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**UNIVERSITY OF ALBERTA**

**SUPPORT NETWORKS OF MALE AND FEMALE CAREGIVERS  
OF COGNITIVELY IMPAIRED OLDER ADULTS**

**BY**

**KARYN JOY HIBBARD**



**A thesis submitted to the Faculty of Graduate Studies and  
Research in partial fulfillment of the requirements for the  
degree of MASTER OF NURSING.**

**FACULTY OF NURSING**

**EDMONTON, ALBERTA**

**SPRING, 1994**



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April 5, 1994

## **Abstract**

**This study explored gender differences in the support networks and perceived satisfaction with support of caregivers of cognitively impaired older adults using the Arizona Social Support Interview Schedule. Differences between men and women caregivers were examined in terms of available, utilized and conflicted network size and caregiver satisfaction with six types of support. A significant difference was found in the size of the conflicted networks for men and women caregivers with women having a larger conflicted network. In comparison to men, women had a significantly larger number of family members in their conflicted social networks. In addition, for men and women caregivers, significant correlations were found for network size and caregiver age, socioeconomic status, and number of years caregiving. Because support networks are an important resource for caregivers, this information has implications for research and clinical nursing practice.**

## **ACKNOWLEDGEMENTS**

I would like to thank the members of my thesis committee, Dr. Anne Neufeld, Dr Margaret Harrison and Dr Lili Liu. A special thanks to Dr. Neufeld for her encouragement, advice, and timely response during the thesis preparation.

I would also like to thank my friend Dr. David Jobson for his special tutoring and patience.

This research was supported by a student bursary from the Alberta Foundation for Nursing Research.

A special thank you to my family; husband Bill, and sons Douglas, Glenn and Neil for all their generous support in such a variety of ways.

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## Chapter I

### Introduction

A significant increase in the proportion of elders in the population and the chronic diseases that occur in conjunction with aging will increase the future need for family caregivers (Government of Canada, 1982; Statistics Canada, 1985). Families, friends, organizations and the formal health care system will be called upon to both provide care to those afflicted as well as to support those who assume caregiving responsibilities. Numerous research studies have demonstrated the negative effect that caregiving has upon the health of the caregiver (Barusch & Spaid, 1989; Chenoweth & Spencer, 1986; Palinkas, Wingard, & Barret-Connor, 1990). Research has also shown that the presence of social support is correlated with positive health status of caregivers (Israel, 1982; Krause, 1987). One measure of the potential for social support is the number of persons in a caregiver's network who provide aid in a variety of forms. Conflict too is an outcome of participation in a social network and has been shown to relate to caregiver well-being and perceived satisfaction (Tilden & Galyen, 1987).

Currently, women comprise the largest group of caregivers, however, men's participation is increasing (Brody, 1981; Enright, 1991; Stone, Cafferata & Sangl, 1987). Several studies have indicated a difference in the

effect of caregiving on men and women, with women experiencing more burden and more health related problems (Borden & Berlin, 1990; Horowitz, 1985; Robinson, 1989). Because of this difference, an analysis of the social support networks that men and women call upon for assistance may help us to understand better the differences in the resources available to them. Also, because fewer caregivers are men, a recognition of the unique characteristics of men and their social support networks is important. Knowledge of the characteristics of support networks of caregivers has implications for the practice of nursing and formal health service delivery.

#### Purpose

The purpose of this study was to explore gender differences in the social networks of caregivers and their perceived satisfaction with support. The relationships between caregivers' social networks and satisfaction with support and demographic characteristics were also explored.

#### Research Questions

1. Are there differences in the size of the available, utilized, and conflicted social networks of male and female caregivers?
2. Are there differences in the composition of the available, utilized, and conflicted social networks of male and female caregivers in relation to family, non-family and professional members?

3. Are there differences in the size and composition of the available, utilized, and conflicted networks of spousal and non-spousal caregivers?
- 4.1 Are there differences in the overall level of perceived satisfaction with social support between male and female caregivers?
- 4.2 Are there differences between male and female caregivers' satisfaction with specific types of support:  
(a) material aid, (b) advice, (c) positive feedback, (d) social participation, (e) physical assistance, and (f) private feelings?
5. Are age, number of years of caregiving, and socioeconomic status associated with available, utilized, and conflicted network sizes?

#### Definition of Terms

**Social Support:** Any input provided to assist with emotional issues, physical assistance or material aid, or to impart guidance (Caplan, 1976).

**Types of Support:** Specific assistance deemed to have a social support function. For the purposes of this study types of support include the following six categories:  
a) material aid, b) physical assistance, c) private feelings, d) advice, e) positive feedback, and f) social participation (Barrera, 1980) (see Appendix A).

**Social Networks:** The web of social ties that surround an individual (Berkman, 1984). For the purposes of this study

social network will be measured using the Arizona Social Support Interview Schedule (ASSIS) which includes assessment of available, utilized and conflicted networks. (see Appendix A).

**Available Network:** Those people in the social network identified by the caregiver as possible providers of a specific type of support (Barrera, 1980). In this study available network is determined by response to the first question for each type of support which asks participants who they could call upon for assistance, (A to F #1).

**Utilized Network:** Those people in the social network identified by the caregiver as actually having provided a specific type of support within the past month (Barrera, 1980). This information is obtained in response to question two for each type of support in the ASSIS which asks from whom have they actually received support in the past month, (A to F #2).

**Conflicted Network:** Those people in the social network identified by the caregiver as sources of interpersonal conflict. For the purposes of this study these persons are identified in response to questions on negative interactions in the ASSIS which ask who are the people they expect to have disagreements with and who in the last month they actually had disagreements with, (G #1 and #2).

**Family:** Those people identified by the caregiver as family members.

**Non-family:** Those people identified by the caregiver as neighbours, acquaintances, friends, or associates with whom the caregiver has contact.

**Professional:** Those people identified by the caregiver as performing a paid service or health-related professional service.

**Spousal Caregiver:** A person in the sample of male or female caregivers who is in a married or common-law relationship to the care recipient.

**Non-spousal Caregiver:** A person in the sample of male or female caregivers who is in a relationship to the care recipient other than marriage, eg. child, friend, other familial relationship.



## Chapter II

### Review of the Literature

#### Social Support

The need for social support of family caregivers of the elderly. A growing elderly population is the reality of the future. There will be a significant increase in the proportion of the elderly population as well as an increase in the actual numbers. Statistical projections of the population composition in the year 2031 indicate that 22 to 26.5% of Canadians will be 65 years of age or older, a population group of approximately seven million people (Statistics Canada, 1985). In 1991, the percentage of Canadians who were over 65 years of age was 12% (Statistics Canada, 1992). Women outnumber men in the population 65 years of age and older and this difference is projected to increase in the future (Baker, 1988). This vertical expansion in the population is due to improvements in health care and a declining mortality (Kaye & Applegate, 1990). A lengthening of the life span has resulted in a greater number of families with several generations.

Unfortunately with longevity usually comes a parallel increase in the incidence of chronic diseases. Three out of four persons aged 65 years of age or over will experience at least one chronic condition in their lifetime (Government of Canada, 1982). Chronic disease affects not only the individual but the family system as well. Affected elders

frequently call upon family members to assist with instrumental tasks such as shopping, banking and general household repairs, as well as activities of daily living such as meal preparation and bathing. Despite the changing nature of family composition (eg. fewer children) and disparate geographic locations, families continue to carry the greatest responsibility for these duties, just as they have in the past (Brody, 1985; Kaye & Applegate, 1990). The challenge of the future is finding ways to support these family caregivers (National Advisory Council on Aging, 1989).

One of the very debilitating and stressful chronic diseases to contend with is the group of diseases related to cognitive impairment, one of this group being Alzheimer disease. Approximately 10% of persons between the ages of 65 and 75 years and 25% of those over 85 years of age suffer from dementia, 60% of which suffer from Alzheimer disease (Evans et al., 1989). Even if the afflicted family member is institutionalized, the subjective responsibility of caregiving remains, merely the location of care delivery changes (Maas & Buckwalter, 1991).

Although most caregivers are currently women, a variety of reasons exist for the likelihood of increasing numbers of men involved in caregiving. Younger women returning to a paid work environment, and a decrease in family size with fewer available children, suggest the future involvement of

more men as caregivers (Brody, 1981; Fitting, Rabins, Lucas, & Eastham, 1986; Mathew, Mattocks, & Slatt, 1990).

The duties and unrelenting responsibilities associated with caregiving often leave long-lasting and sometimes serious consequences on the caregivers' physical and mental health. For example, spousal caregivers have been described as hidden patients, who report that the experience of caregiving includes constant worry, stress and physical demands from providing personal care to their spouse (Fengler & Goodrich, 1979; O'Neill & Ross, 1991). George and Gwyther (1986) found that spouses had more doctors visits and poorer self-rated health than non-spousal caregivers.

Caregivers respond to the demands and the restrictions of caregiving in a variety of ways, some of which do not contribute to their overall sense of well-being. A decrease in social participation is frequently an early change and results in feelings of isolation, loss and frustration. A sense of burden and being overwhelmed are then outcomes of this pulling back with subsequent decreased mental and physical health (Chenoweth & Spencer, 1986; George & Gwyther, 1986).

Persons who care for a cognitively impaired loved one face a risk to their own health (Lynch-Sauer, 1990). Lezak (1978) found that most family members living with and caring for a characterologically altered person suffered from

depression. These caregivers and family members were seeking support through counselling in an attempt to cope with their stress, anger and frustration. The caregivers of brain-impaired victims face one of the more demanding and stressful types of caregiving (Alzheimer Canada, 1992).

Social support and health. The sharing of the specific physical tasks of caregiving is actually very limited with one caregiver usually providing the bulk of care (Cantor, 1983). This primary caregiver however, has people in a network around him or her who contribute to the social support required. While these networks vary in size and composition and in the aid or support given, they do have an effect in reducing stress and positively influencing the caregivers' health (Krause, 1987).

Social support has been defined in the literature in a variety of ways. Ellison (1987) states Cobb's (1976) definition of feeling cared for, loved, esteemed, valued, and knowing that one belongs to a network has been widely accepted as representative of the term social support. A more encompassing definition of social support is from Caplan (1976) who states that social support is any input provided to assist with emotional issues, physical assistance or material aid, or to impart cognitive guidance.

Caregivers who have a large number of people in their networks do not always experience the highest level of support and, in fact, a large size may create stress as

caregivers attempt to maintain contact with everyone (Wellman, 1979). The greatest benefit to the caregiver is in the perception of the value of that support. Thus, a person may have a small social network and receive small amounts of help but if this received help is important to the caregiver then its benefit is great. It is the meeting of the caregivers' expectations that influences the caregivers' health (Fiore, Becker, & Coppel, 1983; Israel, 1982; Robinson, 1989). If a caregiver desires more social support and this support does not materialize, then the overall sense of well-being of the caregiver is negatively affected (Baillie, Norbeck, & Barnes, 1988). In particular, spousal caregivers suffer the greatest psychological distress (Brodaty & Hadszi-Pavlovic 1990).

