

**Understanding Subjective Family Burden in Elder Care**

**by**

**Laura C. D. Morrison**

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**UNDERSTANDING SUBJECTIVE FAMILY BURDEN IN ELDER CARE**

**BY**

**LAURA C.D. MORRISON**

**A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of  
Manitoba in partial fulfillment of the requirement of the degree  
of  
MASTER OF SCIENCE**

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### Abstract

This study investigated burden of caregivers, analyzing data from the Manitoba Study of Health and Aging (MSHA), conducted in 1991 – 1992 (Segall, Montgomery, Manfreda, & Blandford, 1995). The present study used 327 informal familial caregivers using a modified version of a path model developed by Stuckey and Smyth (1997). The model examined the relationship among gender, relationship, living arrangements, activities of daily living (ADLs/IADLs), and cognitive status on caregiver burden through family social network. Findings suggested that gender, relationship, living arrangements, ADLs/IADLs, and cognitive status are correlated with burden, but family social network is not.

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## Understanding Subjective Family Burden in Elder Care

### CHAPTER I

#### Introduction

Over the past decade, the prevalence and importance of family members providing care for the elderly has been studied by numerous researchers in an effort to gain a better understanding of the caregiving experience. Interest in the family member as a caregiver stems from the needs of families contending with a difficult situation.

Research surrounding the topic of caregiving has increased over the past decades and will continue to increase in light of several demographic trends. Increased longevity and declining fertility rates mean that the number of elderly persons in proportion to the rest of the population will increase (Bass & Noelker, 1987). In Canada, the number of seniors has more than doubled in the past 25 years as people are living longer. Concomitant with the growth of the population of older Canadians is an increase in the length of time frail elderly need caregiving (Cranswick, 1997). The population 60 years and older has been increasing steadily since 1900, with the population 75 years and over growing at a faster rate than the elderly population as a whole, a trend which will continue through the 21<sup>st</sup> century (Biegel, Shore, Gordon, & Brutz, 1986; Biegel, Shore, Gordon, & Bumagin, 1986). Those 75 years and older are more likely to have health problems, require assistance in meeting the needs of daily living, and live alone. This group with the most need for assistance is least likely to have an adequate social network (Biegel, Shore, Gordon, & Brutz, 1986; Biegel, Shore, Gordon, & Bumagin, 1986).

Demographic trends and medical developments may account for this increased longevity of older adults, but, with the larger numbers of ill elderly persons living in the

community (Horowitz, 1985), offspring, children and spouses caring for an aging family member are potentially faced with an increasing dependency from care recipients and additional caregiving responsibility (Bass & Noelker, 1987). Specifically, there were 14.3 elderly people for every 100 people of working age in Canada in 1961; by 1991, there were 18.3 elderly people for every 100 people of working age. It is estimated that by the year 2031, 22.7 percent of Canadians will be 65 years of age and older (Elliot, Hunt, & Hutchison, 1996).

While the number of older adults is increasing, the number of individuals available to provide care to older adults is decreasing, due to smaller family size (Elliot, et al., 1996). Recent changes in the health care system and social services have increased the responsibilities for informal caregivers; for instance, shorter hospital stays and greater use of outpatient treatment have increased the need for care at home (Cranswick, 1997). In fact, Brody (1985), Connidis (1983), and Denton (1997) found as much as 80 to 90% of assistance comes from informal care, and as little as 10 to 20% of assistance comes from formal care (community based health, social services, and paid help). Also, women give personal services to elders more frequently than men (Chappell & Guse, 1989). These caregiving demands occur at a time when the majority of women are participating in the labor force, decreasing the time women spend in the home and adding more responsibilities to day-to-day life.

Canadian caregivers may face multiple responsibilities as employees, spouses, children, and parents (Cranswick, 1997; Denton, 1997). The increasing number of women working full-time, higher divorce rates, two-income families and growth in the number of elderly who outlive their children affect family members providing support to

an elderly relative (Jutras & Veilluex, 1991). The results of these factors can have significant effects on the amount and the quality of care elderly family members are receiving. Chappell and Guse (1989), Brody (1985), Connidis (1983), Penning and Chappell (1990), and Denton (1997) indicated that 80% of community-living elderly (elderly living in their own residence) in Canada who receive assistance get it from family and friends. Also, family members are generally the first to be asked for provision of support by community-living elderly.

Some family caregivers provide care without any sense of obligation, while others may view caregiving as a duty, a sacrifice, or a necessity if the formal services are not available (Cranswick, 1997). Regardless of the reasons for becoming a caregiver, the responsibilities potentially entail a significant commitment (Cranswick, 1997). Meeting caregiving demands often necessitates adjustment to the life of the caregiver, affecting the time the caregiver spends with family and friends, personal time, or the priority given to paid employment and household work (Cranswick, 1997; Denton, 1997).

The concept of caregiving burden has been well documented through research. Several definitions and meanings are attached to the concept of caregiver burden. Personal experience and day-to-day situations involving the care recipient's time dependency, developmental burden, physical burden, social burden, and emotional burden are all associated with caregiving (Novak & Guest, 1989a).

Several factors have a relationship to caregiver burden, all of which have been recognized through research (Abel, 1986; Chappell, 1991; Chappell & Guse, 1989; Hess & Soldo, 1985; Jutras & Veilleux, 1991; Stoller & Pugliesi, 1989; Stuckey & Smith, 1997; Thoits, 1995). The health of the care recipient, the impact and problems of

caregiving, the gender of the caregiver, the family relationship between the caregiver and care recipient, the living arrangements of the caregiver and care recipient, the cognitive status of the care recipient, and the social network of the caregiver are important factors in determining the level of caregiver burden.

Stuckey and Smyth (1997) developed a model to examine caregiver and care recipient characteristics, social resources of the caregiver, and caregiver burden. The current study used a modified version of this model to predict burden. Independent effects of gender of the caregiver, relationship between the caregiver and care recipient, living arrangements of the caregiver and care recipient, activities of daily living (ADL/IADLs) of the care recipient, and the cognitive status of the care recipient on subjective caregiver burden were tested. Also, indirect effects of the family social network of the caregiver on burden were examined.



## CHAPTER II

### Review of Literature

The following section reviews the relevant literature related to this study. This section begins with a discussion of the concept of caregiver burden. Then characteristics of care recipients, informal caregivers, and the social network of the caregiver are examined. Next, the literature surrounding the conceptual framework used in this study is reviewed. Finally, eleven hypotheses are developed.

#### Caregiver Burden

The demands of caregiving are becoming a great concern for families. Burden has been a key concept in family caregiving research.

Defining caregiver burden. The concept of caregiver burden is rather broad and a number of definitions have been used. According to George and Gwyther (1986), caregiver burden is “the physical, psychological or emotional, social, and financial problems” (p. 253) that can be experienced by family members caring for impaired elderly. Similarly, Stuckey, Neundorfer and Smyth (1996) measured burden as “caregivers’ perceptions of the impact of caregiving on their lives, physically, mentally, financially, and socially” (p. 687). Braithwaite (1992) suggested that burden refers to “caregivers’ distress arising from dealing with the care receivers’ physical dependency and mental incapacity” (p. 5). Miller and McFall (1992) focused on “the personal and interpersonal” (p. 379) dimensions of caregiver burden. Personal burden refers to the caregiver’s appraisal of his or her limitations in personal activities when providing care. Interpersonal burden represents the caregiver’s appraisal of problematic behaviors of the

older person. Thus, the term has covered everything from the debilities of the care receiver and the feelings of the caregivers to the effects that caregiving has on families.

Types of caregiver burden. Caregivers may often feel anxious, tired, angry, bitter, guilty, and depressed about their caregiving tasks. Several types of caregiver burden have been identified throughout the literature to describe various feelings surrounding caregiving. According to Novak and Guest (1989a) five dimensions of burden exist: time dependence, developmental, physical, social and emotional. Time dependence burden refers to the restrictions placed on the caregiver's time when performing daily tasks for the care recipient. Developmental burden refers to caregivers' feeling that they are not at the right stage of life to provide care. Some older caregivers see their peers enjoying their later years but see themselves with feelings of anxiety and strain. Physical burden is described as caregivers' feelings of decreasing physical health. Social burden refers to the feelings of role conflict experienced by the caregiver. Caregivers may feel unappreciated and neglected and have little time and energy for other activities in their lives. Finally, emotional burden refers to caregivers' negative feelings toward the care recipients (Novak & Guest, 1989a).

Subjective and objective burden. The feelings of the caregiver have been examined in research on both subjective and objective burden. Several findings have recognized the importance of separating events, happenings, and activities from feelings, attitudes, and emotions (Montgomery, Gonyea, & Hooyman, 1985). Subjective burden refers to feelings, attitudes, and emotional reactions aroused in caregivers as they fulfill their caregiving functions. Objective burden involves the concrete events and disruptions of activities in family and household life that result from caring for an elder (Platt, 1985).

Burden is in the experiences of each caregiver; therefore, perceptions and feelings toward caregiving responsibilities will determine the level of caregiver burden.

The research of Montgomery et al. (1985) illustrates the importance of distinguishing between subjective and objective burden. There were two distinct findings on the types of burden indicating that consequences of subjective burden do not necessarily accompany consequences of objective burden. A given family may experience a high level of objective burden and a low level of subjective burden. However, Montgomery et al. (1985) found that certain types of caregivers were likely to experience subjective burden regardless of the characteristics of the care recipient or the tasks performed by the caregiver. The characteristics associated with subjective burden were characteristics that could not be altered, such as the age of the caregiver. The data analysis indicated that while subjective burden and objective burden were correlated, different variables predicted each type of burden.

The Zarit, Reever, and Bach-Peterson (1980) subjective burden scale is widely used when examining feelings about caring for an elderly individual. The scale incorporates both feelings about giving care and the effects of caring on the caregiver's life. The scale consists of questions concerned with the relationship between the caregiver and the care recipient, including feelings about the impact of caring in areas such as finance, social life, and physical and mental health (Novak & Guest, 1989b).

According to Poulshock and Deimling (1984) the importance of caregivers' subjective perspective and interpretations of burden adds a level of caregiving impact to the analysis. Identifying and recognizing the subjective burden will significantly increase the accuracy of the study of caregiver burden.

Caregiver burden and well-being. Caregiver burden has been used to refer to the physical, psychological or emotional, social, and financial problems that can be experienced by caregivers of the elderly. Alternatively, physical health, mental health, social participation, and financial resources also have been identified as dimensions of well-being (George & Gwyther, 1986). George and Gwyther (1986) established that well-being can be demonstrated to be highly useful for examining the impact of caregiving and that burden and well-being are but “opposite sides of the same coin” (p. 253). Also, Stuckey et al. (1996) found that subjective well-being was strongly correlated with burden measures.

The caregiver’s mental and physical health are important factors in determining caregiver burden. According to Poulshock and Deimling (1984), caregivers with lower levels of mental and physical well-being may be limited in their capacity to respond to the demands of caregiving. The mental and physical burden caregivers perceive are important for understanding their level of burden.

### The Care Recipient

Mental and physical health of the care recipient. The mental and physical health of a care recipient can have a significant relationship to caregiver burden. The health and functional ability of the care recipient influence the caregiver, both directly and indirectly, through their relationship to demands for assistance. Caring for elderly in poor health involves emotional and physical burden (Abel, 1986). Stoller and Pugliesi (1989) found that helpers who provided more hours of help experienced greater burden and that providing personal care assistance was especially stressful. Helpers who assessed the older person’s health as poor also found caregiving more difficult and reported higher

levels of burden and depression. According to Jutras and Veilleux (1991), care recipients' characteristics of low levels of functional independence and poor health both contributed to caregiver burden. Specifically, they found caregivers helping with activities of daily living must provide assistance without delay, which can lead to feelings of burden. This finding suggests that caring for elderly individuals in the community might be done at the expense of the caregiver. Also, caregivers willing to help a relative could experience an increase in the level of burden as the care recipient becomes more functionally dependent as his or her health deteriorates. Caregivers' stress levels increase as care recipients' functional dependency increases.

Almberg, Jansson, Grafstrom, and Winblad (1998) suggest that caregivers for demented elderly individuals demand and need much more support practically and emotionally. Caregivers for demented elderly also found it difficult to have a positive outlook on their caregiving task.

Living arrangements of the caregiver and care recipient. Caregivers who live with care recipients may have higher levels of stress. Stress may result from the increased demands on physical space and the loss of personal freedom. Caregivers who live together with the care recipient may experience a loss of privacy, autonomy, and sleep (Stoller & Pugliesi, 1989). Caregivers who share living arrangements with care recipients have reported high levels of caregiver burden, even when the care recipient's health status and level of functional ability are controlled (Jutras & Veilleux, 1991).

In contrast, caring for an elder who lives separately requires managing two households. The total task responsibilities may be great. Caregivers face extra work in running and traveling between two households. However, caregivers living in separate

households maintain greater control over their personal time and space (Stoller & Pugliesi, 1989).

### The Informal Caregiver

Impact and problems of caregiving. Caring for elderly people involves increasing dependency (Braithwaite, 1992). Braithwaite (1992) identified five crises associated with increasing dependency: awareness of degeneration, unpredictability, time constraints, the caregiver-receiver relationship, and lack of choice.

Independence and growth are highly respected in today's society. As elderly people lose their independence and control, they are left with a feeling of frustration and a sense of a loss of security and accomplishment. The future of older adults is unpredictable, as disease can take different courses and the same disease affects people in different ways (Barnes, Raskind, Scott, & Murphy, 1981). As a result, unpredictability in caregiving may affect the caregiver's capacity to plan, threatening his or her sense of order and control (Braithwaite, 1992).

Caregivers' time constraints increase as elders' dependency increases. According to Stoller and Pugliesi (1989) competing family obligations may generate stress as the demands of caregiving impinge on the time available to meet other obligations. Caring for an elder is an additional responsibility and commitment, and the chances of poor performance of other responsibilities and obligations are likely to increase for caregivers. Where competing commitments involve friendships and obligations, interpersonal relationships may also become strained (Braithwaite, 1992). Dautzenberg, Diederiks, Philipsen, and Tan (1999) indicated that caregivers become more distressed when caregiving demands cause interference with social and personal lives of caregivers.

