

R. How did you feel about that?

W.6 I was really upset because what's the point of having that service if you can't use it, especially if you need it.

As the above accounts show, practical assistance supports these wives in their caregiving role. Family members are the first line of support for practical assistance and are perceived as very helpful by the wives in this study. Homemakers, although identified as potentially supportive, were in fact disappointing for most of these wives. Finally, although these wives identified practical assistance as useful, they
experienced difficulty in requesting and receiving this form of support.

C. Acknowledgement as Support

Acknowledgement from family, friends, and health care professionals helped wives in their role as caregivers and validated their role as competent caregivers. When provided, acknowledgement improved the confidence of these wives in their decision-making responsibilities. Conversely, when absent, the wives felt negated and angry. The following accounts address acknowledgement as perceived by these wives.

Acknowledgement from friends and family came in the form of recognition for the care they provided to their husbands. Several wives spoke of how some family members and friends would periodically comment on their strength of character for being so committed to their husbands. Recognition was also given for how well the husband looked, or how well the wife managed her time, or how well the wife managed as caregiver. This acknowledgement as a competent caregiver served to enhance these wives' self-esteem and thus fortified them in performing their caregiving functions. As one wife stated:

W.4 Well, lots of people say they feel I handle [husband] very well, and that he looks well, and we seem to manage all right, you know; I think that makes me feel good.
These wives had a strong desire for recognition. However, as the following account reflects, many of the wives had few resources for such recognition:

W.6 A lot of times when you're constantly making decisions, once in awhile it's nice for somebody to say to you, "great plan, M., that's super". Just once in awhile, and I don't get that... Or just coming up to me and just saying "hey, you're really nice," or "you're really doing a good job"... You know, just a little boost... Something like that would make me feel good for a long time, you know, just a little compliment here and there.

Clearly, these women desired recognition, however small, for a job well done. Even recognition as a good person was highly valued by women and as the above account reflects, a compliment goes a long way.

Not only was acknowledgement from friends and family important to the wives in this study, but acknowledgement from health care professionals was also important. When a health professional validated the information the wife provided to her husband, the wife was made to feel competent. In addition, the wife felt that she had an ally in the decisions regarding disease management and that she was being given recognition for understanding her husband's needs. The following account shows how this recognition facilitated one woman's role as caregiver:

W.2 Oh it's made my life much easier because if they [company doctors] had been saying you can still do more than you're doing, you can still come into work, he'd have been in there... for one thing he would have gotten sicker and I guess it would have fallen on me to make him feel better, but they were saying the same types of things I was.
Decision-making was a large part of caregiving and when a wife made a carefully thought-out decision based on interaction with her husband and on the understanding of her husband's situation, it became very important that health care professionals provide recognition for the wife's competence. One form of recognition was to agree with appropriate decisions the wife made, and to appreciate that the wife may be in a better position to make the decision than the health professional. The positive effect this type of recognition has for these wives is seen in the following account:

W.6 The other week I phoned [doctor] and I said "I think I should get [husband] to rehab."", and he goes "Yea, Okay." I mean, no questions asked, you know, and that feels good because he trusts my judgment and that's important to me.

In not acknowledging the ideas or suggestions of wives had regarding care, the health professional denied the wife's role as caregiver. This was devastating for these women, whose self-identities were closely associated with their roles as wife and caregiver, because it left them vulnerable to question their worth. The following account depicts the hurt some wives felt when health professionals did not acknowledge the wife's concerns regarding disease management:

W.1 She is a wonderful person and she does give me some good advice, although I was a little hurt the other day, ah, I said that [husband] could use some physical therapy. She said just to leave him alone, don't push him into things just let him do what he wants to do, and I was a little hurt by
that, because no-one pushes [husband].

The role of the wife, as described by these women, was to care for her husband. As the above statement suggests, when this role was not acknowledged the wife's self-esteem suffered. In addition to requiring acknowledgment for their role as caregivers and competent decision-makers regarding disease management, these wives also sought recognition from health professionals for their multiple roles as wives and mothers, and recognition that the disease affects everyone in the family, not just the husband. This next account reflects the anger experienced by some wives when this recognition did not exist.

W.5 There is no support up there at the hospital for the wife...They don't seem to think that if he's in any kind of pain, or if he's in any kind of trouble, they're not only affecting one person, they're affecting the whole family....Poor [husband] and to hell with the rest of us [laughs].... [Husband] was having tests [at the hospital]. We said to [doctor] we have to be back cause were having this special bingo and we're supposed to be getting donuts. They said oh, no problem, no problem. Well you know it's 4:30-5:00 and we're still there. And then I started getting I've got to go, I've got to go. My kids are home from school for two hours and they're still not letting us go. I SAT THERE FOR THREE HOURS with nothing but one MS pamphlet to read.... And they kept saying "You shouldn't be so anxious, you're upsetting you're husband".

These accounts of wives indicate that acknowledgment from friends, family, and health professionals was very important in their caregiving role. It is through this acknowledgment that the women validated their roles as
caregivers and consequently maintained their self-esteem. When acknowledgement was not provided these wives felt negated and angry.

D. Finances as Support

Adequate finances assisted wives in caregiving by affording them the capacity to purchase equipment and modify the environment according to their husbands' needs. These needs varied depending on the degree of dependency of the husband. Adequate equipment and facilities increased the husband's mobility and consequently modified the wife's caregiving responsibilities.

Living with a chronic illness was costly for the families in this study. Not only did these families lose the husband's income when he was no longer able to work, but equipment and resources became an extra financial cost. Adequate finances meant wives were able to purchase both the necessities and extras without compromising in other areas of their lives. As the following account indicates, adequate finances meant one less thing to worry about:

W.6 My husband has a good income which makes me able to do things without having to penny pinch, and it's easier on you when you don't have to worry about money... You know, we can just do a lot of things and get a lot of things, which I don't have to second-guess, and I think that really helps me out.
When a husband became wheelchair bound, his ability to move about the house became limited. Consequently, these wives became more involved in assisting their husbands from room to room and as a result, their caregiving responsibilities increased. One solution was to purchase a wheelchair-accessible home or make modifications to the existing home. For most people the cost of this was exorbitant. For those families in this study who were able to afford a wheelchair-accessible home, both the husband and the wife gained greater independence. A wheelchair-accessible home not only allowed the husband to move easily from room to room, it also allowed the husband to maneuver himself in the bathroom. As one woman identified when asked what things made life easier:

W.4 Well, the fact that he can get into the bathroom with his [three wheel scooter], or that he can get into the shower. I don't have to put him in. I mean he just goes.