As well, something other than need may mobilize the social support network (Clipp & George, 1990). This mobilization may be attributed to any one of a variety of factors such as the personality of the individual, the nature of the social ties or the specific situation (Palinkas et al., 1990). While there is a correlation between perceived support and caregiver's health, how this happens or who in the network is responsible for this support remains unclear (Gottlieb, 1991; House, Kaha, McLeod & Williams, 1985).

Social network. Social network is defined as the web of social ties that surrounds an individual (Berkman, 1984).

A similar definition and one that contains a reference to the purpose of a social network is provided by Israel (1982). This definition states that a social network consists of human interactions, some or all of which may or may not provide social support. Social ties provide significant effects and have been shown to influence both morbidity and mortality (House, Umberson & Landis, 1988). There are a variety of ways to approach the analysis of a social network: by function or duties performed, by who actually comprises the network and by characteristics of the membership or the network itself. There are proponents for each method of analysis.

Berkman (1984) advocates analysing the social network in terms of who constitutes the members instead of only the duties performed by members. This analysis does not concentrate on the attributes of those in the network but rather on the linkages within the network (Berkman). Using this network analysis, Stokes & Wilson (1984) found that men have fewer relatives in their networks than do women. In contrast, Palinkas et al. (1990) found that men have significantly more close friends and relatives in their networks than do women. When sons are caregivers they involve their wives in these activities but when daughters are caregivers their husbands are less likely to be involved (Morowitz, 1985). Women are less likely to have a spouse and more likely to participate in voluntary associations

than are men (Barusch & Spaid, 1989; Palinkas et al.). Peer support in the network is greater for both men and women than is family support (Borden & Berlin, 1990).

Wellman's (1979) study of social networks addresses characteristics of the network. This study describes a variety of characteristics in terms of intimate relationships, those persons outside of the home that one feels the closest to and that one could call upon in a crisis. Almost all of the respondents reported at least one intimate tie. Density of networks, or the degree that network members know each other, was not a predominate factor. Neither was reciprocity, or the mutual identification of an intimate relationship between two people, found to be prevalent. Frequency of contact, however, did suggest a greater degree of assistance between intimates and a greater perception of availability of help.

Characteristics of the network such as the direction of support, including the equity and symmetry of the relationship, the perception of the amount of support received, and the actual amount received, all influence and indirectly affect health. As Gottlieb (1991) notes this information does not, however, add to the understanding of the ways in which social interactions actually become engaged in the stress and coping process.

Another method of network analysis is by the functions of the various members. Four types of networks have been

identified: an emotional support group (a few intimates), a larger social support group (involving the exchange of favours), the global network composed of the previous two, and the network outside the global network who are able to provide information about community resources (Bernard et al., 1990). Examples of studies analysing networks in terms of functions are as follows. Horowitz (1985) found that sons acting as caregivers tend to provide assistance with financial management and dealing with bureaucratic organisations while their wives provided the more hands-on services of meal preparation and personal care assistance. Men utilise more service delivery organisations than do women by accepting such services as delivered meals, more nursing services and more home aide services (Barusch & Spaid, 1989). Women engage in more personal sharing with associates as well as close friends, while men tend to share feelings only in an intimate relationship (Stokes & Wilson, 1984). Wives who are caregivers receive the least amount of help from family or friends whether they are working or not (Enright, 1991). Clipp & George (1990) found that caregivers who phone their friends and family and who visit with them, also have high levels of instrumental support. Also, women caregivers have more stable support, but those caregivers in smaller households and those with low income have less stable support (Clipp & George).

Social networks are vulnerable to changes over time as



members die, move, or lose their ability to provide support for any number of reasons. The support from the network influences the health and well-being of the recipient. For example, Palinkas et al. (1990) found the number and frequency of social ties are inversely related to depression in the elderly. Depression is also related to both the structure and the source of social support with the intimacy of a close friend providing a greater degree of support than the intimacy of a close relative (Palinkas et al.).

Types of support. People in the network of the caregiver provide social support through the sharing of the duties and tasks associated with caregiving and by providing emotional support to the caregiver. Social support has been examined in one of three ways: by those who provide it, by the recipient's subjective appraisal of support, and by the activities involved in the provision of social support.

A conceptual analysis of the social support literature by Barrera, Kochanowicz, & Gonzales (1979) identified several categories of tasks or interactions which are performed by network members and perceived to be supportive. The types of support identified are:

1. **Material Aid:** aid in the form of money or other physical objects
2. **Physical Assistance:** sharing of tasks
3. **Intimate Interaction:** the expression of feelings and personal concerns

4. **Guidance:** offering advice or guidance
5. **Feedback:** providing individuals with information about themselves
6. **Social Participation:** social activities for fun, relaxation and diversion.

Another classification of types of support is suggested by Gottlieb (1991). Support in the form of (a) socializing and companionship, (b) tangible goods and services, (c) emotionally sustaining discussions, and (d) advice and guidance are all provided to an individual by his or her social network. This range of functions may be used to identify those people in the network who are available and who actually performed any or all of these types of supportive aid.

Support satisfaction. Caregivers who experience higher levels of satisfaction with their networks also perceive more satisfaction with the affection, affirmation, and aid received. Frequency of support, however, does not exert a direct effect on self-rated health (Krause, 1987; Robinson, 1989; Robinson, 1990). An indirect effect on health seems to occur through depression (Krause; Robinson, 1989). For example, satisfaction with social support received is negatively related to both psychological distress and depression (Baillie et al., 1988). Self-rated health and well-being are positively related to the caregivers' satisfaction with tangible and emotional support received

but not with informational support received or the closeness of the relationship with the provider (Krause). Caregivers with higher levels of both social skills and self esteem perceive a greater satisfaction with the amount of support received (Robinson, 1990). This suggests that an antecedent to social support may in fact be social skills and that mobilising one's network is a skill itself (Robinson, 1988).

Available versus utilized support. Available support as indicated by the caregiver, is supplied by those persons in the network identified as possible sources of help. This perception of availability is significant to the caregivers' well-being as it provides a buffer effect in times of need (House et al., 1988). This effect modifies the caregiver's perception of a potentially stressful situation or event (House, 1987) thus reducing the overall negative outcome. House (1987) goes on to state that there has been a full range of studies (laboratory studies with both animals and humans, longitudinal studies and individual studies) to support the growing pattern of a causal relationship between social relationships, social networks, social support and health, exposure to stress and the relationship between health and stress.

The actual utilised or received support may be substantially less or more when the caregiver provides the details of who in the network actually provides assistance. Changes in the network occur sufficiently often such that a

one time analysis of availability does not provide a complete assessment of a network.

Conflict within the social network. There are times when the same member of one's network may provide positive support and act as a source of conflict as well. Even if support is given, the action may not be perceived as supportive. Those individuals in the network whose actions or behaviours lead to broken promises, cause feelings of anger or conflict, or who invade privacy, negatively impact the caregivers' well-being. Tilden & Galyen (1987) say there is enough evidence now that social support must not be thought of as only providing benefits. There is a cost to the caregiver when conflict occurs in the social network and it must be recognized.

Feelings of anger, frustration, loss of self-esteem, depression, and stress are often a result of conflict. Conflict may have a temporary effect, such as a burst of anger, or a longer more subtle effect, such as decreased well-being or reduction of self-esteem. Depression in caregivers was found to be related to specific types of family events (illness and other intra-family events), as well as specific behaviour and memory problems of the care recipient (Rankin, Naut & Keefover, 1992).

When family caregivers and care recipients were questioned about conflict, both reported that conflict did occur in the relationship. Spousal caregivers reported

conflict as a result of their own failing health. Adult child caregivers reported the conflict as a result of competing demands on their time (Johnson, 1983). Mui (1992) found this to be true for daughters and daughters-in-law. Studies have indicated that proportionately women caregivers experience more conflict in caregiving than do male caregivers (Strawbridge & Wallhagen, 1991). Strawbridge & Wallhagen found that even though there are more women caregivers, these same women expect as much help from their male siblings as they themselves provide and are in conflict when this help does not materialize.

People are generally reluctant to admit to negative aspects of a relationship and yet family conflict has been found to be a relatively common occurrence in the caregiving situation (Smith, Smith & Toeland, 1991; Tilden, Nelson, & May, 1990). Negative aspects of a relationship affect the outcome more than do positive aspects (Rook, 1984). These findings indicate the importance of recognizing conflict as a distinct and likely dimension of the caregiving relationship.

Gender differences in caregiving. Although caregiving is often referred to as a family responsibility, it is an area dominated by women. Women comprise two-thirds of the total number of those performing caregiving duties (Brody, 1981; Cantor, 1983; Zarit, Reever, & Bach-Peterson, 1980) and are found in a variety of relationships to the care

recipient. Men too are found in a variety of relationships to the care recipient and are steadily increasing in numbers. This increase in male caregivers requires a re-thinking of the traditional view of caregiving as a female domain (Fruchno & Rasch, 1989).

When both husbands' and wives' participation is analysed there is no significant difference in the amounts of time that either spend in caregiving duties (Bass & Moelker, 1987; Enright, 1991). However, similar results were not found in a review of caregiving studies completed by Dwyer & Coward (1992). In this review, men reported a greater amount of time spent caregiving. In an earlier study however, Dwyer and Seccombe (1991) speculated that men were performing tasks not previously done (eg. meal preparation, housework, laundry) and included those activities in their caregiving time. Women on the other hand may have under-reported time spent caregiving as they had always done these same tasks and did not consider them as extra duties. When husbands are the caregivers, caregiving becomes a network responsibility, and when wives are the caregivers, caregiving remains an individual responsibility as wives report the least amount of help received (Enright). Because older men are more likely to be married than older women, they more often are spousal caregivers (Stone et al., 1987).

Women also indicate a feeling of spousal obligation to

caregiving and when they must seek help they attribute this to a failure in fulfilling their responsibilities (Robinson, 1989). Women caregivers tend to experience a greater sense of burden and stress than men (Borden & Berlin, 1990; Horowitz, 1985; Miller, McFall & Montgomery, 1991; Sarit, Todd, & Sarit, 1986). More conflict within the social network (Barusch & Spaid, 1989) and a higher rate of depression were also reported by women caregivers (Barusch & Spaid; Fitting et al., 1986; Pruchno & Resch, 1989). In addition, Clipp & George (1990) found that gender (female) and age (older) were predictors of a higher usage of psychotropic drugs among caregivers.

Both men and women caregivers had a negative attitude towards asking for help (Robinson, 1989). Generally their networks were similar in that both had neighbours and friends as the primary social contact (Fitting et al., 1986). Spousal caregivers experienced a higher level of burden and a greater involvement in the duties of caregiving than did adult children caregivers (Miller et al., 1991).