Once a family member has accepted the responsibility to care for an elder, it is not certain that the two will get along in their newly established dependency relationship. Conflict may increase in the caregiver–receiver relationship if one dominates the life of the other (Braithwaite, 1992) and power relations may be competing.

Finally, Braithwaite (1992) recognized that given the strength of the family ties, caregivers might have little choice but to help. The impact of caregiving has been associated with losses in employment, freedom, privacy, and sleep (Stoller & Pugliesi, 1989). Stoller and Pugliesi (1989) reported that the impact of multiple roles contributes to burden when the needs of the older person demand assistance. Hawkins (1996) reported on a non-random sample of 21 caregiving daughters and found that, due to caregiving responsibilities, almost half of employed women changed the amount of time spent working, as well as decreased the number of days worked. Women spent less time on the job to assist a care recipient.

Gender of caregiver. It is well known that women represent frequent informal caregivers for dependent elderly. Family support is usually provided by one or two primary caregivers in the family. Traditionally these caregivers have been women: wives, daughters, and daughters-in-law (Chappell & Guse, 1989). Several researchers have reported that burden experienced by women is greater than that experienced by men. Women are more likely to experience emotional strain associated with caring for the elderly (U.S. House of Representatives, 1988) and perceive caregiving on their lives as negative. Also, wives are more likely to experience health problems as a result of caring. The caregiving role traditionally assumed by women did not disappear when women took on new roles as labour force participants and as mothers. Taking a series of social,

demographic, and economic shifts into account, such as higher divorce rates, increases in two-income families, women's increasing employment commitments, and women's pregnancies taking place later in life, it is not surprising that women reported more burden than men (Jutras & Veilleux, 1991).

In spousal caregiving relationships, some husbands in traditional marriages have been found to experience more burden than wives do, even though women usually provide more assistance. Among today's caregivers, Jutras and Veilleux (1991) suggested a likely reason is that men experience more professional consequences, if still in the work place, than women; the impact of caregiving on professional life is greater for husbands than for wives. Hess and Soldo (1985) suggested that since wives are typically younger than their husbands, they perform caretaking tasks for longer periods of time. In addition, if the marriage had been characterized by traditional gender role allocation, a caregiving husband may have a higher perception of burden, compared to both women and men whose marriages involved a more egalitarian division of expression and responsibilities (Hess & Soldo, 1985).

Daughters are more likely to experience strain than other family caregivers, and the roles played by daughters are different from those of sons. Daughters tend to provide hands-on physical maintenance and emotional care, while sons provide supervision, decision-making and financial care (Chappell & Guse, 1989). Failure of a daughter to respond to the needs of an elderly parent may generate guilt (Stoller & Pugliesi, 1989). Also, Almberg et al. (1998) found that some women reported more strain than men because their relations with family and others were affected due to their supporting role. Daughters' guilty feelings that they are not doing enough for their elderly parents may



stem from societal expectations regarding caregiver responsibilities for women (Gilligan, 1982).

Offspring caregivers versus spousal caregivers. The familial relationship of the caregiver and the care recipient may affect the level of perceived burden. For example, spouses have a different relationship than parents and children; therefore, depending on the caregivers' and care recipients' family relationship, the level of caregiver burden can vary.

According to Jutras and Veilleux (1991), spousal caregivers reported less burden than other family caregivers. The reason may be that the care provided by spousal caregivers is a natural extension of the emotional bond and imposes fewer constraints than a parent-child relationship on commitments and daily activities. Compared to adult children who provide personal care, spousal caregivers appear to be free of competing demands that would tend to increase caregiver burden. Very few older caregiving spouses have paid work or child rearing obligations (Hess & Soldo, 1985). However, spouses who are employed, who have other family commitments, or who are active in community life may have a different caregiving experience than those who are less active outside the household.

On the other hand, the caregiving burden of spouses may be affected by characteristics of their long-standing bond. The closer the caregiver-care recipient relationship, the greater the impact of impairment on everyday life. The very qualities in the marriage that lead to a heightened sense of caring also exacerbate the trauma of caregiving (Hess & Soldo, 1985).

Schneider, Murray, Banerjee, and Mann (1999) examined husband and wife caregivers. They suggested that several factors influence a spousal caregivers' feelings of burden. First, co-resident spouses devote a great deal of time to caring. Second, husband and wife caregivers are, on average, older than other informal caregivers and are more likely to have physical disabilities and so are vulnerable themselves. A caregiver's own functional health limitations will influence the degree of difficulty experienced in performing caregiving tasks. Spouses who provide care are more likely to have needs for assistance themselves. Third, spouses are expected or obligated to care for each other, therefore, the caregiving responsibility is simply a progression or a stage in their relationship. Fourth, dementia can undermine a marital relationship, so reciprocity can be lost. Fifth, changing family structures have reduced the availability of intergenerational informal care, placing greater demands on spouses. Sixth, there are marital concerns about financial security. Also, spouses may have fewer resources to ease the burden of caregiving. Their incomes are typically much lower than younger persons'. However, spouses may have savings and assets to help with expenses (Hess & Soldo, 1985). All these factors make spouses a particularly important group to examine when studying burden.

Overall, it seems clear that spouses have a substantially higher tolerance threshold than other caregivers and are most likely to maintain an extremely impaired older person with fewer mediating resources and at greater personal costs (Hess & Soldo, 1985). Having a spouse has been found to be one of the greatest guarantees of informal support for elderly individuals (Chappell, 1991).

Adult children caring for elderly parents may find it particularly difficult combining care for a parent with other responsibilities, familial and professional. Jutras and Veilleux (1991) found that adult daughters and sons reported consequences to their job performance because of caregiving. Noelker and Wallace (1985) reported that married children, with or without dependent children of their own, experienced family problems resulting from their caregiving responsibilities. The competing demands and obligations that adult children face when caring for an aging parent affect their burden level.

Recall that less burden was reported by caregivers living separately, a finding that challenges evidence that supports spousal caregivers feeling less burden than offspring caregivers (Jutras & Veilleux, 1991). Spousal caregivers are most likely to be living in the same household as the care recipient; therefore, when determining caregiver burden in living arrangements, the familial relationship between the caregiver and care recipient should be considered.

#### Social Network of Caregiver

Several researchers indicate that structural social networks and functional social support aspects of support are different phenomena and should be assessed and examined independently (Stuckey & Smyth, 1997; Thoits, 1995). Social networks describe caregivers' social relationship in structural properties such as density, composition, and multiplexity. Examining caregivers' social networks specifies the degree of social interaction or isolation experienced by caregivers and which family members are available to offer support (House, Umberson, & Landis, 1988).

According to Thoits (1995), social support usually refers to “the functions performed for an individual by significant others” (p. 64). The cohesiveness and the types of relationships in a person’s social network have been shown to influence the acceptance of various kinds of social support. Thompson, Futterman, Gallagher-Thompson, Rose, and Lovett (1993) showed that not all relationships in an individual’s network provide support and the content of support received from particular relationships can differ. Supportive relationships help family caregivers manage the tasks and associated strains of caregiving. The availability of supports might be a way of sharing the caring role and this may serve as a buffer against caregiver strain (Almberg et al., 1998).

Support can be recognized in several forms: informational support, tangible assistance, emotional support, esteem support, and social integration (Cutrona & Russell, 1990; Thoits, 1982; Wellman & Wortley, 1990). Informational support is the guidance and advice given to the family caregiver by others helping to understand and manage stressful situations. Tangible assistance refers to instrumental behaviour and goods subsidizing the caregiver’s responsibilities of caregiving. The emotional support caregivers receive is the behaviour of others promoting the caregiver’s feelings of comfort, ease, and security. Esteem support refers to positive feedback others provide to help increase the caregiver’s self-efficacy and sense of competence. Finally, social integration represents a sense of belonging and is based on participating in social and recreational activities outside caregiving. Thompson et al. (1993) found that all types of support are not equally helpful in diminishing the burden of caring for frail elders. The responsibilities of caregiving for socially isolated caregivers left the caregivers with

strong negative feelings toward the care recipients. They also found that caregiving lead to emotional strain and feelings and that the task of caregiving had placed constraints on their social lives. The lack of an opportunity to socialize and be engaged with friends and family had a relationship to caregiving burden. Wheaton (1985) recognized that pleasant social activities reduced negative feelings. Also, Hawkins (1996) reported that the most used mechanism for coping with the caregiving task was talking with someone. Contact with friends and relatives were most often used when needing help.

### Conceptual Framework

Stuckey and Smyth (1997) developed a model to illustrate the difference among relationships among caregivers and care recipient characteristics, social resources, and burden. Their study employed path analysis to examine these variables in a multivariate context. Stuckey and Smyth (1997) argued that social ties and social support are distinct and demonstrated that social ties should not be used as alternate measures of social support. Social ties were defined by the number of family and friends, frequency of contact with these family and friends, and memberships in volunteer organizations the caregiver had. Social support was determined by aid, affect, and affirmation by others toward the caregiver. Social ties and social support are part of a broader dimension of social resources. First, caregiver and care recipient characteristics were included in Stuckey and Smyth's model, such as the gender of the caregiver, the relationship between the caregiver and the care recipient, the cognitive status of the care recipient, and the behavioral symptoms of the care recipient. Second, social resource variables are measures of social ties, aid, and affect and affirmation. Finally, health outcomes are measures of physical and mental objective and subjective assessments of burden. Using

this model Stuckey and Smyth (1997) found that the subjective perception was more relevant than objective perception, in order to understand health outcomes.

In this research, Stuckey and Smyth's (1997) model was modified and tested (see Figure 1). Similar to Stuckey and Smyth (1997) independent variables used were gender, relationship, and the cognitive status of the care recipient. Since living arrangements and activities of daily living were also found in the literature (Jutras & Veilleux, 1991) as having a relationship to burden, they were added as independent variables. The intervening variable used in this study was family social network that is discussed in the operational definitions. Finally, although Stuckey and Smyth (1997) had several dependent variables, health outcomes and subjective assessment of burden, only the latter was used in this research.

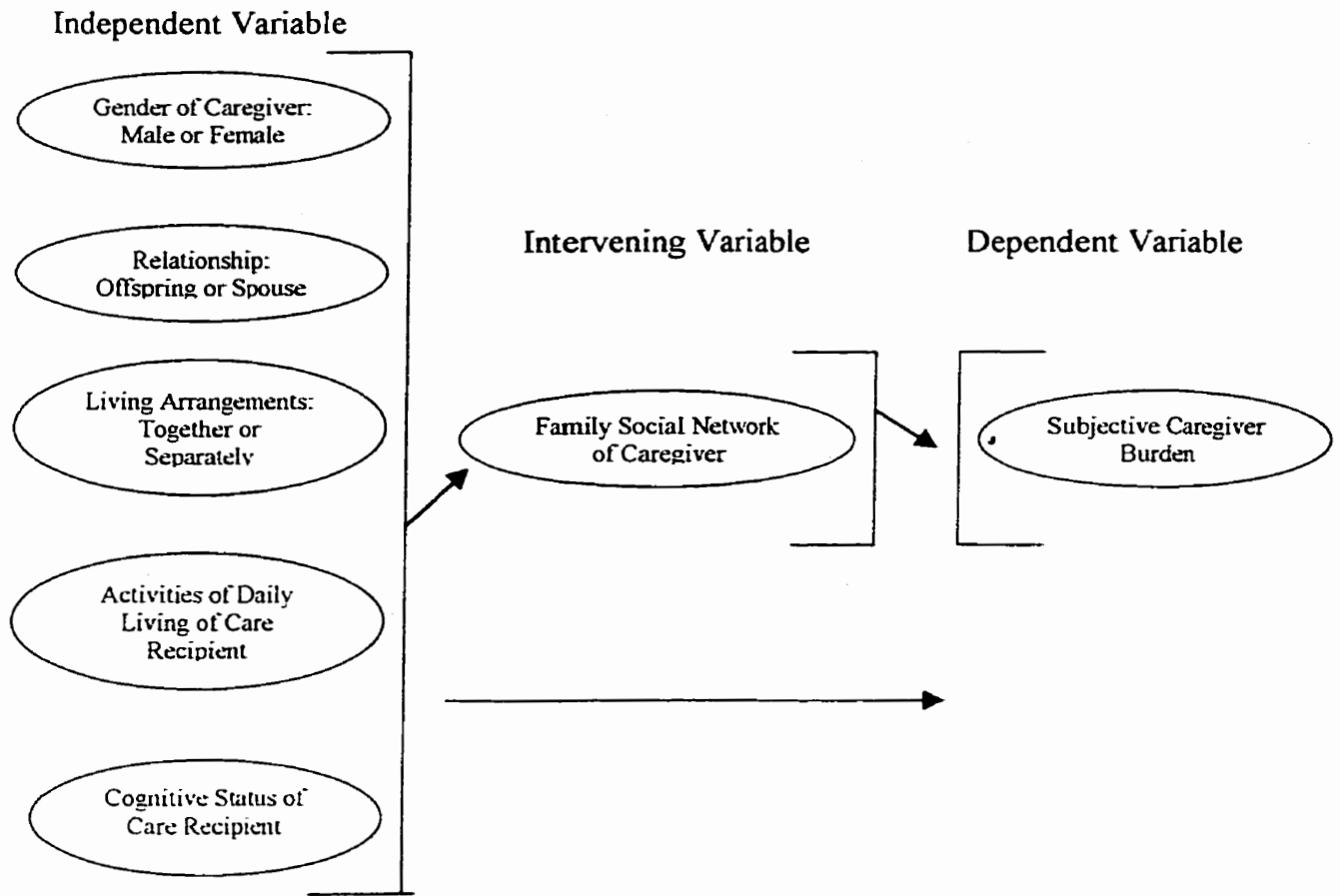


Figure 1. Path model, modified from Stuckey and Smyth (1997).