A wheelchair-accessible home not only eased the physical aspects of caregiving, but it also provided these wives the assurance of being able to maintain their husband at home. Thus, adequate finances also prevented or delayed placing husbands in institutions. As one wife identified when speaking about the advantages of a wheelchair-accessible home:

W.4 It's just changed our life completely. We were in a two story house before and it was, you know, he had to walk up a flight of stairs into the
kitchen and den and living room area, and then upstairs for the bedrooms, and it was just awful... And we just happened upon this house, it was just great. I mean, I said to [husband] that I would never put him in an institution, I mean I just couldn't do that... I mean, we could have live-in help if we had to, and our bedroom wing is down this end, and it would be a perfect set-up for us.

The commitment wives made to caregiving and their reluctance to institutionalize their husbands placed a burden on them when faced with the dilemma of no longer being able to meet the demands of caregiving. As the above account shows, adequate finances provided the security of maintaining husbands at home.

Adequate finances also provided the luxury of purchasing equipment that increased the husband's independence, and as wives so consistently stated, "things that make my husband's life easier, make my life easier". For example, one piece of equipment that was useful was a remote phone:

W.4 I bought a remote phone so that if he was out in the garden or something he doesn't have to run to the phone, it's easier for him. And it's easier for me because I don't have to run in and out to the garden and do whatever, you know.

Adequate finances for equipment not only decreased the time spent in caregiving tasks, it enabled the purchase of more sophisticated equipment which alleviated many of the difficulties involved with lifting. A lightweight wheelchair is easier to lift and therefore less of a physical strain on the wife. The potential
outcome is that more activities out of the home are likely to be attended. This is clearly identified in the following account:

W.4 I feel if he buys some more equipment we can do a lot more. Like a lightweight wheelchair. You know, we have a heavy wheelchair that came with the house. I think if you have more accessible equipment then you can do more.

R. Gives you more mobility?

W.4 Oh yea. I mean it kills me carrying and packing all that junk around, you know... It was my birthday in June so [husband] said "What would you like?" and I said "A lightweight wheelchair" [laugh].

Another piece of equipment that assisted wives with caregiving tasks was an electrical unit called a TOSC unit. This is an electronic system that allows a person with a disability to control his or her environment by turning electrical appliances on and off. In talking about support, the following woman identified the TOSC unit as particularly useful:

W.3 I didn't really realize how tough it was, but it really is though when you've got no back-up at all. Kinsmen were a great help. They bought the TOSC unit. It will enable him to turn on the TV or the radio, or change channels, or turn on the lights and that kind of thing.

When family finances did not adequately cover both family living costs and the purchase of equipment, a great deal of tension was created for wives. Not only was there tension about available funds, there was the added responsibility of having to decide whether the money would be spent on family needs or helpful equipment.
Neither choice was satisfactory. She was caught in a dilemma:

W.7 Everybody is talking about what you have to do for the person who has MS. You've got to install an elevator. It will cost you $10,000 and you will lose your son's bedroom. And there is no-one who will say "Can you afford this?"... Although we had enough money we had put that money away for the kids education. And you have to weigh the things. In some ways I think it's worse for the mate of the person who has MS cause...[husband] never once said how are you making out with money, never once, and umm you panic.

The above accounts reflect the importance of adequate finances for wives in their caregiving role. Adequate finances to purchase wheelchair-accessible homes and equipment increased the husband's independence and subsequently lessened the number of daily tasks in which the wife was involved. Adequate equipment had the potential to increase the number of outside activities for both husband and wife, and decrease the amount of heavy lifting. Finally, adequate finances released wives from the untenable position of choosing between family needs and husband needs.

This sub-theme of support for caregiving has addressed four types of caregiving support that the wives in this study found useful: information, practical assistance, acknowledgement, and finances. The following sub-theme will address support for distancing.
Support For Distancing From Caregiving

All of the wives in this study identified that support for distancing from the caregiving experience was helpful. The need for support for distancing varied widely among these wives and depended upon the degree to which each wife was enmeshed in the caregiving experience. Wives whose husbands were more independent and self-sufficient were less embroiled in caregiving and consequently required less support for distancing. Conversely, wives whose husbands were more dependent upon them were more enmeshed in caregiving and consequently desired more support for distancing. The accounts of these wives revealed three major types of support for distancing: social activities, professional services, anticipatory support. Each of these will now be addressed.

A. Social Activities as Support

Social activities for the husband and the wife, both individually and as a couple, provided opportunities for the wives to distance themselves from the caregiving experience.

Social activities for the husband, such as socializing with friends, participating in bridge or poker, or attending sporting functions became a major consideration for the wives in this study. Due to the
effects of the disease many husbands were less motivated or able to participate in their usual activities. Consequently, these wives invested tremendous energy into encouraging their husbands' involvement in activities and social events. The effect of the husband's inactivity on the wife is reflected in the following account:

W.8 It just depresses me, day in and day out [husband] lying down watching TV, listening to tapes, so I have to push him to do things.

Therefore, when husbands were inactive, not only did the wives spend more time at home with their husbands, but they invested tremendous emotional energy in their concern for him.

When husbands were involved in activities that they enjoyed, the wives did not worry as much about the husband's happiness. As one wife stated, "it takes a load off". This in itself allowed wives to psychologically distance from some of the worry associated with caregiving. In turn, wives gained more freedom to become involved in their own personal activities. This is well illustrated in the following:

W.7 I like it when he's going somewhere, because then I don't worry if I go somewhere.

Opportunities for such separateness were important for these wives. Not only did it allow them to distance from the husband but it also helped to promote a normal family existence which subsequently resulted in greater distance from the caregiving experience.
R. So the more involved [husband] is the more involved you can be?

W.6 Yea. And then we can come back together and compare each others' worlds instead of just being here discussing the same little world, you know.

Many of these wives came to depend on friends and family members to involve their husbands in social activities. However, most wives found that people were uncomfortable with illness and, over time, fewer and fewer friends visited or engaged the husband in outside activities. Although close friends remained in contact there were still fewer opportunities for social contact. As one woman stated:

W.4 I wish they would drop in more and come and visit just for half an hour or something, and that, I think, is a very great need for people who are disabled. You really notice that.

Social activities for the wives provided opportunities to distance from the caregiving experience. Although many wives in this study identified they had little time or opportunity for their own social activities, there was a high value placed on friendships and social exchange. Because many of these wives had competing demands of employment, family and caregiving, opportunities for personal activities provided a tremendous release. As one wife stated about her friends:

W.8 I treasure them... They enrich my life, and I really wonder, well like any one would wonder, what would I do without some very good friends. You know, to enjoy skiing with, to enjoy a good laugh, to enjoy a good party.
Many wives used these social opportunities for pleasure and purposely chose not to discuss their problems with their friends. For example:

W.6 I don't go there [to the lounge with friends] talking about my problems cause I don't want to talk about my problems anyway. I want to get away from it all.