In summary, women experience greater burden, conflict, and depression than do men and are likely to view caregiving as part of the fulfilment of their marriage vows. Men report activities in their caregiving duties that women have always performed but do not consider as extra responsibilities, thus, at times giving the impression that men spend more time caregiving. Both men and women were

able to call upon neighbours and friends as their primary social support.

Spousal and non-spousal caregivers. Spousal caregivers are the first line of response to a caregiving need and comprise 23% of the caregiving population (Stone et al., 1987). In a review of studies comparing spousal and non-spousal caregivers Stoller (1992) reports that spousal caregivers tend to perform more caregiving tasks, carry on with caregiving until they are forced by their own poor health to relinquish caregiving and are the least likely caregiving group to institutionalise the recipient of care. Spousal caregivers are more likely than adult children caregivers to provide care in their home regardless of their employment status, presence of children, the recipient's age, or diagnosis of brain impairment (Baright, 1991). George and Gwyther (1986) found that spouses reported significantly lower incomes, more doctor's visits and poorer self-rated health than did non-spousal caregivers. There is a higher risk to the caregiver when the bond between the recipient and the caregiver is close (Cantor, 1983).

Adult children caregivers are younger, more highly educated and have higher household and personal incomes than do spouse caregivers (Baright, 1991). As well, adult children caregivers are more likely to be employed and to have been caregiving a shorter period of time than spouse caregivers (Baright). The sex of the adult child is one of



the most important and consistent predictors of caregiver involvement, sons only become caregivers when there is no spouse or adult daughter to assume the responsibility (Coward & Dwyer, 1990; Horowitz, 1985).

Sociodemographic characteristics. Enright (1991) in a study of caregivers of brain-impaired adults provides the following results. The differences between caregiving husbands and wives in sociodemographic characteristics such as age, education, years of caregiving, care recipient's age, whether the person lived at home and the amount of time spent in caregiving are not significant. Husbands tend to have higher personal incomes but their household incomes do not differ much from wives.

Walker (1992) attempts to explain women's greater involvement in caregiving by analysing women's actions in light of three perspectives. The psychological perspective suggests that women's caregiving is central to their identity and that generally, women are more caring and nurturant than men. The sociological perspective explains women's greater involvement in caregiving due to the socialization process, aging demographics and social structure of roles within families. The feminist perspective suggests that women's work has been undervalued and unpaid and that the word "caregiving" itself reflects women's place in society. However, neither the psychological, the sociological nor the feminist perspective

fully explain women's involvement as there are weaknesses in each approach (Walker). Further research which incorporates the context of caregiving is needed to address the complexity of both the personal and social aspects of gender-related characteristics.

Although women make up the larger proportion of caregivers, it is important to recognise the unique characteristics of men as well as women and to understand these differences when planning nursing interventions and social programs created for caregivers (Dwyer & Coward, 1992). Further, women's caregiving is viewed as normative and men's caregiving is compared to it (Crawford & Maracek, 1989). A risk of focusing on gender differences is inadequate consideration of the diversity within gender as well as the similarities (Walker, 1992).

While there is concern that by analysing differences between men and women there is a possibility of implying differences that may be related to factors other than gender, it is important to more fully understand the unique characteristics of each group of caregivers. One way to do this is to become more aware of the support received within the caregivers' social networks. This information can assist members of the helping professions and policy makers to become more sensitive to ways in which to support these caregivers in their task. There is sufficient evidence in the research literature to support gender differences while

still acknowledging the similarity between men and women (Dwyer & Coward, 1992).

An analysis of the literature on caregiving reveals many inconsistencies between studies (Barer & Johnson, 1990). The definition of the word "caregiver" is inconsistent, care recipients vary greatly in their physical and cognitive status, the caregivers participating in the studies were often of the same gender, the same ethnic group, part of small samples, and varied in their relationship to the recipient. This has resulted in conflicting data and an unclear conception of the caregiving experience (Barer & Johnson). Nevertheless, the literature describes a well-established link between personal health cost to the caregiver and caregiving (Sarit, 1989). A better understanding of how to support these men and women is possible by developing a greater sensitivity to the differences in their social networks.

The purpose of this study was to describe and compare the social networks of men and women caregivers in terms of total numbers in the network, who is in the network, and the comparative size of the available and utilized social networks. The possible relationship between demographic characteristics of caregivers and the size and composition of their social networks were also examined. The types of help given, the presence of conflict, and satisfaction with support of men and women caregivers were also assessed and compared.

## Chapter III

### Method

#### Method and Procedure

This study involved analysis of data that was previously collected. The data were obtained in interviews with men and women caregivers who were part of longitudinal studies of caregivers of older persons with cognitive impairment (Neufeld & Harrison, 1993; Neufeld, ongoing).

Sample. This study included a volunteer sample of 40 caregivers in total. There were 20 men and 20 women. Caregivers were included if they were caring for a person 60 years of age or older who was described as cognitively impaired by the caregiver in response to several questions about the cognitive functioning of the dependent. This information was gathered as part of the demographic questionnaire. All the caregivers were English-speaking. The dependent either lived with the caregiver, lived alone in his or her own home in the community, or was resident of a long-term care institution. It was not required that the caregiver be related to the care recipient.

Instrument. Data for this study were obtained by the administration of a demographic questionnaire (see Appendix B) and the Arizona Social Support Interview Schedule (ASSIS) (see Appendix A) during an interview. Demographic data included information about age, education, income, number of years of caregiving, and relationship to the dependent.

The Arizona Social Support Interview Schedule developed by Barrera (1980), measures social support network indices and a subject's satisfaction with and need for support. The ASSIS includes information about six types of support and the size of the available, utilized, and conflicted networks. Types of support include: (a) private feelings, (b) material aid, (c) advice, (d) positive feedback, (e) physical assistance and (f) social participation. Caregivers' satisfaction with support in relation to the types of support was also measured. The age, gender and relationship to the caregiver was obtained for each network member identified by the respondent. Information about the perceived need for support was not collected in the earlier studies on which this study is based.

A final area is identification of those in the network with whom the caregiver can expect to have a disagreement or who is likely to upset them. Caregivers were also asked who in the past month actually made them angry or upset.

Barrera (1980) states that using specific criteria to identify network membership leads to a more reliable assessment. The advantage of this instrument is that it measures several aspects of social support (Tardy, 1985). Test-retest correlations range from .37 to .87 ( $p < .01$ ) for 24 female and 21 male university students (Barrera). A high test-retest reliability coefficient was obtained for both available network size  $r(43) = .88, p < .001$ , and utilized

network size,  $r(43) = .88, p < .001$  (Barrera). Internal consistency of the six positive support categories for both available and utilized social support yielded coefficient alphas of .78 and .74 for the first and second interviews (Barrera).

The ASSIS has been utilized with success in other studies also measuring social support (Barrera, 1981). Different adult populations and age ranges were included in these studies. Examples of the groups studied are the following: pregnant adolescents (Barrera, 1981); divorcing mothers (Tetsloff & Barrera, 1987); and correctional officers (Dignam, Barrera, & West, 1986).

Data analysis. Analyses on demographic characteristics comparing men and women caregivers regarding age, number of years caregiving, education, and socioeconomic status (using the Blisshen Index) (Blisshen, Carroll, & Moore, 1987) was completed. Spousal and non-spousal demographic comparisons were completed on age and number of years caregiving. Age and number of years caregiving were compared using Student's t-tests of means. Chi square analysis was employed to establish whether there was an association between gender and education. The analysis of data will be discussed in relation to each question in the study. Analysis of the data was completed using SPSS/PC+ V2.0 with the significance level for statistical analysis set at  $p = < .05$ . The Pearson Product Moment Correlation Coefficient was considered weak

for values of  $r = .1$  to  $.3$ , moderate for  $r = .3$  to  $.5$ , and strong for  $r > .5$  (Burns & Grove, 1993).

**Research Question One:** Are there differences in the size of the available, utilized, and conflicted social networks of male and female caregivers?

The size of the available network was established by counting the number of persons named in response to question one for all six types of support (see Appendix A). The size of the utilized network was established by counting the number of persons named in response to question two for all six types of support (see Appendix A). The size of the conflicted network was established by counting the number of persons named in response to question G (see Appendix A). For each of these three variables, descriptive statistics including the means, standard deviations and ranges were computed. The size of the available, utilized and conflicted networks of men were compared to those of women using Student's t-tests of means.

**Research Question Two:** Are there differences in the composition of the available, utilized, and conflicted social networks of male and female caregivers in relation to family, non-family and professional members?

The number of family members was established by counting the family named for each type of support in the available, utilized and conflicted networks. The same procedure was used to identify the non-family and

professionals named for each network. The numbers of family, non-family and professionals in each network for men and women were described using the means, standard deviations and ranges. A comparison between men and women of the membership in each network type was conducted using a Student's t-test of means.

**Research Question Three:** Are there differences in the size and composition of the available, utilized, and conflicted networks of spousal and non-spousal caregivers?

On the basis of the demographic information, a differentiation of the caregivers into two groups by relationship to the care recipient was done. The subjects, comprised of men and women, were categorized into spousal and non-spousal groups. Descriptive statistics including the means, standard deviations and ranges were computed. The size and composition (family, non-family, professional) of the available, utilized and conflicted networks of spousal and non-spousal groups were compared using Student's t-tests of means.

**Research Question Four (part one):** Are there differences in the overall level of perceived satisfaction with social support between male and female caregivers?

For each caregiver, the overall level of perceived satisfaction was computed by establishing the mean level of satisfaction reported for all types of support. For the overall satisfaction, descriptive statistics including the



mean, standard deviation and range were computed for both the men and the women. Men and women as groups were then described with descriptive statistics (mean, standard deviation and range) and compared using Student's t-test of means.

**Research Question Four (part two):** Are there differences between male and female caregivers' satisfaction with specific types of support: material aid, advice, positive feedback, social participation, physical assistance and private feelings?

The satisfaction with each type of support was measured by response to question three of the ASSIS. Descriptive analysis of each type of support for men and women was computed. Due to the small sample size and limited range of choices in response to this question, Fisher's Exact Test comparing the proportions of men and women in each category was computed for the areas of satisfaction related to material aid. Chi-square analysis was used for the remaining categories of support.

**Research Question Five:** Are age, number of years of caregiving, and socioeconomic status associated with available, utilized and conflicted network sizes?

Age and number of years of caregiving were taken from the demographic questionnaire. The socioeconomic status was computed for each subject using the Blishen Index (Blishen, Carroll & Moore, 1987). For the purposes of these analyses

men and women were combined as well as analyzed separately in order to permit comparison of men and women with the total group. Descriptive statistics were computed. The Pearson's Product Moment Correlation Coefficient was used to determine whether there was a correlation between demographic variables and the size of the available, utilized and conflicted networks.