### Summary of Relevant Literature

In summary, caregiving for the elderly by family members is a prevalent situation in today's society. Understanding the caregiving experience has been an important topic of research in the past decade. Specific characteristics of the caregivers and care recipients, such as gender, relationship as offspring or spouse, living arrangements, activities of daily living, and cognitive status can have a relationship to caregiver burden. Although these variables have a direct relationship to caregiver burden, a spurious

relationship may exist through the social network of the caregiver. This study identifies the relationships that exist among these variables.

### Hypotheses

Gender and burden. The existing literature shows that women provided the most care to dependent elderly and that the burden experienced by these women was greater than that of men (Chappell & Guse, 1989). As caregivers to the elderly, women experience emotional strain and role overload acting as caregivers to their families and/or as participants in the workforce (Jutras & Veilleux, 1991). The first hypothesis tested the effects of gender on caregiving.

- H1. Female caregivers will show greater caregiver burden than male caregivers.

Relationship and burden. The literature predicts that spousal caregivers will experience less burden than other family members. The reason may be that the care provided by spouses is a natural extension of their emotional bond and imposes fewer constraints than parent-child relationships. Offspring who were caregivers had difficulty combining care for a parent with other responsibilities, familial and professional (Jutras & Veilleux, 1991). This hypothesis tested the effects of the caregiver and care recipient relationship on caregiver burden.

- H2. Offspring who care for dependent parents will show greater caregiver burden than spousal caregivers.

Living arrangements and burden. The literature has reported that caregivers that live with care recipients may have higher levels of burden. Stoller and Pugliesi (1989) reported that caregivers experienced loss of privacy, autonomy, and sleep when sharing a



residence with a dependent elder. Caregivers living in separate households have been reported as having greater control over their personal time and space (Jutras & Veilleux, 1991). As mentioned earlier, caregivers living separately reported less burden, contradicting the evidence that spousal caregivers experience less burden than offspring caregivers (Jutras & Veilleux, 1991) and the fact that spousal caregivers were most likely to be living in the same household as the care recipient. Therefore, when determining caregiver burden in living arrangements, the familial relationship between the caregiver and care recipient should be considered. This hypothesis tested the effects of living arrangements on caregiver burden.

- H3. Caregivers and care recipients living together will show greater caregiver burden than caregivers and care recipients living separately, regardless of relationship.

Mental and physical health of care recipient and burden. The literature finds that health and functional ability of the care recipient influences the caregiver emotionally and physically (Adel, 1986). According to Jutras and Veilleux (1991), care recipients' characteristics of low levels of functional independence and poor health both contribute to caregiver burden. Specifically, since immediate action is required of caregivers when helping elders with activities of daily living, caregivers may feel more burden. This finding suggested that care for elderly people in the community might be at the expense of the caregivers. Also, Almberg et al. (1998) suggested that demented elderly individuals demand and need much more support practically and emotionally than elderly who are not demented. Therefore, the fourth hypothesis tested the effects of caregivers caring for care recipients requiring help with three or more ADL/IADLs or help with less

than three ADL/IADLs on caregiver burden. Finally, the fifth hypothesis tested the effects of caregivers caring for care recipients who are cognitively impaired with care recipients who are not cognitively impaired on caregiver burden.

- H4. Caregivers caring for care recipients who require help with three or more ADL/IADLs will show greater burden than caregivers caring for care recipients who require help with fewer than three ADL/IADLs.
- H5. Caregivers caring for care recipients who are cognitively impaired will show greater burden than caregivers caring for care recipients who are not cognitively impaired.

Figure 2 shows the direction of the direct effect of the variables of gender, relationship, living arrangements, ADL/IADLs, and cognitive status on burden. These links were tested in H1 through H5.

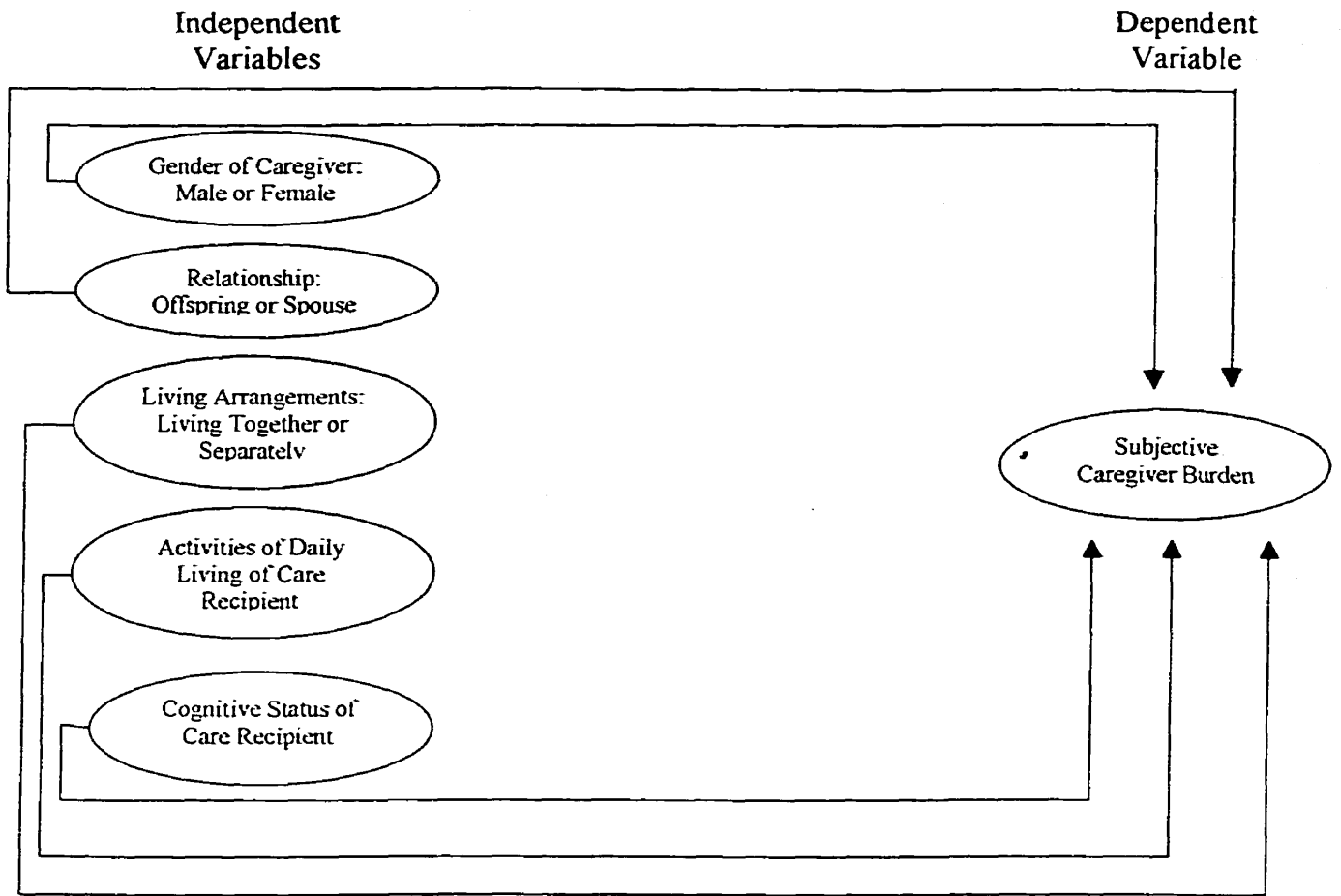
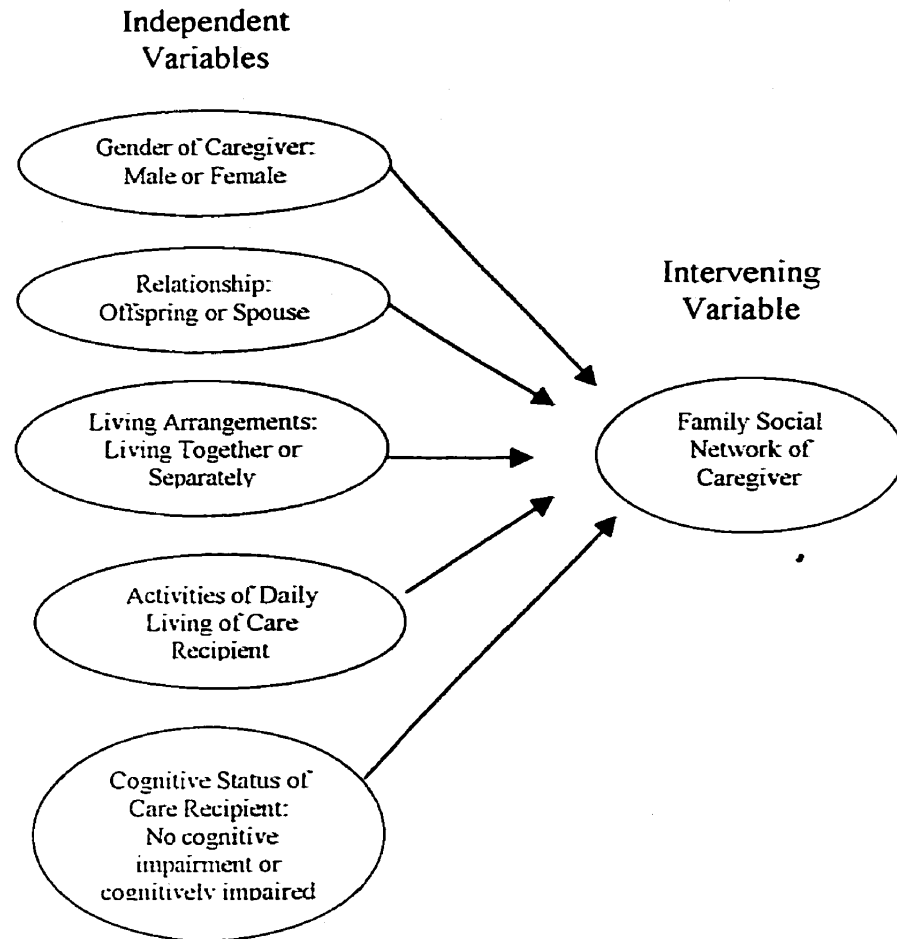


Figure 2. Illustration of the direct effects of gender, relationship, living arrangements, ADL/IADL, and cognitive status on subjective caregiver burden.

Family social network and burden. Examining caregivers' social network specifies the degree of social interaction/isolation experienced by caregivers and which family members are available to offer support (House et al., 1988). Caregiving can lead to a feeling that the task of caregiving places constraints on social lives. The lack of an opportunity to socialize and be engaged with friends and family is related to feelings of burden (Thompson et al., 1993). Also, pleasant social activities reduce negative feelings

(Wheaton, 1985). These hypotheses tested the effects of gender of the caregiver, relationship of caregiver and care recipient, living arrangements of caregiver and care recipient, ADL/IADLs of care recipient, and cognitive status of the care recipient on caregiver burden with social network of the caregiver as the intervening variable (see Figure 3). H6 to H10 are in null hypothesis form. For each, family social network was categorized into three; no people in the caregiver's family social network, 1-3 people in a caregiver's family social network, and 4 or more people in a caregiver's family social network.

- H6. There is no difference in caregiver burden of males or females with zero to four or more people in their family social network.
- H7. There is no difference in caregiver burden of offspring or spouses with zero to four or more people in their family social network.
- H8. There is no difference in caregiver burden of caregivers living together or separately with zero to four or more people in their family social network.
- H9. There is no difference in caregiver burden of caregivers caring for care recipients who require no help, help with between 1 and 2, help with between 3 and 5, or help with more than 6 ADL/IADLs with zero to four or more people in their family social network.
- H10. There is no difference in caregiver burden of caregivers caring for care recipients with or without cognitive impairment with zero to four or more people in their family social network.



**Figure 3.** Illustration of the effects of gender, relationship, living arrangements, ADL/IADLs, and cognitive status on family social network.

Model testing. Finally, it was expected that the independent predictors of subjective caregiver burden would be modified through the effects of family social network. H11 was developed to test the model originally developed by Stuck and Smith (1997) and modified by the present research, as shown in Figure 4.

H11. The effects of gender, relationship, living arrangements, activities of daily living, and cognitive status on caregiver burden will be modified by family social network.

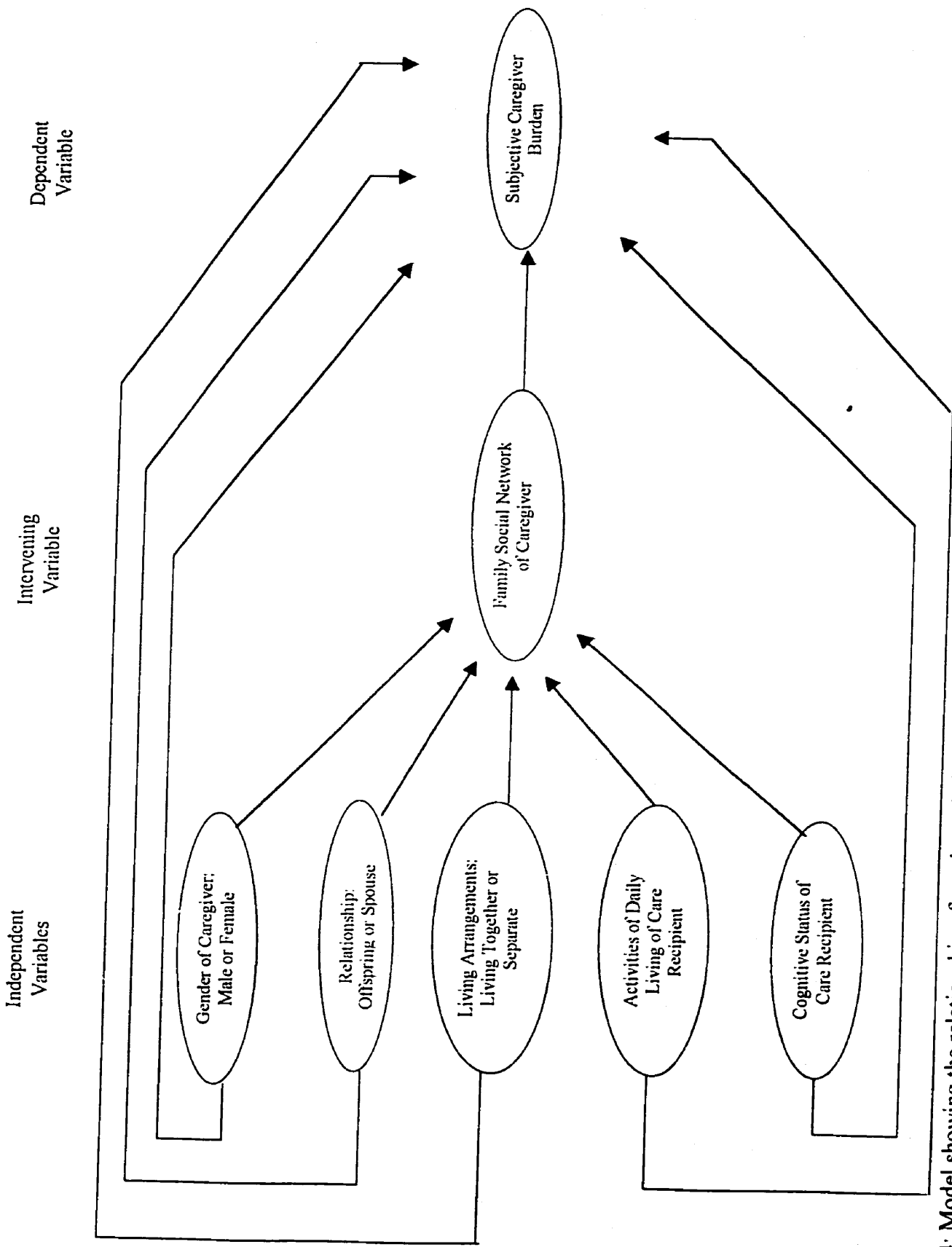


Figure 4: Model showing the relationship of gender, relationship, living arrangements, activities of daily living, and cognitive status on caregiver burden through family social network.