For some women these social events provided an opportunity to get out of the house and be physically removed from the caregiving environment. As well, some women found comfort in just having someone to talk to. Talking about problems was legitimate when it was reciprocal. As previously stated, the wives did not want to be seen as needy and thus discussing problems was more acceptable when reciprocated. Social activity as a way of getting out of the house and having a shared conversation is reflected in the following:

W.7 He'd tell me his troubles...and I told him my troubles and I think it did me a lot of good. Just getting out of the house. Getting a bit of exercise. And having someone to talk to.

For the wives in this study, couple-oriented social activities served to augment a normal existence. This, in turn, allowed wives to temporarily distance from the caregiving experience. For these wives couple-activities primarily centered around dinner engagements either in the home or at the home of friends. In either case, the wife viewed the activity as a break from caregiving. As one woman stated:
W.7 Well I enjoy company. We do have a lot of company. Perhaps I enjoy it cause it is a break.

Dinner engagements outside the home required more energy on the part of the wife, due to the lack of outside wheelchair-accessible facilities. Even so, these events were looked forward to as an opportunity for social contact with people other than the husband. This is reflected in the following account:

W.6 I have to ask the people to make sure they're there to help carry the wheelchair up the stairs and once we're there I have to help him in the bathroom cause the bathrooms are never equipped properly...So you have to go away from the company and stuff like that, but it doesn't bother me one bit. I'm just so glad that I'm out you know with other people instead of just being with him all the time. Cause I think you just have to get out.

During these couple-oriented activities some wives found further support for distancing from friends who assumed some of the wife's typical caregiving tasks. This support allowed wives to attend couple-oriented social functions while at the same time distancing from both the husband and caregiving tasks. This next account shows how one wife was provided this support:

W.8 We went out for dinner with 16 other people... and because I get out so seldom I don't like to sit next to [husband] because I've got to cut up his meat and read the menu to him. But I need a breather, and enough of our friends know what needs to be done, so they'll sit next to him and I'll sit somewhere else.

These accounts show how social activities for the husband, the wife, and the couple, provided opportunities for the wives in this study to distance from the
caregiving experience. As well, the wives perceived social relationships as more supportive when friends did not perceive the wives as needy and were willing to share on equal terms.

B. Professional Services as Support

Although a number of wives (and husbands) in this study did not utilize professional services, such as day programs and respite care, those that did were provided opportunities to distance themselves from the caregiving experience. For wives who were employed outside the home it became particularly imperative that their husbands were adequately cared for and involved with their own activities. When husbands remained at home without adequate home support it created more stress for the wife. Rather than concentrating on her responsibilities at work, the wife worried about her husband's safety. The following account indicates the stress this situation created for one woman:

W.6 I work and I worry at work cause he falls and he can't pick himself up...so even with the two days I work I phone now and if there's no answer I think Oh God! I wonder if he has fallen.

Professional services such as day programs provided a solution to this problem. When husbands were satisfactorily involved in day programs the wife was able to be more fully involved with her other activities, such as work, without worrying about her husband. This
solution offered both the husband and the wife their own activities, providing distance from caregiving. This next account relates how one husband's involvement with a day program created a comfortable distance during the day and subsequently provided them with topics of conversation at night:

W.2 We're really fortunate with [husband's] involvement with Pearson Hospital...He has two free days where he can swim or whatever and three scheduled days where he has to work, and he treats it like work. Then when he comes home we are more apt to talk about what he has done and the people he has seen. And it's great I don't really want to talk about my work when I get home.

Although day programs are set up to specifically provide support to the husband, this support has a direct effect on the wife. In commenting on how helpful the day program has been this same wife stated:

W.2 I'd say all the support things that I need the most are the things that [husband] gets because as long as his life is going smoothly so is mine.

Respite care was also an option for these wives to distance from the caregiving experience. When the husbands spent one or two weeks in a respite care facility these wives were provided a complete break from the caregiving experience. Some wives indicated that their husbands also benefitted from this break and thus, respite care served to provide a break for both the husband and the wife. This is reflected by one wife:

W.6 It's an option where he can get away from the family life, and get away from us, because we're together so much that you can really get on each
other's nerves after awhile...You know, sort of give the family a break but give himself a break also.

However, arranging for respite care was not always easy. Several wives spoke of the "red tape and bureaucracy", and the energy cost seemed at times, to exceed the benefits. The following account reflects the dissatisfaction, of one woman, with the arrangements for respite care, after two and a half years without a break from caregiving:

W.7 And then a week or two before he was supposed to go they phoned and said "Oh he can't go in, they're not prepared to give him as much care as he requires". Which was pretty awful. They knew this in the beginning, and somehow all the wires got crossed. So he was really disappointed and so was I. And then it was too late to arrange for anything else.

These accounts show how professional services provided support for distancing to the wives in this study. Day programs allow wives to be more involved in their own activities and respite care, if accessible, provided a complete break from caregiving for a specified time period. However, unless the support satisfied the wife's perception of quality care, the wife was unlikely to view the services as supportive, and less likely to use them.

C. Anticipatory Support

The wives in this study reported that the anticipation of support, for future needs, was in itself
a powerful form of support for the present. The anticipation of available assistance, to call upon when needed, allowed these wives to psychologically distance from the burden of total responsibility for caregiving. Thus, the very knowing that support would be available if the need arose became an important form of support for these wives.

The value of what could be called "anticipatory support", for these wives, stems from knowing they are the primary providers of care to their husbands. This knowledge left wives feeling they "could not get run down", "could not get sick" because otherwise, "who would look after my husband?". As well, some wives anticipated that a time might come when the husband's disability would extend beyond the wife's capability to provide care. As one wife stated:

W.1 There's always the thought that maybe tomorrow [pause] and how do I lift a 200 pound man; that thought has occurred to me, and I don't think about it all the time, but I have thought about it and worried about it.

This feeling of total responsibility was unquestionably perceived as a burden and at times, an overwhelming one. They identified that the knowledge there was someone they could count on made their lives much easier. To be relieved from this caregiving concern, this next woman had her husband assessed for homemaker service:

W.4 I've had [husband] assessed and so that out there there is help if I want it. I think that makes my
life feel a lot easier, you know. If he does get sick I know where I can phone.

This knowledge of having someone to count on allowed this woman to psychologically distance herself from the caregiving experience. This woman went on to identify that it was not healthy to think about increased caregiving tasks in the future, but that it was very healthy to ensure assistance would be available for future needs:

W.4 I don't want to think about [the future]. I'll cross that bridge when I have to. But there's no way I'm going to start thinking about it now.

R. So that's not a healthy thing to do?

W.4 No. No. I don't think it is, because it upsets me to think I have to do all that. I know that there is help out there if I need it, and that's all I worry about.