### Ethical Considerations

The principal investigators of the two original studies obtained ethical approval from the Faculty of Nursing Ethics Review Committee. Signed consent was also obtained from participants in the original studies (see Appendix C). The consent form outlined the steps involved in the study and the risks and benefits to the respondents. This consent form also informed respondents that the data collected may be analyzed again at a later date upon approval of an ethics review committee. A letter of agreement between the original investigators and the author outlined the conditions under which the data was provided for the purposes of this study. The author had no knowledge of who the respondents were as the ASSIS and demographic data sheets did not include names, but were identified only by a code number.

## Chapter IV

### Findings

#### Purpose

The purpose of this study was to explore gender differences in the social networks of caregivers and their perceived satisfaction with support. The relationships between caregivers' social networks and satisfaction with support and demographic characteristics were also explored. Characteristics of the sample are presented, then size and composition of caregivers' available, utilized and conflicted networks in relation to four groups of caregivers (men, women, spousal, and non-spousal) follows. Overall perceived satisfaction and satisfaction with specific types of support is examined next. Possible relationships between demographic characteristics and size of the available, utilized and conflicted networks are presented last.

#### Characteristics of the Sample

This convenience sample consisted of 20 men and 20 women who were caregivers of cognitively impaired older adults. See Table 1 for description of characteristics of caregivers related to age, education level, years spent caregiving, and income level.

Male caregivers were significantly older than female caregivers ( $t(33.63) = -2.63, p < .05$ ). Spousal caregivers were significantly older than non-spousal caregivers ( $t(28.02) = 5.47, p < .001$ ). Using Student's t-tests of

means, there was no significant difference in the number of years of caregiving for men and women, or spouses and non-spouses. Using a chi-square test no association between gender of caregiver and educational level was found.

Table 1

Sample Characteristics (n = 40)

	Women n = 20	Men n = 20	Spouse n = 22	Non-Spouse n = 18
<u>Age in Years</u>				
Minimum	37	33	60	33
Maximum	71	87	87	77
Mean	58.40	67.90	70.59	54.06
SD	9.13	13.32	7.17	11.06
<u>Years of Caregiving</u>				
Minimum	1	1	1	1
Maximum	20	18	20	11
Mean	7.40	5.35	7.40	5.11
SD	5.33	3.82	5.54	3.08
<u>Education Level</u>				
	<u>n</u>	<u>n</u>	<u>n</u>	<u>n</u>
Less than grade 12	5	7	8	4
Grade 12	2	2	2	2
Some university or post high school diploma	6	7	8	5
University	7	2	3	6
Graduate degree	0	2	1	1
<u>Income Levels by Category</u>				
< \$20 000	3	4	5	2
\$20 000 - \$40 000	7	7	10	4
> \$40 000	10	9	7	12

Fifty-five percent of the caregivers were spouses, 8 women and 14 men. The non-spousal caregivers consisted of 12 women and 6 men in a variety of relationships to the care recipient including adult child, sibling, grand-child, friend or in-law.

Nine spousal and 3 non-spousal caregivers lived with their dependents. The 3 non-spousal caregivers were an adult male child who had been caring for his mother at home for 2 years, a son-in-law who had been caring for his father-in-law at home for 5 years, and a male friend who had been caring for a male dependent in his home for 3 years. Twenty-one care recipients were suffering from Alzheimer disease, 7 from cerebral-vascular accident (stroke) related cognitive impairment and 12 from an undisclosed source of impairment. See Table 2 for further description of men and women caregivers.

Table 2

Caregivers' Relationship to Care Recipient

	Caregivers	
	Women n = 20	Men n = 20
<u>Relationship to Care Recipient</u>		
Spouse	8	14
Adult child (in-law)	11	3
Other family	1	2
Other	0	1

**Size of Caregivers' Support Networks: Research Question 1**

The data for sizes of the available, utilized and conflicted networks of men and women caregivers are presented in Table 3. There was no statistically significant difference between the size of the available network of men and women caregivers although male caregivers reported more sources of support available to them than did female caregivers. Figure 1 displays the frequency distribution of total available network size for both men and women caregivers. It is of interest that some caregivers had very large networks. The largest network was reported by a man who named 42 network members. Of the 6 caregivers who had a network size of over 26 members, only 1 was female.

**Table 3**

**Comparison of Women and Men Caregivers'**

**Social Support Networks by Size**

Type of Network	Women n = 20			Men n = 20			p <sub>1</sub>
	Range	Mean	SD	Range	Mean	SD	
Available	0-28	15.90	6.19	6-42	18.75	9.13	NS
Utilized	4-26	11.00	4.86	3-28	11.50	6.49	NS
Conflicted	0-14	2.50	2.94	0-2	0.75	0.79	.018*

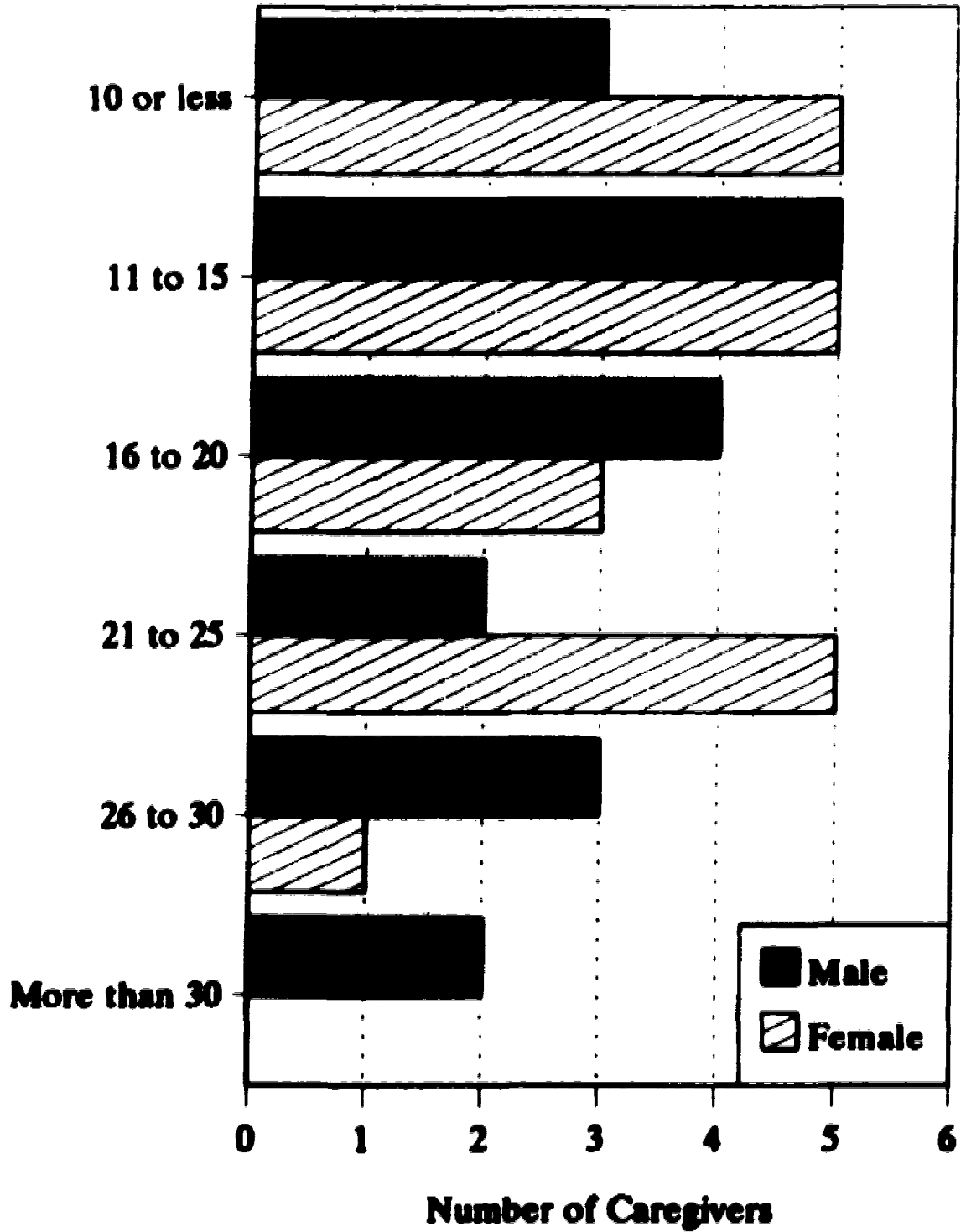
**Nota.** NS = not statistically significant

\*  $t(21.69) = 2.57$

There was no statistically significant difference in the number of sources utilized by men and women in their support networks. There was, however, a statistically significant difference in the size of the conflicted networks of men and women caregivers. Women reported significantly more sources of conflict than men. One of the women caregivers had a conflicted network size of 14, the largest value preceding this for women was 4. The Student's t-test was re-run to compare the size of the conflicted networks for the men and the women with this outlier removed. The value was statistically significant ( $t(30.87) = 3.51, p < .001$ ).

**Figure 1. Available Network Size by Gender**

**Network Size**





**Composition of Social Support Networks: Research Question 2**

Research question two examined the composition of the available, utilized and conflicted networks of men and women caregivers by the category of family, non-family, and professional. See Table 4 for a description of composition of available, utilized, and conflicted networks.

Table 4

**Comparison of Women and Men Caregivers' Available, Utilized, and Conflicted Networks by Composition**

NETWORK COMPOSITION	Range	Women n = 20		Men n = 20		SD	p <sub>t</sub>
		Mean	SD	Range	Mean		
<b><u>Available</u></b>							
Family	1-12	5.50	3.17	1-14	5.75	3.29	NS
Non-family	2-15	8.25	4.05	0-25	9.75	6.84	NS
Professional	0-6	2.15	1.89	0-10	3.25	2.26	NS
<b><u>Utilized</u></b>							
Family	1-11	3.90	2.29	0-11	3.75	2.61	NS
Non-family	0-13	5.65	3.20	0-16	6.0	4.55	NS
Professional	0-6	1.45	1.53	0-4	1.75	1.51	NS
<b><u>Conflicted</u></b>							
Family	0-8	1.65	1.95	0-1	0.15	0.37	.002*
Non-family	0-6	0.55	1.47	0-1	0.20	0.41	NS
Professional	0-2	0.30	0.66	0-2	0.40	0.68	NS

**Note.** NS = not statistically significant

\*  $t(38) = 3.37$

**Family.** There was no significant difference between men and women in the numbers of family members in their available and utilized social networks. There was however a statistically significant difference, ( $t(38) = 3.37, p < .02$ ) in the numbers of family members in the conflicted networks of men and women. Women reported more family sources of conflict than did men. Only 3 men reported any conflict in their networks and each experienced conflict with only 1 family member. Of the 14 women who had family members in their networks as sources of conflict, 7 reported having family members who were sources of conflict only and who provided no other form of social support as measured by the ASSIS questionnaire. None of the men reported this situation in their networks.