## CHAPTER III

### Methodology

The focus of this study was to examine the relationship among the characteristics of family caregivers, social networks and subjective caregiving burden. The data were drawn from the Manitoba Study of Health and Aging (MSHA), conducted in 1991-1992 (Segall, Montgomery, Manfreda, & Blandford, 1995).

#### Data Collection

The Centre on Aging at the University of Manitoba was responsible for the collection of data in Manitoba for the Canadian Study of Health and Aging (CSHA), which was sponsored by Health Canada. One of the purposes of the CSHA was to assess patterns of providing care for people with dementia in a nationally representative sample that included caregivers of elders in the community and in institutions (Canadian Study of Health and Aging, 1994). Manitoba Health funded the Centre on Aging at the University of Manitoba to collect data in Manitoba from an expanded provincial sample as the MSHA. All Manitoba CSHA participants were also included in the MSHA. The study included screening interviews, a clinical phase, caregiver interviews, a risk factor phase, and a formal service utilization phase (Segall et al., 1995). One of the purposes of the community-based caregiver interviews was "to examine the caregiver burden of providing care to an individual with dementia, in contrast to providing care to an individual without dementia" (Segall et al., 1995, p. 2).

The first phase of the MSHA was to conduct a screening survey to test for cognitive impairment of Manitoba elders. A random sample of people age 65 and older was requested from Manitoba Health. In total, 2,890 people were contacted during the

screening interview. This resulted in a community sample of 1,763 people participating in an interview from the period of February 1991 to November 1992. The screening interview also determined which participants would be placed in the clinical assessment. The Modified Mini-Mental State Exam (3MS) developed by Teng and Chiu (1987) was conducted on all individuals who were screened. Those who scored 77 or fewer (N=330) and those who were unable to be screened (N=12) were eligible for the clinical assessment. Those who scored 78 or more were eligible for the control groups of the other phases of the study (N=1421) (Segall et al., 1995).

The MSHA data set focused on a sample of caregivers providing care to elders with cognitive impairment, together with a comparison group of caregivers for elders with no clear cognitive impairment.

Participants who completed the caregiver interview were in one of four groups: (a) caregiver of an elder diagnosed with dementia (N=54); (b) caregiver of an elder diagnosed with cognitive impairment – no dementia (N=78); (c) caregiver of an elder with no cognitive impairment and some functional disability (randomly selected from participants who scored 78 or more on the 3MS and had 3 or more disabilities on ADL/IADLs in the screening interview) (N=72); (d) caregiver of an elder with no cognitive impairment and no functional disability (randomly selected from participants who scored 78 or more on the 3MS and had fewer than 3 disabilities on ADL/IADLs in the screening interview) (N=184).

In total, 388 primary caregivers were successfully interviewed in the community sample. Of the family caregivers in the community, 138 were spouses (94 wives and 44 husbands) and 189 were offspring (122 daughters and 67 sons), for a total of 327



caregivers. Of these 327 caregivers, 216 were female and 111 were male (Segall et al., 1995). In each case, only the “primary” caregiver was interviewed. Primary caregivers were identified by the older respondents in the screening phase as “the person most responsible for day-to-day decision making and provision of their care” (Segall et al., 1995, p. 92), or the most likely to provide care if necessary. The caregiver interview asked for characteristics of the caregiver and the care recipient. Specifically, the present study used data from caregiver spouses and offspring.

The items taken from the caregiver data set for the present study included the gender of the caregiver, the relationship between the caregiver and care recipient, the living arrangements of the caregiver and care recipient, the activities of daily living (ADL/IADLs) of the care recipient, the cognitive status of the care recipient, the social network of the caregiver, and subjective caregiver burden.

#### Advantages and Disadvantages of this Data Set

The CSHA had limitations in the sample size for Manitoba, therefore, the MSHA used the data from the CSHA and expanded the sample throughout southern Manitoba to represent a higher proportion of Manitobans. The MSHA has been published, used, and documented as the basis of many research papers. The Canadian Study of Health and Aging Research Group (1994) stated that “most previous studies have used clinical samples or other selected groups, and extrapolation of their results to the broader population is unlikely to be valid” (p. 482). Also, they believed that the study confirmed the widespread involvement of the informal network in providing care and assistance to elderly persons.

The measure of subjective caregiver burden used in this study has been found to be reliable and valid. The Zarit burden scale (Zarit et al., 1980) has been described as “one of the most often used and most reliable measures of caregiver burden in the literature...and allows for correlation of caregiver burden with a variety of variables” (Novak & Guest, 1989, p. 70).

One disadvantage of using this data set for secondary analysis is the limitations and restrictions on the questions asked. Second, by the time this study used the MSHA data set, the data were almost ten years old.

### Operational Definitions

In this section definitions and scales for the primary caregiver, the gender of the caregiver, relationship between the caregiver and care recipient, the living arrangements of the caregiver and care recipient, the activities of daily living of the care recipient, the cognitive status of the care recipient, the social network of the caregiver, and caregiver burden are described.

The primary caregiver. For the purpose of this study, the primary caregiver was the person identified by the older adults in the screening phase of the MSHA as most responsible for day-to-day decision making and the provision of their care (Segall et al., 1995). A caregiver does not necessarily have to be physically caring for the care recipient; he/she can also be someone whose life is affected mentally, financially, and socially according to Stuckey et al. (1996).

Gender of caregiver. The gender of the caregiver was identified in the MSHA data set using one “sex” item. The caregivers in this study were recognized as either male or female. Throughout the analyses, the value for males=0 and the value for females=1.

Caregiver and care recipient relationship. Caregiver and care recipient relationship in this study was defined by one open-ended question answered by the caregiver: “What is your relationship to (\_\_\_\_\_)?” Specifically, the relationship of offspring or spouse was examined in this study. Therefore, caregivers who responded “son” or “daughter” were categorized as offspring; “wife” or “husband” were categorized as spouses. People with other relationships were excluded from the study. The value for spouses=0 and the value for offspring=1.

Living arrangements: Together or separate. Whether the care recipient and caregiver lived together or separately was defined by one variable. The caregiver was asked, “Are you currently living in the same house as (\_\_\_\_\_)?” Caregivers who responded “yes” were placed in the “living together” category and caregivers who responded “no” were placed in the “living separate” category. This variable was added to the modified path model in Figure 1. The living arrangements of the caregiver and care recipient variable was included in the modified model for several reasons. Shared living arrangements have been reported as generating burden (Jutras & Veilleux, 1991); however, caring for an elder who lives separately requires managing two households, an increase of total task responsibilities (Stoller & Pugliesi, 1989). Also, when examining living arrangements, values for caregivers living together with the care recipient=0 and values for caregivers living separately from the care recipient=1.

Activities of daily living. The caregiver was asked questions concerning how the care recipient managed daily life. In this study, activities of daily living (ADL) and instrumental activities of daily living (IADL) were defined according to the indicators used in the MSHA data set for ADL/IADLs of the care recipient (Appendix A). ADLs

were defined using the variables for eating, dressing and undressing, taking care of his/her own appearance, walking, getting about the house, going up and down stairs, getting in and out of bed, taking a bath or shower, and going to the bathroom. IADLs were defined as using the telephone, getting to places out of walking distance, going out of doors in good weather, going out of doors in any weather, shopping, preparing meals, doing housework, doing light housework, doing yard work, taking medicine, handling money, and handling long-term finances. All care recipients who needed "some help from person" or "some help from person and device" were categorized as requiring some help and given a score of one. Scores were summed, resulting in the total number of ADL/IADLs with which a care recipient required help. Care recipients who scored seven or more on the ADL/IADL scale were collapsed into the "six" ADL/IADL category, resulting in a range from 0 to 6 ADL/IADLs. In the case of missing values, if the caregiver missed only one variable on the scale, this value was recoded as "requiring no help" and his or her total score was still included in the sample. Specifically, there were five caregivers that answered "don't know" and seven caregivers that were missing one variable. All thirteen of these caregivers were still included in the sample. One caregiver answered "don't know" to fourteen variables; therefore, this caregiver was excluded from the study.

Cognitive status of the care recipient. As mentioned earlier, participants who completed the caregiver interview were in one of four groups: (a) caregiver of an elder diagnosed with dementia; (b) caregiver of an elder diagnosed with cognitive impairment – no dementia; (c) caregiver of an elder with no cognitive impairment and some functional disability, randomly selected from participants who scored 78 or more on the 3MS and

had 3 or more disabilities on ADL/IADLs in the screening interview; (d) caregiver of an elder with no cognitive impairment and no functional disability, randomly selected from participants who scored 78 or more on the 3MS and had fewer than 3 disabilities on ADL/IADLs in the screening interview (Segall et al., 1995). Therefore, care recipients who were reported as having dementia or cognitive impairment (a and b) were placed in the "cognitive impairment" category. The care recipients who were reported as having no cognitive impairment (c and d) were placed in the "no cognitive impairment" category. Also, when examining the cognitive status of the care recipient, values for care recipients with no cognitive impairment=0 and values for care recipients with cognitive impairment=1.

Family social network of the caregiver. For this study, family social network was defined by the items used to describe the social network of the informal caregiver (Appendix B). Respondents were asked how often they had contact with family members both inside and outside the household. Family social network outside the household refers to parents, spouse, siblings, and children. Family social network inside the household refers to any individual living in the same household as the caregiver, irrespective of their relationship. These individuals included spouses, offspring and their spouses, siblings, parents, grandchildren and their spouses, aunts and uncles, friends, and others. Therefore, non family members living inside the household were considered as family members in a caregiver's household. The caregivers were asked to identify how many people lived in the same household (which ranged from 0 to 7 people) and the relationship of these people to them. Also, respondents were asked to identify the number of sons, daughters, parents, brothers, and/or sisters they had living outside the household,

as well as the frequency of contact they had with these individuals. All responses were coded as (1) every day or (2) once a week or more but not daily. If a parent or spouse was cared for by the caregiver, he/she was excluded from the family social network of the caregiver. The total numbers of individuals living inside and outside a caregiver's network were summed into one score to determine a caregiver's family social network with whom they had contact once per week, which ranged from 0 to 14 people. Two respondents were eliminated due to missing values in their interview for family social network. One caregiver had missing values in "number of sisters" and "contact with sisters;" another had missing values in "number of daughters and sons" and "contact with them."

Caregiver burden. The caregiver's feelings of burden were measured by the subjective burden scale (Zarit et al., 1980). The scale consisted of 22 items summed on a scale that ranged from 0 to 88, with higher scores indicating higher levels of burden (Appendix C). In order to achieve a normal distribution for the burden scale, all caregivers who scored one standard deviation above the mean were placed into the "23" burden score, resulting in a burden range from 0 to 23. The higher the score on the scale, the more caregiver burden. In the case of "missing" or "don't know" values, if the caregiver missed fewer than two questions on the scale, a mean score replacement was used and respondents were thus retained in the analysis. One caregiver missed fourteen variables; however, and this respondent was excluded from the study.

### Data Analysis

Hypotheses H1, H2, H3, H4, and H5 were analyzed using *t* tests. Hypotheses H6, H7, H8, H9, and H10 were analyzed using analysis of variance.

Hypothesis H11 was analyzed using path analysis. The path model in Figure 5 resulted in two equations as follows:

$$S = \underline{P1} * G + \underline{P2} * R + \underline{P3} * L + \underline{P4} * A + \underline{P5} * C + E1 \quad (1)$$

$$B = \underline{P6} * S + \underline{P7} * G + \underline{P8} * R + \underline{P9} * L + \underline{P10} * A + \underline{P11} * C + E2. \quad (2)$$

The path coefficients P1 to P11 are standardized regression coefficients obtained from multiple regression analysis of the above two equations. E1 and E2 represent the residuals of each path. The value of P1\*P6 represents the effect of the gender of the caregiver (G) on caregiver burden (B) through family social network (S). Similarly, the values of P2\*P6, P3\*P6, P4\*P6, and P5\*P6 represent the effects of relationship (R), living arrangements (L), activities of daily living (A), and cognitive status (C) on caregiver burden (B) through family social network (S), respectively. The values P7 to P11 represent the direct effects of gender (G), relationship (R), living arrangements (L), activities of daily living (A), and cognitive status (C) on caregiver burden (B), not mediated through family social network (S).