The above account dramatically shows the psychological value that anticipatory assistance represented for these women. It allowed them to distance from the worries of caregiving and reduced their anxieties about the future.

Many of these wives also identified their families as providing anticipatory support. Even though these wives identified that "it would have to be something really bad" to call on family members, just the knowledge that family would be available was in itself support for distancing. As one woman stated:

W.5 I don't even know if I've called on them that often, but knowing I can whenever ---
R. And what does that do for you?

W.5 I think it makes me stronger. If you had nobody, some of the things, I don't know what I'd do.

These accounts show how, for the wives in this study, the anticipation of support became support in itself. Knowing they could count on family and health workers allowed these women to psychologically distance from some of the burdens of caregiving. This form of support became particularly valuable in light of the concerns wives had in actually receiving support. Anticipatory support was always viewed positively, and provided access to support without requiring tremendous input from others.

This sub-theme has dealt with three types of support these wives found helpful in distancing from caregiving: social activities, professional services, and anticipatory assistance. This next sub-theme addresses support for living with ambivalence.

**Support for Ambivalence**

This sub-theme addresses the type of support that assisted the wives in this study in living with ambivalence. This support is identified as "being understood", a predominate topic of these wives. "Understanding" as support for ambivalence meant that others understood the conflicting feelings surrounding
the ambivalence. That is, when these wives felt that others understood their commitment to caregiving and the simultaneous desire to distance from caregiving they felt supported in living with the ambivalence. "Being understood" as a form of support will now be addressed.

**Being Understood as Support**

All the wives in this study identified that "being understood" was a key feature of support. In fact, these wives defined support as understanding. As one woman stated when asked what support meant:

> W1 It's just having someone that understands what you're saying and - ah - what you're feeling.

For these wives being understood meant that other people were aware of the burden that accompanied caregiving and the desire for periodic distance from the caregiving experience. This understanding was particularly important because the wives were so accustomed to focusing their attention on their husbands' needs rather than their own. Many of these wives perceived that because they were healthy and their husbands had a disability, their husbands' needs were more important than their own. Therefore, it became very difficult for wives to acknowledge their personal feelings particularly as they related to the ambivalence of caregiving. This is reflected in the following account:
R. Do you mean that your husband's needs are more important than your needs right now?

W.6 Right now, yes. Yes. Well I'm a healthy, medically strong person. I can overcome my needs... So there's always a way... So you can work yourself out of that, but [husband] can't He's handicapped. He's physically handicapped.

When wives felt that someone understood their predicament they were more able to talk freely about their situation. They felt that there was someone who was willing to listen to them, someone willing to recognize their feelings without judgement or condescension. In short, being understood validated these women as competent individuals who at the same time experienced ambivalence. This next account shows the value placed on understanding:

W.8 Lately I've been honest with what my life has been like, and it has opened up this whole area that at least my mom and I talk about. Just being able to let it really all hang out and just the frustration I feel. And knowing that my mother is listening, my mother's listening and she's understanding.

Conversely, not being understood resulted in more guilt for these women. The next account reflects how one wife described her relationship with her mother-in-law, who didn't understand this wife's desire to have a weekend away, and the subsequent guilt it created for the wife:

W.8 She didn't understand. I mean, if she'd understood that, she might have said "Well, have a really nice weekend. Don't worry about [husband] or [son]. We'll make sure everything is fine"... When I say the understanding, the understanding that
you need some time for yourself, the understanding that you're really depressed and pissed off and that type of thing...she doesn't see any of my needs...I won't allow myself to engage into her game of making me feel guilty.

Not all wives felt they had someone who understood them. The tremendous need to have someone to talk to who understands is reflected in the following account of one wife who identified that she had no-one at all to talk to about her feelings:

W.3 I never had anybody to talk to. So the best friend I ever had was my shower. I would go in the shower and I'd turn it on and I would cry, and I'd be just like a wet dishrag when I came out of there.

Many wives received understanding from a variety of different people, such as family, friends and individual health care professionals. An especially important source of understanding, and one of major value, was their husbands. While some wives identified that subsequent to the illness their husbands no longer understood them: "he's too involved with his illness to see my situation", "I've lost my best friend, that's the hardest part", "we don't even talk anymore", other wives identified that it was the husband who was the primary source of understanding and support: "he's my rock, he keeps me going", "he's my best friend and my only confidant". This next account is an example of how one husband provided this understanding:

W.4 He's very good. I've just started to play golf in the last two or three years and it's been [husband] that's made me do it, because he feels I
have to get away, get out and do things, you know, by myself.

These accounts show how being understood supports these wives in living with ambivalence. Understanding allowed these wives to appreciate that their feelings were acknowledged and validated, and decreased the guilt they experienced.

This theme, the nature of support, has addressed three sub-themes: support for caregiving, support for distancing and support for ambivalence. Support for the first sub-theme was explored through discussion of information, practical assistance, acknowledgement, and finances. Support for distancing addressed social activities, professional services, and anticipatory support. Finally, "being understood" was presented as the type of support these wives found helpful in living with ambivalence.

Summary

This chapter presented the findings of this study. The wives perception of support was embedded within their caregiving experience which involved a strong commitment to caregiving while simultaneously desiring some distance from caregiving to pursue personal activities and interests. These simultaneous conflicting needs resulted in ambivalence. Support for caregiving was identified as information, practical assistance, acknowledgement, and
adequate finances. Support for distancing included social activities, professional services, and anticipatory support. Being understood was shown to be a major means of support for living with ambivalence. The findings showed that the wives did not feel comfortable in verbally requesting support and generally only asked for support when they viewed it as absolutely necessary. As well, these wives clearly expressed discomfort with being seen by others as needy. Finally, in spite of the stated burdens of caregiving, these wives were generally satisfied with the amount of support received, although less satisfied with the quality of support received. The following chapter discusses these findings in light of related theory and research.
CHAPTER 5

DISCUSSION OF FINDINGS

Introduction

This chapter discusses the findings of this study in relation to pertinent literature and related research. The following discussion is organized into two sections. The first section focuses on the socialization of women into caregiving, and the second section explores the issues around requesting and receiving support.

The Socialization of Women Into Caregiving

The findings of this study showed that the meaning these wives gave to social support was firmly embedded within their caregiving experience. In fact, when asked about social support these wives spoke at length about caregiving. This interesting finding suggests that for these women their caregiving experience was closely linked to the meaning they gave to social support. Crucial to the caregiving experience was the wives' commitment to providing care to their husbands. This section explores these findings in light of the socialization process of women in our society. Initially, the socialization of women will be discussed in relation to the wives' caregiving commitment. Subsequently, the socialization of women will provide insight in exploring
the relationship between the caregiving experience and social support.