**Non-family.** No statistically significant differences were found in the numbers of non-family members in the available, utilized or conflicted networks of men and women caregivers. Non-family network members appear to be frequently used sources of support as only 2 men and 1 woman reported no assistance from non-family contacts in the month prior to the completion of the questionnaire.

**Professional.** No statistically significant differences were found between men and women caregivers in the number of professional sources of support in the available, utilized, and conflicted networks. Eighty percent (16) of the women caregivers indicated 3 or fewer professional sources in

their available networks, and 80% indicated that they had actually utilized 2 or fewer within the past month. Thirty percent (6) of the women felt they had no professional support available to them.

The men reported slightly more professional support with 55% (11) reporting 3 or fewer sources available and 65% (13) having utilized 2 or fewer sources within the past month. One quarter (5) of the men felt they had no source of professional support they could call upon for assistance. For either the men or the women to experience conflict with their sources of professional support was uncommon.

In summary, the numbers of family, non-family, and professional members in the available and utilized social support networks of the men and the women in this study were not significantly different. However, women reported significantly more family members with whom they had conflict than did men.

### Spousal and Non-spousal Caregiver's Social Support Networks: Research Question 3

Findings. The size of the available, utilized and conflicted networks for spousal and non-spousal caregivers is described in Table 5. There were 22 spousal caregivers consisting of 14 men and 8 women. Two male spousal caregivers reported rather large available networks of 30 and 42 sources of support. The largest female spousal network reported was 21 members. The smallest spousal

network available was for a male caregiver who had only 7 sources of support.

**Table 5**

**Comparison of Spousal and Non-spousal Caregivers' Social Support Networks by Size**

Type of Network	Spousal n = 22			Non-spousal n = 18			p <sub>≤</sub>
	Range	Mean	SD	Range	Mean	SD	
Available	7-42	16.36	8.26	6-33	18.50	7.35	NS
Utilized	4-28	10.59	6.15	3-26	12.06	5.07	NS
Conflicted	0-3	1.18	1.10	0-14	2.17	3.18	NS

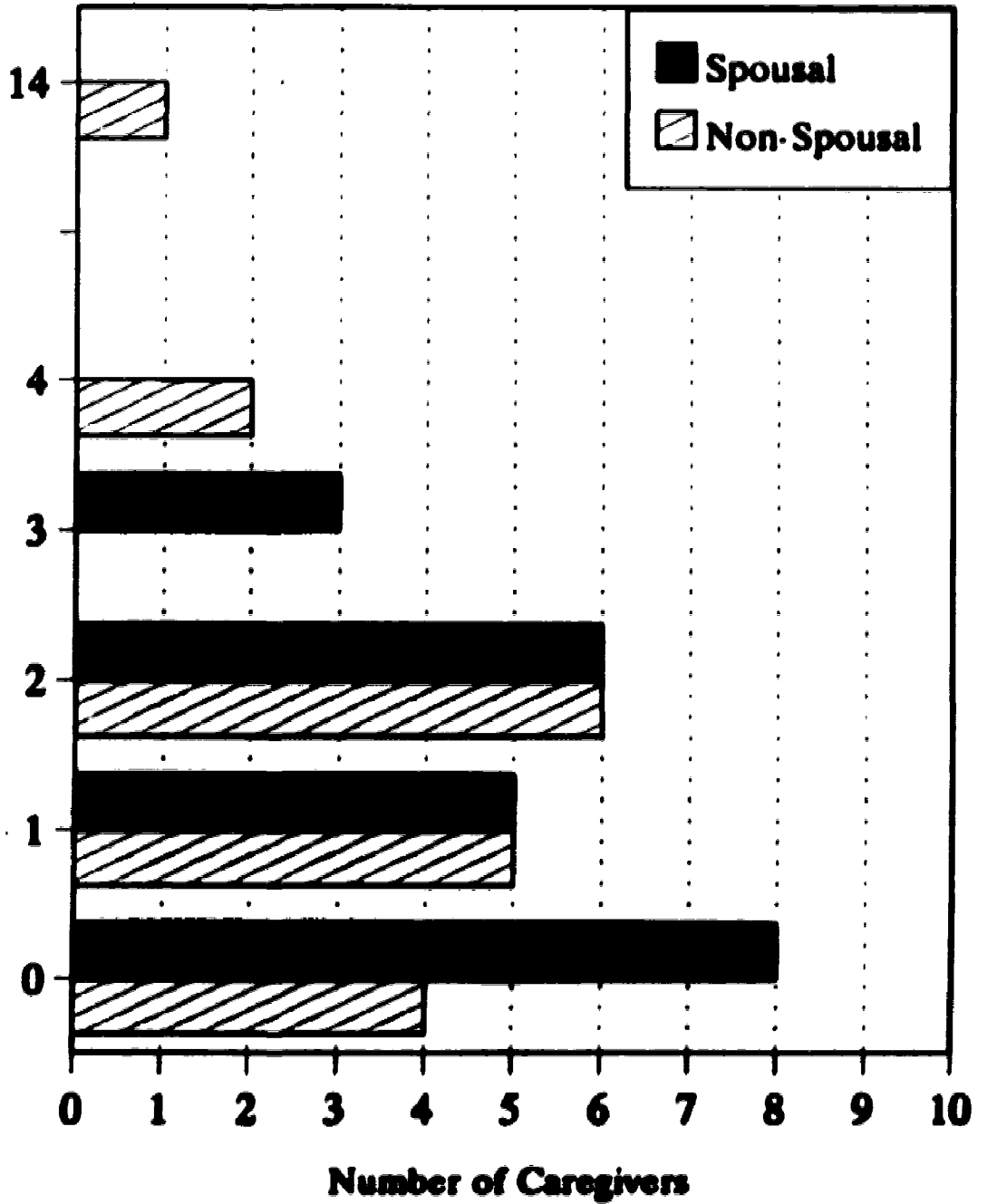
**Note.** NS = not statistically significant

Conflicted network size for spousal caregivers was small and 8 spouses reported no network members with whom they had conflict in the previous month. Figure 2 displays the conflicted network size of the spousal and non-spousal caregivers.

Twelve women and 6 men comprised the non-spousal group of caregivers: 11 daughters (in-law), 3 sons (in-law), and 1 each of granddaughter, grandson, brother and friend. The smallest available network as well as the largest conflicted network were reported by non-spouses. A 33-year-old grandson caring for his grandmother in a longterm care facility had the largest available network (33) while an elderly man of 77 years caring for his brother who was in a longterm care facility had the smallest available network (6).

**Figure 2.** Conflicted Network Size by Caregiver Relationship

**Network  
Size**



The non-spousal caregiver who reported the largest number of sources of conflict was 52 years old, employed full-time, and was caring for her mother-in-law. This woman experienced conflict with her husband, children, mother, sister, brother, friend, co-workers and her mother-in-law. Her conflicted network size appears to be somewhat unusual as the next largest non-spousal conflicted network size was 4.

Composition. Table 6 describes the composition of available, utilized, and conflicted networks in terms of family, non-family, and professional sources of support for spousal and non-spousal caregivers. Non-family members were the largest group available for spousal caregivers followed by family then professional. Three spousal caregivers felt they had no professional support available to them.

In each of the three categories for the spousal caregivers, there were few members in the utilized support network. Caregivers used non-family sources of support most often followed by family and professional sources.

Table 6

Comparison of Spousal and Non-spousal Caregivers' Available,  
Utilized, and Conflicted Networks by Composition

NETWORK COMPOSITION	Spousal n = 22			Non-spousal n = 18			p <sub>&lt;</sub>
	Range	Mean	SD	Range	Mean	SD	
<b>Available</b>							
Family	1-14	5.31	3.07	2-12	6.0	3.37	NS
Non-family	2-24	7.95	5.65	0-25	10.27	5.42	NS
Professional	0-10	3.09	2.34	0-6	2.22	1.80	NS
<b>Utilized</b>							
Family	0-11	3.68	2.53	1-11	4.0	2.35	NS
Non-family	0-16	5.22	4.24	0-13	6.65	3.38	NS
Professional	0-4	1.68	1.42	0-6	1.50	1.65	NS
<b>Conflicted</b>							
Family	0-3	0.59	0.91	0-8	1.28	2.11	NS
Non-family	0-3	0.23	0.68	0-6	0.56	1.42	NS
Professional	0-2	0.36	0.66	0-2	0.33	0.69	NS

**Note.** NS = not statistically significant

Conflict in the spousal networks was very low with 14 spouses (64%) reporting no conflict with family, 19 (86%) reporting none with non-family and 16 (73%) reporting none with the professionals in their available network.

Similar characteristics were noted in the composition of non-spousal networks. Non-family members were the largest group available and utilized followed by family then professional members.

Comparison of spousal and non-spousal social support networks. There were no statistically significant differences in the numbers of members in the available, utilized, and conflicted networks of spousal and non-spousal caregivers. As well, there were no statistically significant differences in the size of their available, utilized, and conflicted networks by composition of family, non-family, and professional members. The average number of family, non-family, and professional sources of utilized support varied by 1 or less in each of these 3 areas. A similar pattern was found for the conflicted networks.

#### Gender Differences in Perceived Overall Satisfaction With Social Support: Research Question 4.1

In general, caregivers' perceived overall satisfaction with the social support available to them was high and no statistically significant difference was found between men and women. In the scoring system of the ASSIS the minimum perceived overall satisfaction score possible is 6 and the



maximum score possible is 18. Women, on average, rated their satisfaction as 16.65 (SD = 1.72, range 13 to 18). The average overall satisfaction score for male caregivers was 17.30 (SD = 1.08, range 15 to 18).

**Gender Differences in Perceived Satisfaction With Specific Types of Social Support: Research Question 4.2**

Despite minor differences between men and women in some of the specific areas of support, caregiver perceived satisfaction is very positive. (See Table 7 for description of findings). Fisher Exact Test and chi-square analyses did not reveal any statistically significant difference between men and women related to any of the six areas of support satisfaction. Each specific category of support received was evaluated on a score from 1 to 3, with 1 indicating a feeling of dissatisfaction, described in the ASSIS as the need for "a lot more opportunities, etc.", and 3, a feeling of satisfaction described in the ASSIS as "about right". The six areas of support evaluated were material aid, physical assistance, private feelings, advice, positive feedback, and social participation. The caregiver's satisfaction was based upon the amount of support he or she had received within the past month.

Table 7

**Comparison of Women and Men Caregivers' Satisfaction  
With Overall Support and Type of Support**

	Women n = 20			Men n = 20			
	Range	Mean	SD	Range	Mean	SD	p <sub>≤</sub>
<b><u>OVERALL SATISFACTION WITH SUPPORT*</u></b>	13-18	16.65	1.72	15-18	17.3	1.08	NS
<b><u>Support Satisfaction by Type of Support</u></b>							
Material aid	3	3.0	0	3	3.0	0	NS
Physical assistance	1-3	2.75	0.55	2-3	2.9	0.3	NS
Private feelings	2-3	2.85	0.37	2-3	2.9	0.3	NS
Advice	1-3	2.75	0.63	3	3.0	0	NS
Positive feedback	1-3	2.65	0.67	2-3	2.85	0.37	NS
Social participation	1-3	2.65	0.59	1-3	2.65	0.67	NS

\* Maximum possible overall satisfaction score = 18

**Note.** NS = not statistically significant

Material aid. Material aid, as defined by the ASSIS, is aid in the form of money or a valuable physical object that has been loaned or given to the caregiver. The satisfaction with this type of support was identical for both the men and the women. All 40 caregivers indicated they felt they had received about the right amount of material aid during the past month.