Also, in H11, the independent variables, gender, relationship, living arrangements, activities of daily living, and cognitive status will be tested for multicollinearity. This test will determine if any of the independent variables are highly related.

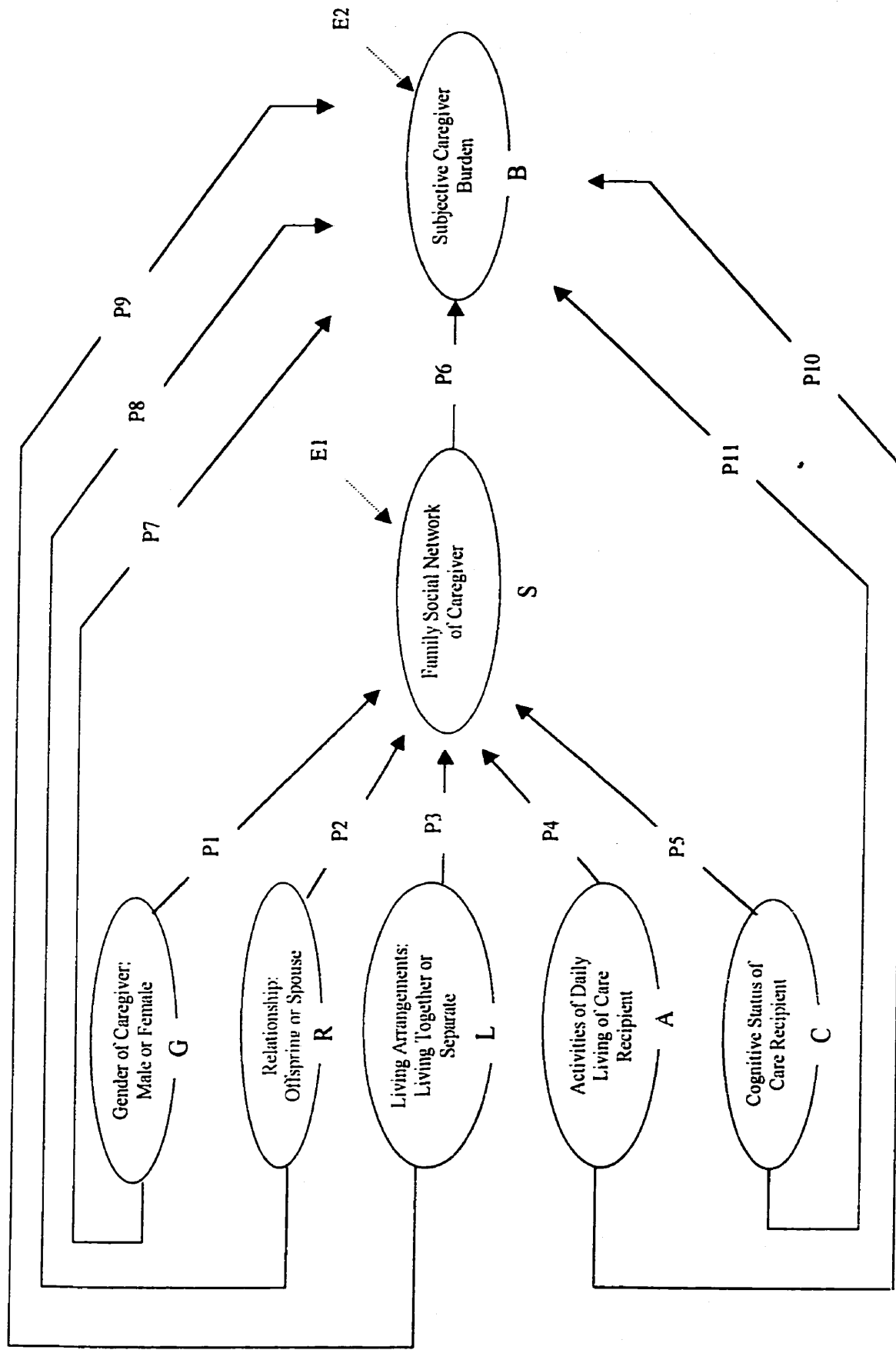


Figure 5: Path model showing variable labels for gender (G), relationship (R), living arrangements (L), activities of daily living (A), and cognitive status (C), family social network (S), caregiver burden (B), path coefficients (P1 to P11), and residual variances (E1 and E2).



## CHAPTER IV

### Results

In this chapter, results of the analysis of the MSHA data are discussed. Eleven hypotheses were tested. Before presenting results of hypothesis testing, it is appropriate first to describe characteristics of the sample.

#### Sample Description

There were 388 caregiver interviews in the original MSHA data; this study examined 327 familial caregivers. These family caregivers were primarily females (66.1%). Approximately one quarter were in the 60 – 69 age group, with a mean age of 57.93 years. In terms of relationship of the caregiver to the care recipient, 37.3% were daughters (n=122), 20.5% were sons (n=67), 28.7% were wives (n=94), and 13.5% were husbands (n=44). Therefore, 57.8% were offspring (n=189) and 42.2% were spouses (n=138). There were 161 caregivers living with the care recipients (49.2%) and 166 caregivers not living with the care recipient (50.8%); therefore, caregivers were almost equally split between living together or separately (see Table 1).

Care recipients were primarily female (58.7%). There were 117 care recipients aged 65-74, 147 aged 75-84, and 62 care recipients were 85 years or older (see Table 1).

The MSHA focused on a sample of caregivers providing care to elders with cognitive impairment, together with a comparison group of caregivers for elders with no clear cognitive impairment. The total number of care recipients diagnosed with dementia or cognitive impairment but not dementia was 104 (31.8%) and those with no cognitive impairment totaled 223 (68.2%) (Table 1).

Table 1

Characteristics of the Caregivers and Care Recipients

Variable	N	Valid percent distribution
<b>Caregiver sex</b>		
Male	111	33.9
Female	216	66.1
Total	327	
<b>Caregiver age</b>		
26-49	108	33.0
50-59	55	16.8
60-69	92	28.1
70-79	55	16.8
80+	17	5.2
Total	327	
<b>Caregiver relationship</b>		
Daughter	122	37.3
Son	67	20.5
Total offspring	189	57.8
Wife	94	28.7
Husband	44	13.5
Total spouse	138	42.2
Total	327	
<b>Caregiver living arrangements</b>		
Together	161	49.2
Separately	166	50.8
Total	327	
<b>Care recipient sex</b>		
Male	135	41.3
Female	192	58.7
Total	327	
<b>Care recipient age</b>		
65-74	117	35.9
75-84	147	45.1
80+	62	19.0
Total	326	
<b>Care recipient cognitive status</b>		
Cognitive impairment	104	31.8
No cognitive impairment	223	68.2
Total	327	

Caregivers were asked a series of questions about care recipient's ability to perform ADLs and IADLs. The specific scores for each variable in the ADL/IADL scale are provided in Table 2. This table illustrates the number of caregivers who responded to each individual variable and how many care subjects were classified into one of two categories: (1) needing no help with ADL/IADLs or some help with ADL/IADLs from a device only (score 0 and 1, N=123), or (2) need help with ADL/IADLs (score 2-20, N=203). Interestingly, the most frequent help required by someone was for doing yard work (186 care recipients), followed by doing housework (156 care recipients), handling long-term finances (125 care recipients), going shopping for groceries and clothes (121 care recipients), and going out of doors in any weather (102 care recipients). One reason outdoor activities require help is the climate. The winters in Manitoba are cold and windy, making outdoor activities difficult. Activities with which assistance was least likely to be required by someone was for eating (1 care recipient), getting about the house (4), getting in and out of bed (7 care recipients), and going to the bathroom (7 care recipients).

Table 2

ADL/IADL Variables Without Any Help/Some Help From Device and NeedHelp/Unable To Do Activity

ADL or IADL	N	
	Without any help or some help from device	Need help or unable to do activity
a. Can eat	326	1
b. Can dress and undress	308	18
c. Can take care of appearance	310	16
d. Can walk	309	18
e. Can get about the house	323	4
f. Can go up and down stairs	279	47
g. Can get in and out of bed	320	7
h. Can take a bath or shower	268	58
i. Can go to bathroom	320	7
j. Can use the telephone	288	38
k. Can get places out of walking distance	245	81
l. Can go out of doors in good weather	287	39
m. Can go out of doors in any weather	224	102
n. Can go shopping for groceries or clothes	205	121
o. Can prepare own meals	257	70
p. Can do housework	170	156
q. Can do light housework	286	40
r. Can do yard work or gardening	140	186
s. Can take own medicine	286	40
t. Can handle own money	258	69
u. Can handle long-term finances	201	125

Table 3 shows that 166 care recipients required help with fewer than three ADL/IADLs and 160 care recipients required help with three or more ADL/IADLs. There were 78 care recipients who did not require any help (see Table 3). The number of activities with which the care recipients required help from someone ranged from 0 to 20. Care recipients who scored seven or more on the ADL/IADL scale were collapsed into

the “six” ADL/IADL category, resulting in a range from 0 to 6 ADL/IADLs, as shown in Table 3. Figures 6 and 7 show the distribution change from the original ADL/IADL scale to the distribution after the ADL/IADL scale was collapsed. The collapsed ADL/IADL scale was used throughout the path analyses.

Table 3

Summated ADL/IADL Scale Compared to Collapsed ADL/IADL Scale

Number of ADL/IADLs	<u>ADL/IADL summed</u>			<u>ADL/IADL collapsed &amp; summed</u>		
	<u>N</u>	<u>Percent distribution</u>	<u>Valid percent</u>	<u>N</u>	<u>Percent distribution</u>	<u>Valid percent</u>
0	78	23.9	23.9	78	23.9	23.9
1	45	13.8	13.8	45	13.8	13.8
2	43	13.1	13.2	43	13.1	13.2
3	29	8.9	8.9	29	8.9	8.9
4	24	7.3	7.3	24	7.3	7.4
5	24	7.3	7.3	24	7.3	7.4
6	13	4.0	4.0	83	25.4	25.5
7	13	4.0	4.0	-	-	-
8	14	4.3	4.3	-	-	-
9	11	3.4	3.4	-	-	-
10	1	.3	.3	-	-	-
11	7	2.1	2.1	-	-	-
12	8	2.4	2.5	-	-	-
13	6	1.8	1.8	-	-	-
14	1	.3	.3	-	-	-
15	1	.3	.3	-	-	-
16	4	1.2	1.2	-	-	-
17	1	.3	.3	-	-	-
19	2	.6	.6	-	-	-
20	1	.3	.3	-	-	-
Total	326	99.7	100.0	326	99.7	100.0
Missing	1	.3		1	.3	
Total	327	100.0		327	100.0	

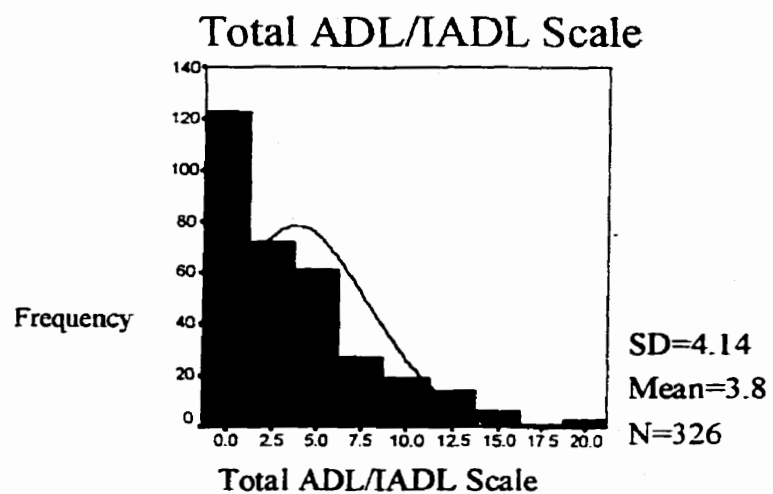


Figure 6: Frequency distributions, means, and standard deviations of ADL/IADLs before collapsing the variable.

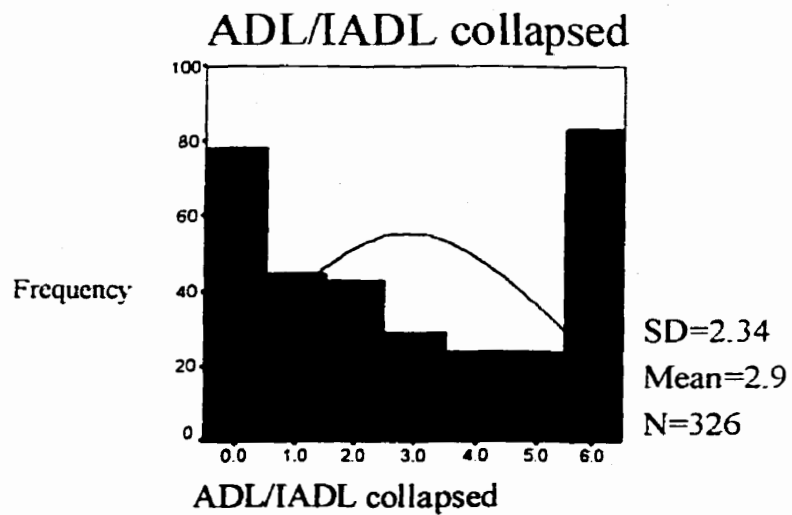


Figure 7: Frequency distributions, means, and standard deviations of ADL/IADLs after collapsing the variable.

Caregivers were asked a series of questions concerning the number of family members they had. Family social network included the total number of individuals living inside and outside the household with whom they had contact at least once a week. The mean number of people in the caregiver's family social network was 3.19 (SD = 2.11). There were 24 caregivers who had no one in their family social network (7.3%), 169 caregivers who had 1-3 people in their family social network, and 132 caregivers who had 4 or more people in their family social network (see Table 4).