The socialization process provides a basis for understanding the commitment the wives in this study made in caring for their husbands. This is not to suggest that commitment to caregiving is entirely gender specific, but that the basis of the commitment is different for each gender. In our society, women are ascribed, to a much greater extent than men, expressive and nurturing functions (Graham, 1983). In fact, women are presumed to be responsible for the well-being of their family members (Sommers, 1985), and today, as in the past, it is expected that women will care for ill family members regardless of competing demands and personal sacrifices (Doyal, 1981). According to Adams (1971) "...woman's primary and most valuable social function is to provide the tender and compassionate components of life and that through the exercise of these particular traits, women have set themselves up as the exclusive model for protecting, nurturing, and fostering the growth of others" (p. 556). Not only are these nurturing functions central to a woman's place in society, but through enactment, they become central to how a woman defines herself in relation to the world around her. As women define themselves as nurturers and protectors of family
members so do they assume the responsibilities of caregiving for a chronically ill family member.

The nurturing functions of women incorporates the notion that the needs and concerns of others become a central concern for women in both the home and work settings. Implicit in this is that a woman's personal value and reward is derived from the "...virtue of subordinating individual needs to the welfare of others..." (Adams, 1971, p.559). As well, research shows that girls are socialized to anticipate environmental demands, and attend to stimuli, especially from other people (Bardwick and Douvan 1971). This ability, carried over into adulthood, equips women with the ability to empathize with others. The wives in this study repeatedly identified that their caregiving responsibilities took precedence over their personal needs and interests. While some women challenged this by briefly distancing from caregiving to partake in personal interests, their ability to empathize with their husbands' circumstance and their experience of guilt ultimately resulted in recommitment to caregiving. The power of the socialization of women, that is, in learning to be aware of the needs of others and to consider those needs prior to their own, explains the guilt these wives felt when distancing. Alternatively, when the husbands were satisfactorily occupied, the wives perceived the
husbands' needs to be met and it was only then that they were freed to attend to personal activities without guilt.

The wives' commitment to caregiving is further understood through women's relationships with others. Bardwick and Douvan (1971) identify that women's primary source of self-esteem is gained through the positive responses of others. As a result, relationships as daughters, friends, wives, and mothers become crucial sources of esteem and validation as worthwhile people. The social and familial expectation to assume the caregiving role encourage women to conform to these expectations as a way of seeking and obtaining approval, and of avoiding the loss of love. If esteem is derived through the approval of others it would become very difficult for these wives to behave in a way that resulted in serious disapproval from family and friends. In fact, this socialized need for external approval may explain why these wives identified acknowledgement and understanding as effective supportive measures.

The socialization of women can also provide insight into the finding that, for these wives, the meaning of social support was embedded within their caregiving experience. For these women discussing their caregiving experience was a natural way of addressing their perceptions of social support. In fact, several wives,
when asked about people or things that made their day
easier or more difficult responded by directly discussing
their caregiving experience. This was an unexpected
finding and the following discussion attempts to provide
some understanding of this relationship between
caregiving and social support.

As previously identified, the nurturing and
protective functions are primarily ascribed to women, and
it is through these functions that women formulate their
identities (Graham, 1983). In fact, for some women these
nurturing functions are central to their self-concepts
(Adams, 1971). Given this understanding, it may be that
some women are socialized so strongly to provide care
that they interpret social support as something they give
rather than something they receive. In this sense, it
becomes quite natural for a wife to discuss her
caregiving experience when asked about support. All of
the wives in this study spoke at length about caregiving.
They identified a number of supportive activities they
provided to their husbands such as practical assistance,
emotional and social companionship, information, and
management of daily activities. In fact, several women
expanded their supportive activities to include the
provision of information and comfort to members outside
the family. It would appear that, for the wives in this
study, the provision of support was as important to their
meaning of social support as was the receiving of support.

The socialization of women as nurturers implies that the needs and demands of others become a woman's major concern and that the meeting of these needs takes precedence over all other claims (Adams, 1971). Thus, women learn to subordinate and suppress personal needs in favor of meeting the needs of others. This was true of the wives in this study who repeatedly spoke of placing their husbands' needs before their own. It may be that as these wives became increasingly involved in caregiving, their awareness of their own needs were suppressed, and consequently so were their perceptions of the need for support. Therefore, these women became much more attuned to the support needs of their husbands than of their own support needs and consequently addressed their role in providing care to their husbands as a way of explaining their perceptions of social support.

This concept of suppressing one's own needs in favor of others may also explain why these wives so clearly identified that support for their husbands was support for themselves. Their primary concern for the well-being of their husbands led these women to place their husbands' needs for support at the forefront.

Given these wives' perceptions, that support for their husband was support for themselves, it was
inevitable that these women would discuss their caregiving experience when addressing social support. These women are the primary providers of support to their husbands. If the wives primary source of support was received through the support provided to the husbands, and the wives themselves were the primary providers of that support, it would have been impossible to discuss the meaning of support without addressing their caregiving experience. In this analysis it may be that the wives' perceived ability to provide quality care to their husbands was a more powerful factor in their well-being than external sources of support. In fact, almost all the wives in this study addressed their personal strength and ability to provide quality care as powerful positive factors in their daily lives. Similarly, Marcus and Jaegar (1982) found that "coping", "getting results", and "doing a good job" provided the greatest degree of daily satisfaction for caregivers.

In summary, the socialization process of women in our society leads some women to be deeply committed to providing care to their chronically ill husbands. Providing care is a way of fulfilling society's expectations of women as nurturers and protectors of family members. Moreover, this nurturing function, as well as the tendency for women to subordinate their own needs, provides some insight into why the wives in this
study embedded social support within the caregiving experience.

Issues Around Requesting and Receiving Support

The findings of this study showed that although the wives identified a number of types of support they found useful, there were several issues around the literal requesting and receiving of support. This section discusses the difficulties wives had in requesting support and the lack of perceived need for more support than presently receiving, in spite of the identified burdens.

These wives identified practical assistance, from family, friends and health professionals, as a valuable form of support. At the same time, these wives expressed a lack of willingness to request this type of support and were more likely to wait until this support was offered, and even then sometimes refused it. Similarly, Johnson (1983) found that spousal caregivers were less likely to call upon outside help than other types of caregivers. One explanation of the resistance in accepting support lies in the socialization of women as nurturers and protectors of family members. As such, women's self-definition is based, in part, on their ability to enact these nurturing functions (Anderson, 1983), and it may be that the wives in this study viewed support as a
reflection of their competency as caregivers. Moreover, the lack of distinction between caregiving and homemaking responsibilities, due to the lack of clear role definitions (Baruch, Biener, & Barnett, 1987), suggests that women may expect the same degree of competency in performing caregiving tasks as they expect of themselves in performing homemaking tasks. Thus, the ability to independently and competently carry out caregiving responsibilities becomes central to how a woman values herself. Given this understanding, it is clear that accepting practical assistance, however appropriate, may result in the woman's self-esteem being compromised. This may be perceived by some women as more detrimental than the associated burdens of independent caregiving.