Physical assistance. Physical assistance is help which involves time or energy on the part of the person named by the caregiver. Help may be given in the form of assistance with shopping, banking, household duties or other similar activities. Sixteen women and 18 men (85% of the total group) rated their satisfaction at the maximum, feeling they had received the right amount of assistance in this area within the past month.

Private feelings. Private feelings support is an opportunity for the caregiver to speak to someone about personal and private matters. Again most caregivers (35 or 87.5%) felt they had sufficient opportunity to express their thoughts and concerns within the past month and the remainder felt only slightly dissatisfied with their recent opportunities.

Advice. All 20 men were satisfied with the amount of advice they had received within the past month. Only 2 women wished they had received a lot more advice, 1 wished for a bit more advice. The remainder of the women (17 or

856) felt they had received the right amount.

Positive feedback. Positive feedback relates to the times when someone gave the caregiver supportive feedback about their actions or ideas. Of the six areas of support satisfaction, positive feedback and social participation were the weakest in terms of satisfaction, although both were still strong. Fifteen women and 17 men felt they had received about the right amount of positive feedback. Only 2 women felt they would have liked a lot more support in this area. None of the men felt they would have liked a lot more support in this area.

Social participation. As mentioned social participation was a less satisfying area for both men and women caregivers. Five men and 6 women would have liked a little more or a lot more opportunities for social participation within the past month. However 14 women and 15 men were satisfied with their past month's activities.

#### Relationship of Demographic Characteristics to Network Size: Research Question 5

Caregivers were examined as a total group and by gender. Pearson Product Moment Correlation Coefficients were computed with age of the caregiver, number of years caregiving, and socioeconomic status and size of available, utilized, and conflicted networks. See Table 8 for this data. Using the Pearson Product Moment Correlation Coefficient the strength of the correlation may be

considered weak for values of  $r = .1$  to  $.3$ , moderate for  $r = .3$  to  $.5$ , and strong for  $r = >.5$  (Burns & Grove, 1993).

Age and network size. Size of available network was negatively associated with age for combined male and female caregivers. When network size was examined by gender, this relationship was statistically significant for male caregivers. Older male caregivers had fewer sources of available support than did younger male caregivers.

Negative correlations were also found for age and conflicted network size for caregivers as a group as well as for men and women. A statistically significant negative correlation was found for age and size of conflicted networks for all caregivers. This indicates that older caregivers had fewer sources of conflict.

**Table 8**  
**Correlations of Demographic Variables and Size of**  
**Available, Utilized and Conflicted Networks**

	n	Age	Years Caregiving	Blishen Index
<b><u>Available</u></b>				
Men and women	40	- .29	.01	.38 *
Men	20	- .52*	.21	.52 *
Women	20	- .16	-.11	.00
<b><u>Utilized</u></b>				
Men and women	40	- .27	-.09	.41 *
Men	20	- .29	.14	.46 *
Women	20	- .36	-.30	.27
<b><u>Conflicted</u></b>				
Men and women	40	- .33*	.24	.08
Men	20	- .17	.36	-.04
Women	20	- .31	.15	.23

\*  $p < .05$

Years of caregiving and network size. Years of caregiving and size of available and utilized networks produced no statistically significant correlations for the total group of caregivers nor for men or women caregivers.

Blishen Socioeconomic Index and network size. The Blishen Socioeconomic Index was calculated for each of the caregivers. This index is computed from income, education and social standing. To find the appropriate number on the index the person's occupation is located in the chart and the resulting value is then assigned.

A statistically significant and moderately positive correlation between socioeconomic status and both available and utilized social network size was found for the total group of caregivers as well as male caregivers. The Blishen Index and the size of the conflicted network produced no statistically significant correlations for the total group of caregivers or for men or women caregivers. The small number of significant correlations found regarding demographic variables and network size may be related to the sample size when the groups were divided according to gender.

### Summary of Study Findings

This study involved forty caregivers who had participated in two previous studies. Data were analyzed from the ASSIS questionnaire regarding the size of the social support networks of men and women caregivers who

ranged in age from 33 to 87 years and who had been providing care to a dependent for an average of 6 years.

Men had both the smallest (6) and the largest (42) number of available sources of support. Indeed the male caregiver with the largest available network had 14 more sources of support than did the female with the largest network (28).

A statistically significant difference was found in the size of the conflicted networks of women and men. Women reported more sources of conflict than did men.

A statistically significant difference was also found in the numbers of family members in the conflicted networks of men and women caregivers. Women had more family sources of conflict than did men.

When spousal and non-spousal caregivers were compared, there were no statistically significant differences in the size of the available, utilized, and conflicted networks. In addition, there were no statistically significant differences in the number of family, non-family, and professional members of these networks.

satisfaction with the social support they had received in the month prior to the survey. Caregivers' perceived overall satisfaction with support available indicated no statistically significant gender differences.

Satisfaction with the six specific types of support was also high for both men and women. No statistically



significant difference was found between the men and the women for any areas of satisfaction with specific support.

For women caregivers, there was no significant relationship between age, years of caregiving, socioeconomic status, and the size of their networks. However, older men had significantly smaller available networks. Also men of higher socioeconomic status had larger available and utilised networks.

## Chapter V

### Discussion

#### Sample Characteristics

The subjects of this study were all volunteers. They were generally white, middle class men and women caregivers who were caring for a dependent who either lived with the subject, lived in their own home or who resided in a longterm care institution. There was no ethnic diversity among the group.

Spousal caregivers are the first line of response to a caregiving need and in fact comprise 23% of the largest proportion of the general caregiver population (Stone et al., 1987). Also, because more older males are likely to be married than older females they are more often spousal caregivers (Stone et al.). In this study, 55% of the total caregiver sample were spouses, 8 wives and 14 husbands. This is consistent with the literature.

Adult children caregivers have higher incomes and more education than do spousal caregivers (Baright, 1991; George & Gwyther, 1986). Findings of this study are again consistent with the literature. Proportionately, more non-spousal caregivers in this study (89%) reported incomes of over \$20 000 than did spousal caregivers (77%). Seventy-eight percent of the non-spousal caregivers and 64% of the spousal caregivers reported a grade 12 or higher education.

The total group of caregivers and the non caregivers

had a significant correlation between size of available and utilised support networks and socioeconomic status. This indicates that caregivers with higher education and income tended to have more sources of support available to them than did those caregivers with less education and income. It is interesting to note that this relationship did not exist for women.

#### Size of Social Support Networks of Caregivers

The social support literature indicates that the perception of availability of support is the important factor in the caregivers' sense of well-being and in fact acts as a buffer in times of need thus reducing overall stress (House et al., 1988). No research studies were found that assessed the optimal number of sources of available support. Wellman (1979) found that the size of a network did not demonstrate a high degree of realised support, and hypothesized that a large available social network may itself be a strain on the caregiver as he or she attempts to stay in touch with everyone. In this study there was no difference between the average size of the network available to women and the average size of the network available to the men.

There was, however, a significant negative relationship for men between size of available network and age. Older male caregivers tend to be spousal caregivers while younger men are adult children. Because spousal caregivers have

been shown to receive less help than caregivers in general (Stoller, 1992), older male caregivers may be at risk for inadequate support.

The positive relationship between socioeconomic status and size of both available and utilized networks was significant for men but not for women. One possible explanation may be that men's greater economic resources allowed them to purchase more services to help with their caregiving duties. Pension benefits, as well as higher salaries generally available to men, and women's inconsistent employment history may account for this difference. However, there were no significant gender differences in the number of professional sources of support.

Mobilization of a caregiver's support network depends upon the nature of the social ties, the personality of the caregiver, and the nature of the specific situation (Palinkas et al., 1990). Having the ability to mobilize those in their network has been illustrated to be a skill in itself and a skill that should be taught if not already possessed by the caregiver (Robinson, 1988). As both men and women utilized on average 11 sources of support in the month prior to the survey it would appear that the ability to mobilize their networks was a skill possessed by both groups of caregivers.

### Network Conflict

When expected support was not given or when the assistance provided was not deemed supportive by the caregiver, this resulted in conflict. Broken promises and an invasion of privacy are such examples. These and other similar conflicts were found by others to have a negative effect on the health of the caregiver (Tilden & Galyen, 1987). Women caregivers in particular experience more conflict in their social network than do men caregivers (Barusch & Spaid, 1989; Fitting et al., 1986; Fruchno & Resch, 1989). Previous research has also found that women were more likely than men to experience conflict with family and with a broader range of family members (Seiple, 1992). Depression has also been found to be more prevalent among women caregivers (Barusch & Spaid, 1989; Fitting et al., 1986; Fruchno & Resch, 1989). In addition, regardless of gender, intrafamily conflict has been shown to be a predictor of caregiver depression (Rankin, Naut, & Keefover, 1992).

Gender difference in the size of the conflicted network was a statistically significant finding in this study. Conflict was experienced by 55% of the men and 85% of the women caregivers. Not only did more women experience conflict, those that did experience it reported more network members with whom they had conflict than did men.

In this study 70% of the women reported conflict with

family members while only 15% of the men reported conflict with family. Men, however, were more likely to have conflict with non-family and professional sources.

It is interesting to note that both men and women had network sources who engaged the caregiver in conflict only. These people were excluded from the available and utilised networks in relation to all types of support. Nine women and 1 man indicated they had 1 or more family members who were sources of conflict exclusively. Three men and 3 women indicated 1 or more sources of non-family conflict who provided no other support. Similarly, 4 men and 4 women indicated 1 or more professionals who were sources of conflict but not support.

Stewart (1993) found that alienation and estrangement in the network were effects of chronic illness that had a negative impact on the caregiver. The timing of this impact and identification of the individual situational factors that lead to this outcome are important issues for research.

Negative interaction has been hypothesised to have a greater influence on an individual than positive interaction (Rook, 1984). It is also a predictor of caregiver depression (Rankin et al., 1992). In view of this finding that caregivers identified members of their network who were sources of conflict but not of help, clinical implications must be considered. Numerous research studies have shown the personal effect of conflict and found that conflict may

be experienced in an intimate relationship as well in a relationship with representatives of a bureaucracy (Rook). Caregivers may at some time find themselves experiencing conflict that they may not be able to resolve simply because their caregiving role or their relationship as a family member eliminates the option of excluding these contacts from their network.