Table 4

Frequency Distribution of the Size of the Caregiver Family Social Network

Size of network <sup>a</sup>	N	Percent distribution	Valid percent
0	24	7.3	7.4
1	50	15.3	15.4
2	46	14.1	14.2
3	73	22.3	22.5
4	68	20.8	20.9
5	29	8.9	8.9
6	17	5.2	5.2
7	4	1.2	1.2
8	6	1.8	1.8
9	3	.9	.9
10	3	.9	.9
11	1	.3	.3
14	1	.3	.3
<b>Total</b>	<b>325</b>	<b>99.4</b>	<b>100.0</b>
Missing	2	.6	
<b>Total</b>	<b>327</b>	<b>100.0</b>	

<sup>a</sup> Includes number with whom the caregiver had contact at least once per week.

Scores shown by caregivers on the Zarit burden scale ranged from 0 to 62. In order to achieve a normal distribution for this scale, scores one standard deviation above the mean were recoded to a score of 23, resulting in a burden range from 0 to 23 (see Table 5). Figures 8 and 9 show the distribution change from the original Zarit burden scale to the distribution after it was collapsed. Figure 9 shows a more evenly distributed scale; therefore, the collapsed Zarit burden scale was used for all data analyses. As can be seen in Figure 9 and on Table 5, these caregivers did not display high levels of burden (mean=9.37).



Table 5

Zarit Burden Scale Collapsed

Score	N	%	Valid percent
0	64	19.6	19.6
1	7	2.1	2.1
2	25	7.6	7.7
3	10	3.1	3.1
4	24	7.3	7.4
5	10	3.1	3.1
6	13	4.0	4.0
7	8	2.4	2.5
8	13	4.0	4.0
9	7	2.1	2.1
10	15	4.6	4.6
11	8	2.4	2.5
12	10	3.1	3.1
13	10	3.1	3.1
14	10	3.1	3.1
15	7	2.1	2.1
16	10	3.1	3.1
17	3	.9	.9
18	8	2.4	2.5
20	11	3.4	3.4
21	2	.6	.6
22	1	.3	.3
23-62	50	15.3	15.3
Total	326	99.7	100.0
Missing	1	.3	
Total	327	100.0	

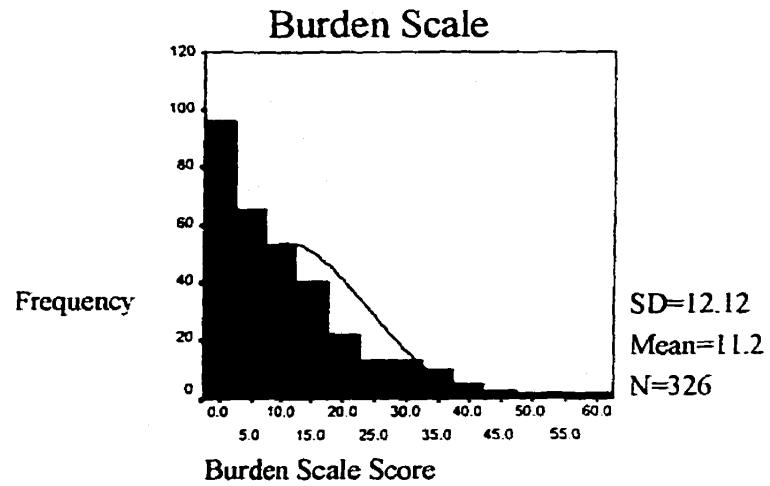


Figure 8: Frequency distributions, means, and standard deviations of Zarit burden scale before collapsing the variable.

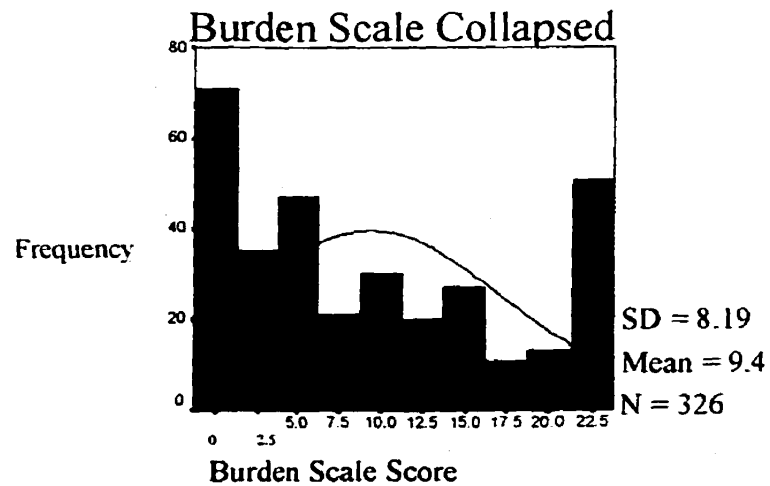


Figure 9: Frequency distributions, means, and standard deviations of Zarit burden scale after collapsing the variable.

The total number of caregivers for whom a score on the subjective burden scale was available was 326. The specific means and standard deviations for each item on the burden scale range from .08 to 1.69 (Table 6). Note that there are highest means are reported for items 7, 8, and 14, as follows: Afraid of what the future holds (1.06), feel recipient is dependent upon you (1.69) and recipient expects caregiver to care (1.18).

Table 6

Ns, Means, and Standard Deviations of the Zarit Burden Scale Items

Items	N	Mean	SD
1. Asks for more help than needed	327	.32	.72
2. Not enough time for yourself	327	.40	.88
3. Stressed by caring for subject and other responsibilities	327	.60	.99
4. Feel embarrassed over behavior	327	.29	.77
5. Feel angry around subject	327	.54	.86
6. Subject affects relationships	327	.29	.74
7. Afraid what the future holds for subject	327	1.06	1.23
8. Feel subject is dependent upon you	326	1.69	1.56
9. Feel strained	326	.49	.90
10. Feel your health has suffered	326	.24	.69
11. Feel you don't have privacy	326	.26	.74
12. Social life has suffered	326	.36	.92
13. Uncomfortable inviting friends over	326	.08	.48
14. Subject expects you to care	326	1.18	1.55
15. Haven't enough money to care	326	.11	.51
16. Unable to care much longer	326	.33	.82
17. Lost control of life	326	.20	.69
18. Wish you could leave care to someone else	326	.31	.79
19. Uncertain what to do about subject	326	.55	1.01
20. Feel you should be doing more	326	.79	1.10
21. Feel you could do a better job caring	326	.56	.98
22. How burdened do you feel	327	.49	.88
Total burden score	326	11.2	12.12
Total burden score collapsed	326	9.4	8.19

Note: Burden scale responses range from 0 (Never) to 4 (Nearly always).

Hypotheses Testing: Caregiver Burden by Gender, Relationship, Living Arrangements, ADL/IADLs, and Cognitive Status

H1 stated that female caregivers would show greater caregiver burden than male caregivers. Results did not reach statistical significance for Hypothesis 1; therefore, it was not supported (see Table 7).

H2 stated that offspring who care for dependent parents would show greater caregiver burden than spousal caregivers. Results showed that offspring caregivers tended to show more burden than spousal caregivers ( $p < .001$ ), supporting H2 (see Table 7).

H3 stated that caregivers and care recipients living together would show greater caregiver burden than caregivers and care recipients living separately. Results showed that caregivers and care recipients living separately tended to show more burden than caregivers and care recipients living together ( $p < .001$ ). This hypothesis was not supported (see Table 7).

For analysis of activities of daily living two categories were used: (1) three or more ADL/IADLs and (2) fewer than three ADL/IADLs. H4 stated that caregivers caring for care recipients who require help with three or more ADL/IADLs would show greater burden than caregivers caring for care recipients who require help with fewer than three ADL/IADLs. Results showed that caregivers caring for care recipients who required help with three or more ADL/IADLs tended to show more burden than caregivers caring for care recipients who require help with fewer than three ADL/IADLs ( $p < .001$ ), supporting H4 (see Table 7).

H5 stated that caregivers caring for care recipients who were cognitively impaired would show greater burden than caregivers caring for care recipients who were not cognitively impaired. Results showed that caregivers caring for care recipients who were cognitively impaired showed more burden than caregivers caring for care recipients who were not cognitively impaired ( $p < .001$ ). H5 was thus supported (see Table 7).

Table 7

Differences in Zarit Burden Scale by Gender, Relationship, Living Arrangements, Activities of Daily Living, and Cognitive Status

Variable	Mean burden score	N	t	P
Sex				
Male	8.40	110	-1.595	.112
Female	9.87	216		
Relationship				
Spouse	5.98	137	-6.974	<.001
Offspring	11.84	189		
Living Arrangements				
Together	6.92	160	-5.552	<.001
Separate	11.74	166		
ADL/IADLs				
Fewer than 3	5.52	166	-9.923	<.001
3 or more	13.43	159		
Cognitive Status				
No Cognitive Impairment	7.73	222	-5.306	<.001
Cognitive Impairment	12.88	104		

In summary, significantly more burden was reported by offspring, caregivers living separately from the care recipient, and caregivers caring for recipients needing help with three or more ADL/IADLs and care recipients who were cognitively impaired. Significantly less burden was reported by spouses, caregivers living together with the care recipient, and caregivers caring for recipients needing help with fewer than three ADL/IADLs and care recipients who were not cognitively impaired. However, it must be recalled that all caregivers experienced very low levels of burden, with a mean of 9.37 out of a possible 88, as measured on the Zarit burden scale.

#### Hypotheses Testing: Family Social Network and Burden

Analysis of variance was used to test Hypotheses 6 through 10. These analyses tested caregiver burden on family social network by sex, relationship, living arrangements, ADL/IADLs, and cognitive status. Specifically, analysis of variance was used to test for mean differences on burden between the family social network of males, females, offspring, spouses, living together, living separately, 0 ADL/IADLs, 1-2 ADL/IADLs, 3-5 ADL/IADLs, 6 or more ADL/IADLs, cognitive impairment, and no cognitive impairment. Family social network was divided into three categories: (1) 0 people in a caregiver's family social network; (2) 1-3 people in a caregiver's family social network and; (3) four or more people in a caregiver's family social network. Results for analysis of variance are listed in Appendix D.

H6 stated that there is no difference in caregiver burden of offspring or spouses with zero to four or more people in their family social network, and mean differences between males and females were in the predicted direction. However, results did not

reach statistical significance in the analysis of variance test for burden on family social network for males or females ( $F=2.673$ ,  $df=2$ , and  $p=.074$  for males;  $F=.450$ ,  $df=2$ , and  $p=.638$  for females). Therefore, in the case of both males and females, the number of people in a caregiver's family social network had no relationship to burden.

H7 stated that there is no difference in caregiver burden of caregivers living together or separately with zero to four or more people in their family social network. Results did not reach statistical significance in the analysis of variance test for burden on family social network for offspring or spouse ( $F=.207$ ,  $df=2$ , and  $p=.813$  for offspring;  $F=1.119$ ,  $df=2$ , and  $p=.330$  for spouses). Therefore, in the case of both offspring and spouses, the number of people in a caregiver's family social network had no relationship to burden.

H8 stated that there is no difference in caregiver burden of caregivers living together or separately with zero to four or more people in their family social network. Even though mean differences were observed, results did not reach statistical significance in the analysis of variance test for burden on family social network for living together or separately ( $F=.769$ ,  $df=2$ , and  $p=.465$  for living together;  $F=.382$ ,  $df=2$ , and  $p=.683$  for living separately). Therefore, in the case of caregivers living together or separately from the care recipient, the number of people in a caregiver's family social network had no relationship to burden.

H9 stated that there is no difference in caregiver burden of caregivers caring for care recipients who require no help, help with between 1 and 2, help with between 3 and 5, or help with more than 6 ADL/IADLs with zero to four or more people in their family social network. Results did not reach statistical significance in the analysis of variance

test for burden on family social network for 0 ADL/IADLs ( $F=.946$ ,  $df=2$ ,  $p=.393$ ), 1-2 ADL/IADLs ( $F=3.012$ ,  $df=2$ ,  $p=.055$ ), and 3-5 ADL/IADLs ( $F=.449$ ,  $df=2$ ,  $p=.640$ ). Statistical significance was observed for 6 or more ADL/IADLs ( $F=4.228$ ,  $df=2$ ,  $p=.018$ ). Overall, only two caregivers were reported as having no family social network. Therefore, in the case of ADL/IADLs, the number of people in a caregiver's family social network had no relationship to burden.

H10 stated that there is no difference in caregiver burden of caregivers caring for care recipients with or without cognitive impairment with zero to four or more people in their family social network. Results did not reach statistical significance in the analysis of variance test for burden on family social network for cognitive impairment or no cognitive impairment ( $F=.370$ ,  $df=2$ , and  $p=.692$  for cognitive impairment;  $F=.663$ ,  $df=2$ , and  $p=.516$  for no cognitive impairment). Therefore, in the case of cognitive status, the number of people in a caregiver's family social network had no relationship to burden.

In summary, in the case of gender, relationship, living arrangements, ADL/IADLs, and cognitive status, a caregiver's family social network has no relationship to burden. The null hypotheses H6 through H10 were thus supported.

Hypotheses Testing: Gender, Relationship, Living arrangements, Activities of Daily Living, and Cognitive Status on Caregiver Burden through Family Social Network

Hypothesis 11 stated that the effects of gender, relationship, living arrangements, activities of daily living, and the cognitive status on caregiver burden would be modified by family social network. This hypothesis was tested using path analysis.

A test for multicollinearity showed that relationship (tolerance = .255) and living arrangements (tolerance = .258) were highly correlated (Table 8). Therefore, for the



purpose of H11, living arrangements were excluded. There are several reasons for including relationship instead of living arrangements. First, since the focus of this study was the examination of offspring and spousal caregivers (relationship), this variable was important to keep in the analysis. Spousal caregivers are most likely to be living in the same household as the care recipient and offspring are most likely to be living in different households from the care recipient; therefore, the high correlation between relationship and living arrangements was anticipated. Second, the path model was based on the model developed by Stucky and Smith (1997), which examined relationship. The present study initially included living arrangement in the model because shared living arrangements had been reported as generating burden (Jutras & Veilleux, 1991).