Gilhooly (1984) found that satisfaction with assistance received was more closely correlated to caregiver well-being than the amount of assistance received. Consequently, if practical assistance is viewed as conflictual by the caregiver this assistance is less likely to be used in the future.

Social expectation may also influence a person's willingness to accept support. Gourlash (1978), notes that a person's social network transmits attitudes, values, and norms about help-seeking. She states that if the norms of a social network discourage help-seeking and encourage self-sufficiency it is more likely that a
person, who has adopted the norms of the group, will be motivated to manage their situation independently.

For the wives in this study, it might be that help-seeking behaviours were antithetical to their group norms, and thus, these women likely adopted similar values, attitudes and behaviours. Because caregiving and homemaking lack clear role definitions and consequently may overlap in certain areas, the burdens of caregiving are less likely to be seen as different from those of homemaking. Consequently the group norms of self-sufficiency may be extended to include caregiving responsibilities. If the expectations of the social network are that women are able to perform caregiving tasks competently and independently it is likely that the wives themselves internalized this expectation and were less likely to request or accept support. As well, it is primarily through their social network that these wives received acknowledgement and understanding. To accept assistance, and behave in opposition to the group norms would mean these wives would jeopardize a major source of support in the form of acknowledgement and understanding.

Interestingly, research shows that wife caregivers receive less support than husband caregivers (Johnson, 1983; Polansky, 1982). In fact, Polansky (1982) found that while 65% of male caregivers received formal support, only 42% of female caregivers received similar
support. It may be that group norms are less accepting of help-seeking behaviours of wives than of husbands with respect to caregiving.

Social isolation, resulting from the demands of caregiving, is well documented in the literature (Cantor, 1983; Chenoweth & Spencer, 1986; George & Gwyther, 1986; Marcus & Jaeger, 1982). The consequences of social isolation may provide insight into the issues around accepting support. As caregiving demands increase, women have less time for social activities with friends (Cantor, 1983). In a study of 23 caregivers, primarily wives, Scott, Roberto, and Hutton (1986) found that social visits by other family members were infrequent, even though they were identified as the type of support most appreciated by caregivers. This decreased opportunity for socialization may result in less awareness by friends of the associated burdens of caregiving and consequently lead to less offers of assistance. Not only did the wives in this study have fewer opportunities for social activities but they preferred to use social opportunities as a way of distancing from caregiving, thus spent minimal time sharing with their friends the burdens of caregiving. Consequently, friends may have continued to assume that these wives did not require support.
Social isolation can also preclude caregivers from meeting other caregivers who are in similar situations. Without this exposure, caregivers may experience feelings of insecurity, believing that others are able to cope and therefore so should they. Interestingly, most of the women in this study asked if the other wives had similar feelings about certain issues. Exposure to other caregivers could lead to awareness of common issues and concerns. Through exposure to other caregivers, the wives would have an opportunity to experience other group norms more conducive to help-seeking behaviours, thus legitimizing the acceptance of support.

Robinson (1988), in a study of 20 caregivers, developed a social skills program aimed towards mobilizing social support in the caregiver's environment. Although burden scores were lower for the treatment group than for the control group, Robinson notes that the subjects found the sharing of caregiving experiences more significant in decreasing burden than the gaining of social skills. She does note however, that the post-test did not allow adequate time to detect the impact of social skills training.

The discussion of requesting support is not complete without exploring the implications of individual personality differences. The literature on social support documents that social skills are important to maintain
and mobilize social support (Robinson, 1988). In this sense social skills are those that predispose an individual to develop a functional support network. Robinson (1988), identifies a number of social skills necessary to effectively utilize available support: introducing self to others, making phone calls to initiate social contact, participating in groups, using assertive behaviour to meet needs, engaging in self-disclosure, and being responsive.

Caregivers who are unskilled in utilizing these assertive skills and who have less experience in negotiating bureaucracies are less likely to receive the support needed to lessen the burdens of caregiving (Robinson, 1988). In this study, a number of women, identified that they were reluctant to ask for help from family and friends. They viewed these people as having their own responsibilities and were reluctant to make additional demands on their time. This may reflect a lack of assertiveness resulting from little experience in openly expressing personal needs. As discussed in the previous section women have been socialized to place other people's needs before their own. Consequently these wives may have limited assertive abilities in requesting support from others, however justified.

Not only did the wives in this study have difficulty requesting support, they were also reluctant in
expressing the need for support. In fact, although they identified a number of useful types of support, they frequently identified support as something they would use in the future rather than the present. This finding will now be addressed.

Research findings show that spousal caregivers identify a lower need for social support than do other types of caregivers (Cantor, 1981; Hess & Solo, 1985; Soldo & Myllyluoma). Hess and Soldo (1985) identify this as a differential tolerance threshold. This suggests there is something about the marital dyad that diminishes the perceived need for support. Hess and Soldo suggest that one explanation is that "spouses are willing to do almost anything, including reluctantly admitting service providers into their own homes, to prevent the nursing home admission of their lifelong companion" (p.79). They go on to say that companionship of a spouse is a crucial interpersonal resource, even if the relationship is distant or in conflict. At the very least, a spouse is an "accustomed other" and just being together "confers an authenticity to each partner's identity" (p.75). It may be that the wives in this study, genuinely do not perceive a need for more support than they are already receiving because they have incorporated the demands of caregiving into their daily regime.
Interestingly, in a study of 167 family caregivers, Johnson (1983) found that the use of all formal support was significantly lower among spousal caregivers than non-spousal caregivers. She concluded that inherent within the marital dyad is the expectation that husbands and wives fulfill each other’s instrumental, social, and emotional needs. Consequently, spousal caregivers when facing chronic illness, seek and use less formal support than off-spring or other types of caregivers. In contrast to this finding, Robertson and Reisner (1982) found that over one-half of the 26 caregivers (11 spouses) expressed the need for community services, although only four were actually receiving these services.

A further explanation as to why these wives did not perceive the immediate need for support lies in the concept of reciprocity which is said to be the foundation of social interaction (Gouldner, 1960). According to Longino and Lipman (1985) "people in kinship patterns reward each other for their contributions, investments, continuity, and loyalty, thus maintaining a network of mutual rights and duties" (p. 220). Thus, there is a normative obligation on the part of kin to both help and to receive help.