Conflict may also arise as young and middle-aged women struggle to cope with the variety of roles they pursue in addition to the role of caregiver (Franks & Stephens, 1992). The effects of competing roles, including the role of caregiving, need more study (Walker, Martin & Jones, 1992). Potential for competing roles was also evident in this study as 8 women were employed either full or part time outside of their homes and 1 of these women had children at home under the age of 18 years.

It is interesting to note that conflicted network size was significantly different for the men and women caregivers but not for the spousal and non-spousal caregivers. This may indicate that conflict is a gender issue and not a relationship issue. While this finding does not have strong support from previous research it is an accepted concept by older persons, caregivers, practitioners, and researchers who frequently interpret their findings in a way consistent with the idea of women experiencing more conflict (Miller & Cafasso, 1992). Consequently it is an area that should be

investigated further (Miller & Cafasso).

### Network Composition

Men and women caregivers. Family members are the first source of support to the caregiver and the care recipient, and have remained so despite the reduction in family size, increased female participation in the paid labour force and disparate family geographic locations (Brody, 1985; Kaye & Applegate, 1990). Family duties are varied and often include such tasks as assisting with shopping, household repairs, banking and the provision of emotional support.

The findings of this study also support the availability of family members for each of the six areas of support examined. However only 7 male and 9 female caregivers received help from family in each of the six areas (material aid, physical assistance, private feelings, advice, positive feedback, social participation) as measured in the ASSIS. The remainder of the male and female caregivers received help in some but not all of the six areas measured. The men received assistance in 2 to 5 of the areas, while the women received assistance in 1 to 5 of the areas.

In one study, caregivers of dementia victims received less help from family members than caregivers of stroke victims (Draper et al., 1992). In this study approximately half the care recipients (21) had a diagnosis of Alzheimer disease and 7 had cognitive impairment related to a stroke.



However, possible differences in help from family was not explored for these two groups of caregivers.

Previous research has found that men had a significantly greater number of close friends in their networks than did women (Palinkas et al. 1990). These research studies have found that both men and women caregivers had greater numbers of friends than family in their social support networks (Borden & Berlin, 1990; Fitting et al., 1986). Skaff & Pearlin (1992) in a study of role engulfment and loss of self related to spousal and adult child caregivers of victims of Alzheimer disease, found that caregivers who had a greater amount of contact with friends appeared to experience less loss and be protected more than those who had greater contact with family members.

In this study 18 men and 19 women reported they had utilized non-family members for at least one of the six specific types of support within the past month. There was no statistically significant difference between the numbers of non-family (including friends) in the available and utilized networks of men and women caregivers.

Conflicting results about gender differences and composition of social networks have been found in the literature with some studies indicating that men had more relatives in their support networks, and others indicating that women had more relatives in their networks (Palinkas et

al., 1990; Stokes & Wilson, 1984). Perhaps the similarities between men and women in availability of family members as indicated by this study provide support for similarity between the groups. Nevertheless, inconclusive findings in this area suggest that the situation is more complex than gender differences alone.

Spousal and non-spousal caregivers. Enright (1991) found that wives who are caregivers receive the least amount of help from family or friends whether they are employed or not. Wives also view caregiving as an individual responsibility. Husbands, on the other hand, permit and encourage caregiving to become a network responsibility (Enright).

Despite these differences between men and women, spousal caregivers experience a higher level of burden and a greater involvement in the duties of caregiving than do adult child caregivers (Miller et al., 1991). Also spousal caregivers are more likely to provide care in their homes regardless of their employment status, presence of children or the recipient's age (Enright, 1991). Cantor (1983) in a study of caregivers found that there is a higher risk to the caregiver when the bond between the recipient and the caregiver is close.

Spousal caregivers in this study had similar available, utilized, and conflicted network sizes as did non-spousal caregivers. The composition of their networks in terms of

family, non-family, and professional members also did not differ.

### Caregiver Satisfaction

Satisfaction with support received and self-rated health have been shown to be related (Baillie et al., 1988). A negative relationship of conflict in a social network to self-rated health has also been demonstrated in previous research (House, 1987).

In this study, caregivers' overall perceived satisfaction and satisfaction with specific areas of support received from their family, non-family and professional network members was high. Since women reported the greatest amount of conflict, their high level of satisfaction with support is interesting. The reason for this is unclear. However, as both men and women experienced conflict from network members whose only contribution was conflict, this may demonstrate the perception of two separate networks.

This dichotomy of high satisfaction with support received and high conflict in the network for women warrants further examination. Perhaps this group of caregivers had high levels of social skills and self-esteem which are also found to be associated with perceived satisfaction with support received (Robinson, 1990).

Another possible explanation is a reluctance to admit dissatisfaction with support received. Both men and women may have felt that admission of dissatisfaction reflected

their inability to clearly state their needs or handle their caregiving responsibilities. They may also have been concerned that admitting dissatisfaction with support would reflect negatively on their family members or health care providers.

## **Chapter VI**

### **Implications**

The purpose of this study was to examine differences between the social support networks of male and female caregivers of cognitively impaired older adults. Caregivers were also differentiated into spousal and non-spousal categories for the purpose of analyzing possible differences. Gender differences and differences associated with the relationship to the care recipient may suggest specific directions for future research.

### **Implications for Research**

While the difference in size of the conflicted networks of men and women caregivers was a statistically significant finding in this research and a finding that has been noted in previous research, conflict is not an automatic outcome of a caregiving situation. Some families are drawn closer together by the experience. This contradiction in family experience with conflict is an issue that requires more research to better understand why caregiving may be a positive experience for some families and a negative experience for others (Strawbridge & Wallhagen, 1991).

When men and women were grouped together, there was a significant negative correlation between age and numbers of sources of conflict in the network. The finding of increasing numbers of sources of conflict among older caregivers is important as conflict is related to depression

and caregiver well-being. Further research is needed to understand the implications of conflict and health.

Women experienced significantly more family conflict than did men. While there often is one primary caregiver in a caregiving situation, frequently other family members are actively involved as well. In view of the findings of others that intrafamily conflict is a predictor of caregiver depression (Rankin, Haut & Keefover, 1992), a better understanding of the relationship of familial conflict and caregiver health is an important issue to be examined in future research.

In this study, negative correlations for age of the caregiver and size of the available, utilized and conflicted networks of male and female caregivers combined suggest a trend that warrants further study. Although only correlations for age and available network size of men, and age and conflicted network size for all caregivers were significant, the moderate correlations identified for other groups may still illustrate a note-worthy trend. As Barusch & Spaid (1989) suggest, even trends may have important clinical implications and should be investigated further.

#### Implications for Practice

Findings from this study add to our understanding of the social support networks of male and female caregivers of cognitively impaired adults. Specifically, this study has attempted to generate information about who supports the

caregiver and with which categories of support the caregivers experience satisfaction. Such information may be useful in several ways to nurses and other health professionals who work with caregivers of older adults.

**Assessment.** Several findings from this study suggest the importance of a detailed assessment of caregivers' social networks and may help to identify those at potential risk for inadequate support. For example, for men there was a statistically significant negative correlation between age and network size. Older male caregivers had smaller available networks. Men were also found to have a significant correlation between their socioeconomic status and size of their networks. Those with a higher socioeconomic status had larger networks. Professional caregivers should be alert to the possibility of inadequate support for male caregivers who are older and of low socioeconomic status.

Age and conflicted network size were significantly correlated for the total group of caregivers in this study. There was also a statistically significant gender difference in the size of the conflicted network, with women reporting more sources of conflict. These findings indicate the importance of a complete assessment of the social networks, including conflict, of all caregivers but particularly women.

**Interventions.** Interventions to facilitate dealing with conflict and to increase access to sources of support may be important contributions of the professional caregiver. Knowledge gained from this study may influence clinical practice by contributing to health professionals' understanding of the characteristics of caregivers' networks and identification of caregivers who may be at risk for inadequate support or depression.

Others have suggested that social support networks exist partly as the result of the skills of the person whose network is being examined (Robinson, 1988). While this study did not specifically address the issue of caregiver's skills in maintaining a network, the importance of possessing these skills has been demonstrated in previous research. When caregivers are at risk, interventions may include strategies to strengthen skills in accessing support. For example, specific skills such as assertiveness, social skills (initiating conversation, speaking fluently on the telephone, understanding nonverbal communication), and network building were part of an experimental training program for caregivers. These skills led to an increase in caregiver self-esteem (Robinson, 1988). With professional guidance, skill development to assist caregivers to access their networks in different ways, to expand their networks if necessary, and to develop social skills as required to foster a more effective network



are all possible outcomes of this knowledge (Clipp & George, 1990; George & Gwyther, 1986; Gwyther, 1992; Wilson, 1989).

### Limitations

The examination of the social support networks of male and female caregivers using the ASSIS provides information about the size of the conflicted network, and the available and utilized social networks that provide six different types of social support. A limitation of the instrument is that it does not provide an indication of the density of the network nor of other related factors such as loss in the network. Also the ASSIS has not been tested specifically with the elderly population although it has been used with adult populations. In this study 55% of the caregivers were over 65 years of age.

One other limitation is the measurement of satisfaction by the ASSIS. The co-existence of high levels of satisfaction and high numbers of network members who were in conflict with the women may indicate a social desirability factor that was impossible to control or affected true satisfaction. The limited number of possible responses (3) to the items on satisfaction may also have contributed to the lack of variability in caregivers' responses.

The nature of the sample also suggests limitations. One limitation is the lack of inclusion of caregivers of different ethnic backgrounds. In addition, as all caregivers were volunteers, the subjects may not adequately

represent caregivers of cognitively impaired adults. Recruitment of subjects in the community does however provide access to caregivers who may not be reached when samples are obtained exclusively through the health care system.

The diagnoses recorded are those provided by the caregiver and could not be verified. It is not possible therefore to specify the diagnosis for some individuals.

The cross-sectional nature of the data collection of the actual support network size must be interpreted with caution. A longitudinal study of the changes in the network composition itself would present a more comprehensive picture of what influences the network and what kinds of support remain for the caregiver over extended periods of time.

Attrition from the larger longitudinal study of which this study was a part may also be a potential threat to the utility of the findings. In the study of women caregivers however, none of the women withdrew from the study although four women did not complete all interviews because of the death of the persons they were caring for. In the study of male caregivers, 25 men were recruited. Several withdrew from the study because the person they were caring for died (3) or for other reasons. A total of 20 men completed the ASSIS which was used for this study.

Another limitation of the study is small sample size.

Twenty subjects in each of the gender groups may account for the lack of statistical significance between groups in size of available and utilized networks and comparisons of groups related to their composition. Lack of significant correlations between demographic variables and network size may also be attributed to the small sample size.

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**APPENDIX A**  
**ARIZONA SOCIAL SUPPORT INTERVIEW SCHEDULE (ASSIS)**

In the next few minutes I would like to get an idea of the people who are important to you in a number of different ways. I will be reading descriptions of ways that people are often important to us. After I read each description I will be asking you to give me the first names, initials, or nicknames of the people who fit the description. These people might be friends, family members, teachers, ministers, doctors, or other people you might know.