Table 8

Collinearity of Gender, Relationship, Living Arrangements, Activities of Daily Living, Cognitive Status, and Family Social Network

Independent variable	Tolerance
Gender	.961
Relationship	.255
Living Arrangements	.258
ADL/IADLs	.795
Cognitive Status	.786
Family Social Network	.934

Note: Values for tolerance range from 0 to 1. When tolerance is small (close to 0), these variables are almost a linear combination of each other variable.

Table 9 shows a correlation matrix between family social network and the variables of gender, relationship, activities of daily living, and cognitive status. Table 10 shows a correlation matrix between burden and the variables family social network,

gender, relationship, activities of daily living, and cognitive status. These correlation coefficients are also equal to the direct path coefficients in the path model if each direct path was run independent of the other (Polit, 1996). For example, in Table 9 the direct path coefficient for family social network and gender would equal  $-.027$ , and in Table 10 the direct path coefficient for burden and gender would equal  $.089$ .

Table 9

Correlation Matrix of Family Social Network, Gender, Relationship, Activities of Daily Living, and Cognitive Status (N=324)

Variable	1	2	3	4	5
1. Family social network	--				
2. Gender	$-.027$	--			
3. Relationship	$.204$	$-.032$	--		
4. ADL/IADLs	$.027$	$.028$	$.203$	--	
5. Cognitive status	$.093$	$.168$	$.084$	$.408$	--

Table 10

Correlation Matrix of Burden, Family Social Network, Gender, Relationship, Activities of Daily Living, and Cognitive Status (N=323)

Variable	1	2	3	4	5	6
1. Burden	--					
2. Family social network	.042	--				
3. Gender	.089	-.034	--			
4. Relationship	.356	.199	-.037	--		
5. ADL/IADLs	.537	.033	.034	.209	--	
6. Cognitive status	.295	.091	.165	.082	.412	--

The relative magnitude of the direct effects of gender, relationship, activities of daily living, and cognitive status on burden compared to the indirect effects of gender, relationship, activities of daily living, and cognitive status on burden through family social network was determined. To test Hypothesis 11, equations (1) and (2) were estimated using multiple regression. The path coefficients are shown in Table 11.

Table 11

Path Coefficients for P1, P2, P4, P5, P6, P7, P8, P10, and P11

Path coefficient	<u>B</u>	<u>SE B</u>	<u>β</u>
<u>P1</u> Gender on family social network	-.164	.247	-.037
<u>P2</u> Relationship on family social network	.875	.238	.205**
<u>P4</u> ADL/IADLs on family social network	-5.090E-02	.055	-.057
<u>P5</u> Cognitive status on family social network	.476	.274	.105
<u>P6</u> Family social network on burden	-.119	.179	-.031
<u>P7</u> Gender on burden	1.218	.792	.070
<u>P8</u> Relationship on burden	4.390	.777	.264**
<u>P10</u> ADL/IADLs on burden	1.570	.176	.448**
<u>P11</u> Cognitive Status on burden	1.398	.880	.080

Note.  $R^2 = .051$  for P1, P2, P4, and P5;  $R^2 = .363$  for P6, P8, P9, P10, and P11  
 \*\* $p < .001$

Recall equation (1) and (2), minus living arrangements:

$$S = \underline{P1} * G + \underline{P2} * R + \underline{P4} * A + \underline{P5} * C + E1 \quad (1)$$

$$B = \underline{P6} * S + \underline{P7} * G + \underline{P8} * R + \underline{P10} * A + \underline{P11} * C + E2 \quad (2)$$

The effects of gender, relationship, activities of daily living, and the cognitive status were obtained by substitution of the values for P1, P2, P4, and P5; P6, P7, P8, P10, and P11 into equations (1) and (2) (excluding living arrangements) as follows:

$$S = -.037 * G + .205 * R + -.057 * A + .105 * C + .700 \quad (3)$$

$$B = -.031*S + .070*G + .264*R + .448*A + .080*C + .800 \quad (4)$$

The net effect of gender (G), relationship (R), activities of daily living (A), and cognitive status (C) on burden (B) is therefore:

$$B = (.001*G + -.006*R + .002*A + -.003*C) + (-.037*G + .205*R + -.057*A + .105*C) + E. \quad (5)$$

$$\text{Total effects} = (\underline{P1*P6+P7}) + (\underline{P2*P6+P8}) + (\underline{P4*P6+P10}) + (\underline{P5*P6+P11}) \quad (6)$$

$$\text{Total effects} = .071 + .258 + .450 + .077 \quad (7)$$

In equation 5, .001, -.006, .002, -.003 are the indirect effects of G (gender), R (relationship), A (activities of daily living), and C (cognitive status) on B (burden) through S (family social network); and -.037, .205, -.057, .105 are the direct effects of G (gender), R (relationship), A (activities of daily living), and C (cognitive status) on B (burden). Not all path coefficients, and thus the total effects (equations 6 and 7), were significant, but the direction of the effects were as predicted.

Table 12 and equations 6 and 7 show that the total effects of gender (P1\*P6+P7) and activities of daily living (P4\*P6+P10) on burden through family social network were greater in magnitude than their direct effects; and relationship (P2\*P6+P8) and cognitive status (P5\*P6+P11) were lesser in magnitude than their direct effects. Gender (P7), relationship (P8), activities of daily living (P10), and the cognitive status (P11) all had positive direct effects on burden, and positive total effects on burden.

Table 12

Direct and Indirect Causal Effects of P1, P2, P4, P5, P6, P7, P8, P10, and P11 on Family Social Network (FSN) and Zarit Burden Scale (N = 323)

Path Coefficient	Direct effect	Indirect effect	Total effect
<u>P1</u> Gender on FSN	-.037	--	-.037
<u>P2</u> Relationship on FSN	.205**	--	.205
<u>P4</u> ADL/IADLs on FSN	-.057	--	-.057
<u>P5</u> Cognitive status on FSN	.105	--	.105
<u>P6</u> Family Social Network on Burden	-.031	--	-.031
<u>P7</u> Gender on Burden	.070	.001 <sup>a</sup>	.071 <sup>c</sup>
<u>P8</u> Relationship on Burden	.264**	-.006 <sup>b</sup>	.258 <sup>f</sup>
<u>P10</u> ADL/IADLs on Burden	.448**	.002 <sup>c</sup>	.450 <sup>g</sup>
<u>P11</u> Cognitive Status on Burden	.080	-.003 <sup>d</sup>	.077 <sup>h</sup>

<sup>a</sup> P1\*P6. <sup>b</sup> P2\*P6. <sup>c</sup> P4\*P6. <sup>d</sup> P5\*P6. <sup>e</sup> P1\*P6+P7. <sup>f</sup> P2\*P6+P8. <sup>g</sup> P4\*P6+P10.

<sup>h</sup> P5\*P6+P11. \*\*p<.001

The following path diagrams and summaries present the results of the path model. Figure 10 summarizes the path coefficients. Only two direct paths (relationship and activities of daily living) and one indirect path (relationship) were significant. As Figure 10 shows, gender, activities of daily living, and the cognitive status have weak positive effects on family social network, and relationship has relatively stronger and significant positive effects on family social network. Figure 10 also shows that the effects of gender,

relationship, activities of daily living and cognitive status on burden are stronger than the effect of family social network on burden; however, only relationship and activities of daily living are significant. Gender and activities of daily living lead to higher levels of burden indirectly through family social network. Relationship and cognitive status lead to lower levels of burden indirectly through family social network. However, family social network has no significant effect on burden; therefore, hypothesis 11 was rejected. The relationship between relationship and caregiver burden does not exist through family social network.

Relationship and activities of daily living both have a positive direct effect on burden, where caregivers caring for care recipients who require more help with ADL/IADLs scored almost twice as high on the burden scale than offspring caregivers. Relationship was the only independent variable significantly directly related to family social network.

The residuals (E1 and E2) in Figure 10 indicate the effect of variables not included in the model. E1 (.700) represents all the residual causes of S and E2 (.800) represents all residual causes of B. Both E1 and E2 are other factors or the unexplained portion of the path model.

Figure 11 illustrates the trimmed path model, including only the significant path coefficients. This model shows the two direct paths and one indirect path that had an effect on burden. Relationship and activities of daily living are significantly and positively related to caregiver burden.

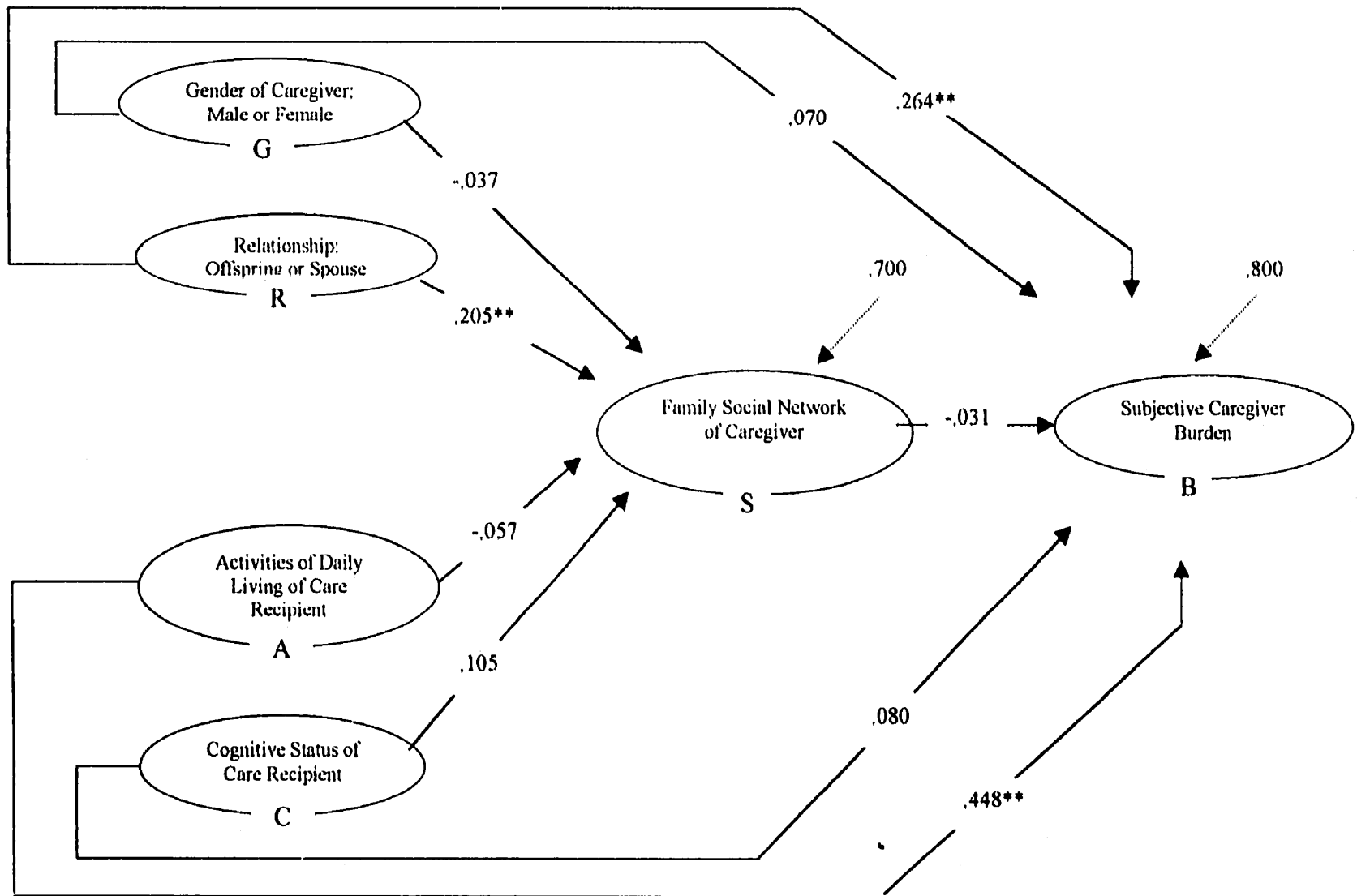


Figure 10: Path model showing effect of gender, relationship, activities of daily living, and cognitive status on caregiver burden through effects on family social network.  $** = p < .001$



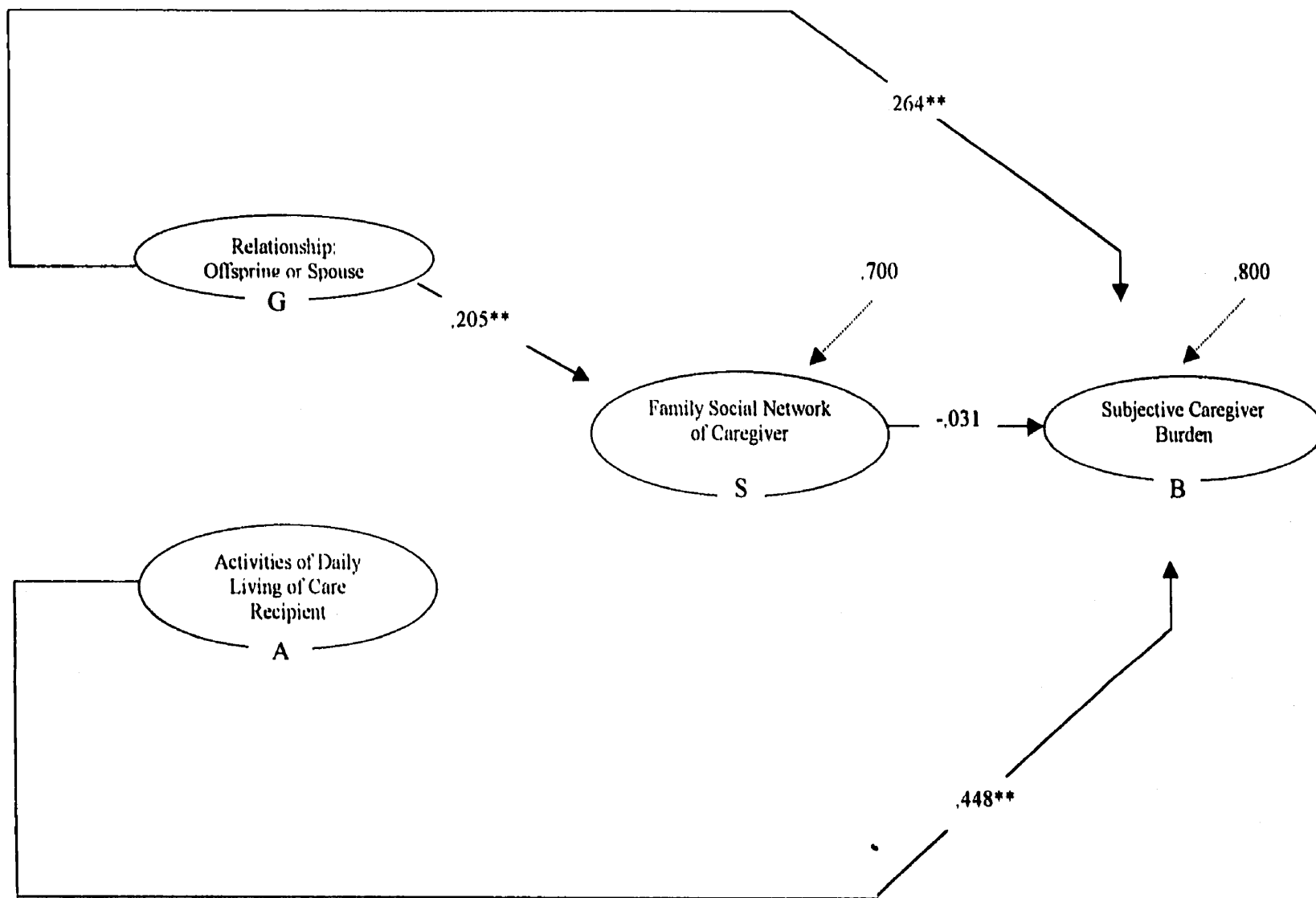


Figure 11: Trimmed path model showing the direct effects of relationship, activities of daily living, on burden, and the indirect effects of relationship on caregiver burden through effects on family social network. \*\* =  $p < .001$