It may be that the wives in this study have adjusted to their caregiving experience and have redefined the reciprocal roles within their marital relationship. As
reciprocity is calculated over time, it may be that these wives view their caregiving responsibilities as balancing previously unequal exchanges. Or it may be that the wives are building up a store of credits in the hope that someone would be available to care for them, given the necessity. It may also be that these wives view reciprocal exchange as extending beyond the marital dyad and that their indebtedness accrued from the outside support received is balanced through meeting the caregiving responsibilities.

Research shows that over time marital partners perceive increasing equality of exchanges within the marital dyad, and that when it is not perceived as equal most partners find their marriage imbalances in their favor (Schafer & Keith, 1981). It may be that the wives in this study, viewed an equitable marital relationship due to the husbands' continued financial provisions in the form of investments and pensions as balancing the wives' provision of care. As well, a number of these wives identified their husbands as their primary confidant and major source of emotional support. This may have been a factor in the perceived balance of exchanges, and may further explain why these wives did not perceive the need for support regardless of the burdens.
Summary

This chapter has discussed the findings of this study. Exploring the socialization of women helped to clarify why these wives were so committed in providing care to their husbands. It also provided some insight into why the wives experienced such guilt when distancing from caregiving. This discussion also explored the possible reasons why these wives experienced difficulty in requesting and receiving support and why these wives identified a lack of perceived need for immediate support.
CHAPTER 6
SUMMARY, CONCLUSIONS, AND IMPLICATIONS FOR NURSING

Summary

This study was designed to explore and describe wives' perceptions of social support while living with and caring for husbands who have multiple sclerosis. The emotional and physical burdens of caregiving have resulted in caregivers being identified as "the hidden patients" (Fengler and Goodrich 1979). The importance of providing support to family caregivers, such as information or practical assistance, is well recognized to modify the burden of caregiving (Zarit and Zarit, 1982). However, there has been little research that has explored the subjective nature of social support and, as nurses are a major source of support to caregivers of family members, it is critical that they understand the caregivers' perspective of support. It is only through this understanding that nurses will be able to offer support in a meaningful way.

In order to understand social support from the caregivers' perspective, the qualitative method of phenomenology was used. Phenomenology seeks to understand "...the human experience as it is lived" (Oiler, 1982, p.178). This approach examines peoples' perceptions of events in their lives and tries to understand the meaning
these experiences have for them. The participants are viewed as knowledgeable informants, who work with the researcher to fully explain their perspective.

Eight wives participated in this study. They ranged in age from 38 to 61 years, with a mean age of 47.5 years. The wives were married an average of 21 years and had assumed caregiving functions at the time of diagnosis, between one and fifteen years previously. As well, four wives worked outside the home and all but one husband were retired as a result of multiple sclerosis.

Data collection and data analysis occurred concurrently. Each wife was interviewed twice. The initial interview was unstructured and the questions were broadly stated in order to encourage the wives to discuss those events that held greatest meaning for them. In exploring the ideas that the women identified as meaningful, the researcher gained a deeper understanding of the meaning these wives gave to social support. Each interview was analyzed separately and in relation to the other interviews. Emerging themes were identified and subsequently validated and clarified in second interviews. By constantly moving back and forth between the data and the themes an overall framework was developed that reflected the wives perceptions of social support. Two central themes emerged from the data
analysis: the caregiving experience, and the nature of support.

The first theme explored the caregiving experience. The wives in this study embedded their discussion of support within their caregiving experience. Within this first theme three sub-themes emerged: committing to caregiving, distancing from caregiving, living with ambivalence. These wives were strongly committed to providing care to their husbands. Their commitment to their marriages, their lack of distinction between the role of wife and caregiver, and their empathy towards their husbands all contributed to this caregiving commitment. As the role of caregiving became increasingly demanding of time and emotional energy, these wives experienced a desire to have some distance from the caregiving experience. The simultaneous commitment to provide care and the desire for distance resulted in feelings of ambivalence and guilt.

The second theme explored the nature of support. Three sub-themes were discussed: support for caregiving, support for distancing, and support for ambivalence. These wives identified information, practical assistance, acknowledgement, and finances as types of support helpful in their caregiving role. Support for distancing was provided through social activities for both the husband and wife as individuals and as a couple; professional
services such as homemakers and respite care; and through anticipatory assistance. Finally, these wives identified a strong desire for family and health professionals to understand their caregiving experience and this understanding was support for living with ambivalence. In general these wives felt that social support for their husbands was support for them and although they were satisfied with the support provided by family and friends, they were less satisfied with the support provided by health professionals.

Conclusions

The research findings led to a number of conclusions about these wives' perceptions of social support while living with and caring for husbands with multiple sclerosis:

1. The meaning these wives gave to social support was embedded within their caregiving experience. Support was viewed within the context of how adequately the husband was cared for and how successful efforts were to maintain the husband's independence. Therefore, support provided to the husband indirectly acted as support to the wife by altering her caregiving experience.

2. Although these wives identified a number of different types of support they found useful, requesting and receiving support was often difficult as many wives did
not perceive themselves as "needy" regardless of the perceived burdens.

3. Many wives did not perceive the need for more professional support than they were receiving at the present time. These wives did, however, anticipate that professional support would be available when needed and this anticipation of support acted in itself as a strong supportive measure.

4. Those wives who had used professional support in the form of information, acknowledgement, homemaker service, and respite care, were largely disappointed in the quality of support provided.

5. These wives had a strong desire to be acknowledged as competent caregivers and to be understood by family, friends, and health professionals. This acknowledgement and understanding supported wives by enhancing their identities as capable, caring and knowledgeable people.

**Nursing Implications**

The findings of this study suggest a number of implications for nursing practice, nursing education, and nursing research. The following section discusses these implications.
Implications for Nursing Practice

The results of this study provide direction for nursing practice. Of primary importance is the need for nurses to recognize the everchanging physical and emotional demands caregiving places on wives of husbands with chronic illnesses. Due to the downward trajectory of multiple sclerosis and the resulting increase in caregiving responsibilities nurses must ensure adequate and regular assessment of the support needs of both the caregiver and the chronically ill family member.

In assessing the need for support it is critical that nurses recognize that support provided to the husband is in itself support for the wife. This study found that wives viewed support within the context of their caregiving experience and those services that assisted the husband to maintain or gain independence simultaneously supported the wife by providing opportunities for her to attend to personal needs. Therefore, one nursing approach would be to offer support aimed towards enhancing the husband's independence. For example, day programs that involved the husband in activities outside the home would provide the wife opportunities to attend to household and professional demands. Self-help groups could be viewed as an opportunity for chronically ill persons to share their concerns while simultaneously allowing the caregiver to
distance from caregiving responsibilities. Arranging regular and consistent volunteer visits in the home would provide social opportunities for the husband and simultaneously provide the wife opportunities for personal activities out of the home. Finally, respite care would provide both the husband and wife a complete break from their usual routine and the intense amount of time spent together.