I will only want you to give me the names of people you actually know and you have actually talked to during the last month. It's possible, then, that you won't get a chance to name some important people if for one reason or another you haven't had any contact with them in the last month.

If you have any questions about the description after I read each one, please ask me to try and make it clearer.

**A. PRIVATE FEELINGS**

1. If you wanted to talk to someone about things that are very personal and private, who would you talk to? Give me the first names, initials or nicknames of the people that you would talk to about things that are very personal and private.  
 PROBE: Is there anyone else that you can think of?
2. During the last month, which of these people did you actually talk to about things that were personal and private?  
 PROBE: Ask specifically about people who were listed in response to #1 but not listed in response #2.
3. During the past month, would you have liked:
  - 1 - a lot more opportunities to talk to people about your personal and private feelings
  - 2 - a few more opportunities
  - 3 - or was this about right?
4. During the past month, how much do you think you needed people to talk about things that were very personal and private?
  - 1 - not at all
  - 2 - a little bit
  - 3 - quite a bit

**B. MATERIAL AID**

1. Who are the people you know that would lend or give you

\$25 or more if you needed it, or would lend or give you something (a physical object) that was valuable? You can name some of the same people that you named before if they fit this description, too, or you can name some other people.

**PROBE:** Is there anyone else that you can think of?

2. During the past month, which of these people actually loaned or gave you some money over \$25 or gave or loaned you some valuable object that you needed?

**PROBE:** Ask about people named in response to #1 that were not named to #2.

3. During the past month, would you have liked people to have loaned you or to have given you:
- 1 - a lot more
  - 2 - a little more
  - 3 - or was it about right?
4. During the past month, how much do you think you needed people who could give or lend you things that you needed?
- 1 - not at all
  - 2 - a little bit
  - 3 - quite a bit

#### C. ADVICE

1. Who would you go to if a situation came up when you needed some advice? Remember, you can name some of the same people that you mentioned before, or you can name some new people.

**PROBE:** Anyone else?

2. During the past month, which of these people actually gave you some important advice?

**PROBE:** Inquire about people who were listed for #1 but not for #2.

3. During the past month, would you have liked:
- 1 - a lot more advice
  - 2 - a little more advice
  - 3 - or was it about right?

4. During the past month, how much do you think you needed to get advice?

- 1 - not at all
- 2 - a little bit
- 3 - quite a bit

#### D. POSITIVE FEEDBACK

1. Who are the people that you could expect to let you



know when they like your ideas or the things that you do? These might be the people you mentioned before or new people.

**PROBE:** Anyone else?

2. During the past month, which of these people actually let you know that they liked your ideas or liked the things that you did?  
**PROBE:** Ask about individuals who were listed for #1 but not for #2.
3. During the past month, would you have liked people to tell you that they liked your ideas or things that you did:
  - 1 - a lot more often
  - 2 - a little more
  - 3 - or was it about right?
4. During the past month, how much do you think you needed to have people let you know when they liked your ideas or things that you did?
  - 1 - not at all
  - 2 - a little bit
  - 3 - quite a bit

#### **E. PHYSICAL ASSISTANCE**

1. Who are the people that you could call on to give up some of their time and energy to help you take care of something that you needed to do--things like driving you some place you needed to go, helping you do some work around the house, going to the store for you, and things like that? Remember, you might have listed these people before or they could be new names.  
**PROBE:** Anyone else you can think of?
2. During the past month, which of these people actually pitched in to help you do things that you needed some help with?  
**PROBE:** Ask about people who were named in response to #1 but who were not named in response to #2.
3. During the past month, how much do you feel you needed people who would pitch in to help you do things?
  - 1 - not at all
  - 2 - a little bit
  - 3 - quite a bit

#### **F. SOCIAL PARTICIPATION**

1. Who are the people that you get together with to have fun or to relax? These could be new names or ones you

listed before.

PROBE: Anyone else?

2. During the past month, which of these people did you actually get together with to have fun or to relax?  
PROBE: Ask about people who were named in #1 but not in #2.
3. During the past month, would you have liked:
  - 1 - a lot more opportunities to get together with people for fun and relaxation
  - 2 - a few more
  - 3 - or was it about right?
4. How much do you think that you needed to get together with other people for fun and relaxation during the past month?
  - 1 - not at all
  - 2 - a little bit
  - 3 - quite a bit

#### G. NEGATIVE INTERACTIONS

1. Who are the people that you can expect to have some unpleasant disagreements with or people that you can expect to make you angry and upset? These could be new names or names you listed before.  
PROBE: Anyone else?
2. During the past month, which of these people have you actually had some unpleasant disagreements with or have actually made you angry and upset?  
PROBE: Ask about people listed for #1, but not for #2.

#### H. PERSONAL CHARACTERISTICS OF NETWORK MEMBERS

Now I would like to get some information about the people you have just listed. For each person on the list, could you tell me:

1. What is this person's relationship to you? For family members, specify the exact relationship (mother, father, sister, brother, grandmother, etc.). For professional people, also specify the exact profession (teacher, minister, doctor, counsellor, etc.).
2. How old is this person?
3. What is this person's sex?
4. How long have you known this person?

## Appendix B

**RESEARCH STUDY: \* WOMEN AS CAREGIVERS: PERCEPTION  
OF RECIPROCITY IN SOCIAL SUPPORT  
DEMOGRAPHIC DATA**

In order to describe the women who have participated in the study, we would like you to answer the following questions:

1. What was your age on your last birthday? (years) \_\_\_\_\_
  2. Indicate by an X the amount of formal education you have.
    - Less than Grade 12 \_\_\_\_\_
    - Grade 12 \_\_\_\_\_
    - Some university or post-high school diploma \_\_\_\_\_
    - University degree \_\_\_\_\_
    - Graduate degree \_\_\_\_\_
  3. Into which category would you place your yearly family income?
    - Less than \$20 000 \_\_\_\_\_
    - \$20 000 to \$40 000 \_\_\_\_\_
    - Over \$40 000 \_\_\_\_\_
  4. What is your current or past occupation? \_\_\_\_\_
- 
5. \*\*Number of years caregiving. \_\_\_\_\_
  6. \*\*Relationship of caregiver to care recipient. \_\_\_\_\_

7. If you are caring for an older person who is confused:

a) Please mark with an X each of the major difficulties which the person you care for experiences:

unaware of the time	_____
unaware of where they are	_____
unaware of who is around them	_____
forgets events in the recent past	_____
forgets events in their early life	_____

b) Do you live with the older person you are caring for?

\_\_\_\_\_

\* This same demographic questionnaire was used for the male caregiver study.

\*\* Information supplied by Principal Investigator.

## APPENDIX C

FACULTY OF NURSING  
UNIVERSITY OF ALBERTARESEARCH STUDY: MALE CAREGIVERS' PERCEPTIONS  
OF SOCIAL SUPPORT AND RECIPROCITY**RESEARCHER:**

Principal Investigator  
Dr. Anne Neufeld  
Associate Professor  
Phone: 432-2699

The purpose of this study is to understand the social relationships of men who are caregivers. This study will provide no direct benefits to you but the results of the study will help nurses plan programs to assist other caregivers.

**Part A:**

You will be interviewed between 3 and 5 times during a 12-18 month period; each interview will last 1 to 1 1/2 hours. The interviews will be held at a time you choose in your home or at another location which you choose. The interviews will be tape recorded. You will be asked to describe your relationship with the person you care for and to describe the help that you get from and give to others. You will also be asked to say what you consider to be important in life.

The information you give in the interviews will be typed out. Your name will not appear on the typed interviews, or questionnaires, or in any reports of the study. During the study, only code numbers will be used to identify the interviews and questionnaires which will be stored in a locked file cabinet.

At the end of the study, the code list will be destroyed. The information you have given will be stored in a locked file cabinet for possible future analysis by Dr. Neufeld. Before the information is looked at again, the researchers will get permission from the appropriate ethical review committee.

Taking part in this study is voluntary. You may refuse to answer any question and you may withdraw from the study at any time by telling the interviewer. If you have any questions while you are participating in the study, you can contact Dr. Neufeld. A copy of this consent will be given to you.

Research AssistantSignature of SubjectDate

**Part B:**

In addition to the interviews, you may also agree to be part of a discussion group with other caregivers who have also been interviewed for this study. The group will be asked to comment on the findings from all of the interviews in the study. This information will be presented in such a way that no one knows who said what. There will be one or two group discussions that will last one hour. The group discussions will be held at the end of the study. If you want to attend the discussion group, please sign below. If you want to decide later, or if you do not want to attend the group discussion, do not sign below.

Taking part in this study is voluntary. You may refuse to answer any question and you may withdraw from the study at any time by telling the interviewer.

If you have any questions while you are participating in the study, you can contact Dr. Neufeld. A copy of this consent will be given to you.

\_\_\_\_\_  
Research Assistant

\_\_\_\_\_  
Signature of Subject

\_\_\_\_\_  
Date

If you wish to receive a typed summary of the information from the study, please write your mailing address here:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**FACULTY OF NURSING  
UNIVERSITY OF ALBERTA**

**RESEARCH STUDY: WOMEN AS CAREGIVERS: PERCEPTIONS  
OF RECIPROCITY IN SOCIAL NETWORKS**

**RESEARCHERS:**

**Principal Investigator  
Dr. Anne Neufeld  
Associate Professor  
Phone: 432-6764**

**Co-Investigator  
Dr. M. Margaret Harrison  
Associate Professor  
432-5931**

The purpose of this study is to understand the social relationships of women who are caregivers. This study will provide no direct benefits to you but the results of the study will help nurses plan programs to assist other women who are caregivers.

You will be interviewed four times during a 12 month period; each interview will last 1 to 1 1/2 hours. The interviews will be held in your home at a time you choose and will be tape recorded. You will be asked to describe your relationship with the adult or baby you care for and to describe the help that you get from and give to others. You will also be asked to say what you consider to be important in life.

The information you give in the interviews will be typed out. Your name will not appear on the typed interviews, the questionnaires, or in any reports of the study. During the study, only code numbers will be used to identify the interviews and questionnaires which will be stored in a locked file cabinet.

At the end of the study, the code list will be destroyed. The information you have given will be stored in a locked file cabinet for possible future analysis by either Dr. Neufeld or Dr. Harrison. Before the information is looked at again, the researchers will get permission from the appropriate ethical review committee.

Taking part in this study is voluntary. You may refuse to answer any question and may withdraw from the study at any time by telling the interviewer.

If you have any questions while you are participating in the study, you can contact either Dr. Neufeld or Dr. Harrison. A copy of this consent will be given to you.

**Research Assistant** \_\_\_\_\_

**Signature of Subject** \_\_\_\_\_

**Date** \_\_\_\_\_