In offering these services it is critical for nurses to recognize that wives do not want to be seen as "needy". Consequently, the approach used in offering support will determine the wife's willingness to accept support. For example, nurses can explore with the wife the importance of maintaining personal health and that using the available services provides the wife with time to meet her own needs. In this way the wife's sense of competency is not compromised. The nurse could also explore the importance of the husband having social opportunities and activities apart from the wife, thus encouraging the concept of independent activities for both husband and wife.

The study results provide direction as to the nature of caregiver education. Information is of particular importance. The more specific the information the more useful it is to the caregiver. Nurses attuned to the need for specific information equip wives with the knowledge
and skill to perform tasks such as daily hygiene, transferring, diet, and exercise. Information concerning financial and practical resources increase caregiver knowledge with which to make decisions.

In addition, caregiver education could focus on the ways and means of accessing and utilizing professional services. Support groups geared towards the development of self awareness may lead to recognition of personal and common concerns related to caregiving. This in turn, might validate for the wife legitimate use of help-seeking behaviours. In addition, the development of assertive skills may equip caregivers with the resources necessary to effectively utilize professional services.

Finally, the findings of this study indicated that these wives desired greater acknowledgement and understanding from health care professionals. Not surprisingly, one of the most valuable nursing interventions is the use of therapeutic communication skills, such as empathic active listening. Due to the evolving responsibility of caring for husbands with multiple sclerosis it is critical that nurses provide to caregivers ongoing recognition of this significant role. Because women's identities are formed, to a large extent, through the responses of others, this acknowledgement would reinforce to the caregiver the significance of her role, and consequently enhance self-confidence in the
performance of her caregiving responsibilities. Similarly, taking time to listen closely to the caregiver in a non-judgmental manner may assist in lessening the emotional burden and result in the feeling that she is understood and valued.

Implications for Nursing Education

The findings of this study suggest that the education of the professional nurse should include information that leads to awareness of chronic illness as an event that involves all family members. This study clearly showed that the role of caregiving was often demanding and arduous, and that the provision of support to the wife was closely linked to the provision of support to the husband. Awareness of the caregiving experience and the unique qualities of this experience can lead to a better understanding of the support needs of individual caregivers.

Nursing education should incorporate the concept of collaboration. A collaborative relationship between the nurse and caregiver would incorporate the knowledge of the nurse and the value system of the caregiver. This type of collaborative effort has potential to result in greater caregiver satisfaction with services provided. Nursing education that focused on collaboration would ultimately lead to respect for the caregiver's ability to
make informed decisions suitable to his or her own best interests. The education of nurses should focus on the role of nurses as information providers and facilitators of client decisions. It is only when nurses are educated to genuinely collaborate with their clients that meaningful supportive services will be provided.

Implications for Nursing Research

This study has focused on the perceptions of support of caregiving wives. It is a beginning in the understanding of social support for caregivers; much remains to be learned. The findings of this study suggests several areas for further research.

In order to build on this knowledge base, further research could explore perceptions of social support of caregiving wives during various stages of the husband's illness. This study did not focus on the changing support needs of caregivers and it is likely that perceptions of support change over time. For example, the type and amount of information and practical assistance is likely to vary depending on the stage of illness. Anticipatory support may not be perceived as support for those wives who have reached the stage of using professional services such as homemaker and respite care. Finally, the need for acknowledgement and understanding may be greater at certain stages, such as following the diagnosis when both
the caregiver and family members are dealing with adjustments to an uncertain future. Although support needs remain individualistic this information would provide nurses with knowledge of support needs over time.

Findings from this study showed that these wives identified issues around requesting and receiving support. Not only did wives express discomfort around requesting support but they did not perceive a need for more practical support than currently being received, in spite of the identified burdens. This finding raises a number of questions. What is the meaning wives give to requesting support? Is requesting support a learning process? If so, what is involved with this process? What is the meaning behind women's perceived lack of need for support in spite of the accompanying burdens? This information is crucial for health care professionals whose primary function is the assessment and provision of specific supportive measures.

Finally, research exploring the health care relationships between caregivers, care receivers, and nurses would provide valuable information. Research of this nature might shed some light on why these wives frequently expressed dissatisfaction with the professional services received. These wives clearly identified hopeful expectations that health professionals would meet their future support needs, however they were
inevitably disappointed. Information that would shed some light on this concerning finding would equip nurses with the information to provide more meaningful support.

In conclusion, this study has described the wives' perceptions of social support while living with and caring for husbands who have multiple sclerosis. It provides insight into how some women see their role as wives and caregivers, and contributes to understanding the meaning wives give to social support. As well, it provides nurses with additional knowledge to use in assessing, planning, and implementing supportive strategies.
REFERENCES


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APPENDIXES
APPENDIX A

LETTER OF INFORMATION

My name is Toni Stovel. I am a registered nurse currently working on my thesis for the Master of Science in nursing program at the University of British Columbia. I am exploring women's perceptions of help received while living with a husband who has Multiple Sclerosis.

This letter is an invitation for you to participate in this study. You are under no obligation to participate and if you choose to participate you may withdraw from the study at any time. The health care you or your family members receive will in no way be affected by your decision to participate or to not to participate.

If you are interested in sharing your perceptions of the assistance you receive, or would like to receive, I would like to meet with you privately two or three times. We would meet either in your home or at a place of convenience for you. Each interview will last approximately 1-2 hours. On the initial interview I will ask questions such as: What is it like for you living with a husband with Multiple Sclerosis? What are the things/people that make a difference in your day-to-day activities? The second interview will be approximately six weeks later and will be an opportunity for you to clarify and expand on the information you initially shared with me.

Each interview will be audio-taped and subsequently typed. This is done so that I may listen closely to what you are saying without having to take notes. All information you share with me is confidential. Your name will not be on the tapes. Access to the tapes and typed transcripts will be limited to my thesis advisors and myself. You may request erasure of taped information at any time. All taped and typed transcripts will be destroyed upon completion of the study. All written material arising from this study will maintain your anonymity.

Participation in this study is voluntary. This information will lead to improved health care services for women who provide care to husbands with Multiple Sclerosis. Participants will be sent a summary upon completion of the study. In order to complete this study I am looking for English speaking women who are over twenty years of age, have husbands with Multiple Sclerosis, but no other chronic illness.
APPENDIX B

INTERVIEW GUIDE

1. What is it like for you living with a husband who has Multiple Sclerosis?

2. How would you describe the role of a wife whose husband has Multiple Sclerosis?

3. How do you see yourself fitting into this role?

4. Are there people/things that make a difference in your daily activities?

5. Who/what helps you in living with someone who has Multiple Sclerosis?

6. Who/what hinders you in living with someone who has Multiple Sclerosis?

7. What does support mean to you?

8. How does support fit into your daily activities?