In summary, of the 327 familial caregivers, few showed high levels of caregiver burden. Caregivers who were offspring, living separately from the care recipient, caring for a care recipient requiring help with three or more ADL/IADLs and cognitively impaired was associated with more caregiver burden than being a spouse, living together with the care recipient, caring for a care recipient requiring help with fewer than three ADL/IADLs and having a care recipient who was not cognitively impaired. Therefore, H2, H4, H5, and H5 were supported. Gender did not have any relationship to burden; therefore H1 was not supported. H3 stated that caregivers and care recipients living together would show greater caregiver burden than caregivers and care recipients living separately. Results showed that caregivers and care recipients living separately tended to show more burden than caregivers and care recipients living together; therefore, this hypothesis was not supported.

In the case of gender, relationship, living arrangements, ADL/IADLs, and cognitive status, an increase in the number of people in a caregiver's family social network had no relationship to burden. The null hypotheses H6 through H10 were thus supported.

Hypothesis 11 stated that the effect of gender, relationship, living arrangements, activities of daily living, and the cognitive status on caregiver burden would be modified by family social network. Family social network was not significantly related to burden; therefore, H11 was rejected.

## CHAPTER V

### Discussion and Conclusion

This chapter begins with a discussion of findings. Then limitations will be identified, followed by implications for future research.

#### The Dependent Variable

Low levels of subjective burden as measured by the Zarit burden scale were exhibited by a sample of caregivers in the current study. One reason for this may be the fact that the scale was developed to test burden levels in caregivers caring for care recipients who had been diagnosed with Alzheimer's Disease. Although Zarit et al. (1980) found that burden was not associated with severity of behavioral problems in their sample, all caregivers were caring for demented elderly individuals. In Zarit et al. (1980) scores for burden ranged from one to 66, with a mean of 31. Similarly, use of this scale by Freyne, Kidd, Coen, and Lawlor (1999) showed a high mean (45.6). In contrast, Bond, Harvey, and Hildebrand (1987) used the Zarit burden scale on a sample of elders living independently in southern Manitoba. The range on the Zarit burden scale for the Bond et al. (1987) sample was one to fifteen, with a mean of 7.09. Similarly, Novak and Guest (1989b) found low levels of burden with a mean score of 12.66 on the Zarit burden scale with a community sample.

In this study, the same two items on the Zarit burden scale with high scores were found by Zarit et al. (1980). Afraid what the future holds for subject and feel subject is dependent upon you showed the highest scores in this analysis and in Zarit et al. (1980), indicating that these two items may require further investigation.

### The Model

The conceptual framework by Stuckey and Smyth (1997) was adapted to suit the needs of the present study. Living arrangements and ADL/IADLs were added as independent variables in the model. The original model used social resources (social ties, tie satisfaction, aid, aid satisfaction, and affect/affirmation) to measure the intervening variable, whereas the present study used family social network as the intervening variable. As mentioned earlier, social support could specify the size of the network, the cohesiveness of the network, and the types of relationships in the network (Thoits, 1995). Also, if a caregiver knows who is available to offer support, this may act as a buffer against caregiver strain (Almberg et al., 1998). Stuckey and Smyth (1997) were able to examine details about caregivers' social networks and support that the present study was unable to examine. For this reason, future research should examine social network along with social support. One key finding in Zarit et al. (1980) was that the availability of social support for the caregivers was crucial in relieving stress.

In this analysis, the variable for activities of daily living did not identify the caregiver as the individual providing the help, although that information is available in the MSHA data set. The caregiver was asked if the care recipient can or cannot complete a task and not if he or she was the one providing the help. Therefore, this variable could only determine if the care recipient required help but could not identify who was providing the help. So, caregivers may or may not have been the individuals providing the help to the care recipient.

### Hypotheses

Hypothesis 1 postulated that female caregivers would show higher levels of burden than male caregivers. This hypothesis was rejected. However, Hypothesis 2 postulated that offspring caregivers would show higher levels of burden than spousal caregivers (Jutras & Veilleux, 1991; Noelker & Wallace, 1985), and it was accepted ( $p < .001$ ). In the case of this study, relationship was found to be a significant indicator of burden, while gender was not. The result for relationship supported the findings of Jutras and Veilleux (1991) that spousal caregivers reported less burden than other family caregivers. The reason may be that the care provided by spousal caregivers is a natural extension of the emotional bond and imposes fewer constraints on commitments and daily activities than a parent-child relationship. Noelker and Wallace (1985) also reported that married offspring experienced family problems resulting from their caregiving responsibilities. These competing demands and obligations that adult offspring face when caring for an aging parent compared to spousal caregivers affect their burden level.

Hypothesis 3 postulated that caregivers and care recipients living together would show higher levels of burden than caregivers and care recipients living separately (Stoller & Pugliesi, 1989). Results showed that living separately was significantly related to higher levels of burden than living together; therefore, this hypothesis was rejected. When determining burden for living arrangements, the relationship between the caregiver and care recipient should be considered. An interesting analysis would be to test the burden felt by offspring with different living arrangements. In the current study, the number of offspring who lived with the care recipient was too small to conduct this analysis.

Hypothesis 4 postulated that caregivers caring for care recipients who required help with three or more ADL/IADLs would show higher levels of burden than caregivers caring for care recipients who required help with fewer than three ADL/IADLs (Abel, 1986; Jutras & Veilleux, 1991; Stoller & Pugliesi, 1989). This hypothesis was accepted ( $p < .001$ ). These results are similar to that of Abel (1986), who reported that caring for elderly in poor health involves emotional and physical burden. Stoller and Pugliesi (1989) found that helpers who provided more help experienced greater burden, supporting the current findings.

Hypothesis 5 postulated that caregivers caring for care recipients who had cognitive impairment would show higher levels of burden than caregivers caring for care recipients who had no cognitive impairment (Almberg et al., 1998). This hypothesis was accepted ( $p < .001$ ). These findings coincide with Almberg et al. (1998) who found that caregivers caring for demented elderly demand and need much more support practically and emotionally.

Hypotheses 6, 7, 8, 9, and 10 were rejected because the size of a caregiver's family social network when tested along with gender, relationship, living arrangements, ADL/IADLs, was not related to burden. A reason that these hypotheses were rejected may be because the measure of the family social network used here, which will be discussed in the limitations of this study.

Hypothesis 11 was rejected because the size of a caregiver's family social network did not modify the effects of gender, relationship, ADL/IADLs or cognitive status and was also not related to burden. Only three direct paths were significant. First, relationship was directly related to burden. An offspring caregiver showed higher levels

of burden than a spousal caregiver. Second, the relationship between the caregiver and care recipient was also directly related to family social network. Offspring caregivers had significantly more people in their family social network that they saw once a week or more than spousal caregivers. Offspring were younger than spouses, more likely to be in the labor force and had more people living with them, all factors that could have influenced this finding. Third, activities of daily living were directly related to caregiver burden. The more help the care recipient required, the higher level of caregiver burden. Jutras and Veilleux (1991) found that those care recipients with low levels of functional independence and poor health contribute to caregiver burden, coinciding with the current finding.

#### Limitations

The limitations for this study should be recognized. Several are related to the conceptual framework that guided the study. Also, several methodological limitations existed.

First, family social network did not show any relationship to caregiver burden and was not related to the independent variables. Several reasons may account for these results. Family social network outside the household was defined as parents, spouses, siblings, and children. Several other people exist in social networks of caregivers, such as other relatives, friends and neighbors. The original data set included questions about other relatives, friends, and neighbors, but they were asked in a manner that could not be combined or used in this analysis. The variables for children and siblings asked for specific numbers of family members and how often the caregiver had contact with the people in their family social network. The variables for other relatives, friends, and

neighbors only asked how often they had contact with these individuals and did not specify the number of these individuals in the caregiver's family social network.

Also, in this study family social network was defined as the number of individuals in a caregiver's network with whom they contact once a week or more. The individuals in a caregiver's family social network can only be assumed as potential help or support to the caregiver. Components of family social network, such as density, were not measured. Family social network identified which individuals were available to offer support (House et al., 1988) and how often the caregivers had contact with these individuals, but it did not show if these individuals did, in fact, offer support. Not all relationships in an individual's network provide support or the same type of support (Thompson et al., 1993). In fact, Thompson et al. (1993) reported that the different ways in which types of social support were linked to the measures of burden strongly suggested that the types of support were significantly related to burden. For this reason, social support should be examined along with social network. Social support could specify the size of the network, the cohesiveness of the network, and the types of relationships in the network (Thoits, 1995). Knowing the availability of supports might be a way of sharing the caregiving role and serve as a buffer against caregiver strain (Almberg et al., 1998).

Second, this study did not take into account other types of care. Although only ten to 15% of assistance came from formal care (community-based health care, social services, and paid help), it still should be considered (Brody, 1985; Connidis, 1983; Denton, 1997). Knowing there may be other available supports might be a way of sharing the caregivers' responsibilities (Almberg et al, 1998).



Third, the conceptual framework developed by Stuckey and Smyth (1997) was tested originally on a sample of caregivers caring for older adults living in the community diagnosed with Alzheimer's Disease. This present study examined community living older adults, and was not restricted to those with Alzheimer's Disease. As mentioned earlier, Almberg et al. (1998) suggested that demented elderly individuals, demands and needs are high and that caregivers for demented elderly found it difficult to have a positive outlook on their caregiving responsibilities.

Fourth, the present study findings were based on a one-time measurement of caregiver burden. Jutras and Veilleux (1991) reported that caregivers willing to help a relative could experience an increase in the level of burden as the care recipient ages and becomes more functionally dependent and his or her health deteriorates. It would be interesting to observe changes in the burden levels in this sample to determine if this is similar to Jutras and Veilleux (1991) existed.

Finally, the sample included 78 care recipients who required no help with ADL/IADLs. Since caregivers can extend emotional or financial help to care recipients, people who needed no ADL/IADL help were still included in the study (Stuckey et al., 1996). Other studies define caregivers differently.

#### Implications and Future Work

This study has important implications for future research, as it adds to the existing research surrounding the topic of caregiving. It has been shown here that offspring perceive subjective burden of caregiving differently than spouses. The relationship between a caregiver as offspring or spouse and a care recipient differs in obligations, priorities, and responsibilities, and this relationship should not be examined

simultaneously. It is suggested that the word "caregiver" is used too broadly in research, because caregivers have been shown to operate differently depending on the relationship. It is recommended that future research always separate spouses from offspring, rather than putting them together in a "caregiver" group. Not only are there implications of this study for research, but also service providers should plan services to caregivers differently. Practitioners who are developing intervention programs for caregivers should keep in mind that the caregiving issues for offspring and spouses are different and should be developed to suit the needs of the caregiver. For example, offspring caregivers tend to concentrate on all their responsibilities and have difficulty juggling their time between caring for a parent and completing their other obligations. Spousal caregivers tend to concentrate on their relationship with the spouse and see their task as an extension of their marital commitments. These differences should be reflected in services, such as educational programs for caregivers or direct interventions.

Empowering and educating adults about their choices before they are elderly and frail could encourage them to use this knowledge to make their own decisions about their health and living arrangements. Adults educated in the issues surrounding caregiver burden may choose to use the formal system more frequently, which, in turn, may decrease the burden on the informal caregiver. It is also possible that some respondents had a great deal (or lack) of knowledge about available services, which may have affected the results. If respondents were aware of community services or agencies that offer help and assistance, perceived burden may be affected. Future research should investigate the service knowledge base of both caregivers and care recipients.

Future research should examine caregivers over an extended period of time to see if the level of burden increases as the care recipient ages and becomes more functionally dependent as his or her health deteriorates, as Jutras and Veilleux (1991) found. Longitudinal research on the topic of caregiver burden could find changes in care recipients and caregivers over an extended period of time.

The family social network variable should be expanded in a future study to include both size and density of familial and other social support. In doing this, future research would have more accurate details of the social resources in a caregiver's life, in turn, creating less room for methodological error.

### Conclusions

Results from this study confirm that gender, relationship, living arrangements, activities of daily living, and cognitive status have significant effects on perceived caregiver burden. Even though subjective caregiver burden scores were relatively low, burden is associated with caregiving and this research showed some correlates of burden.

The findings of the present study should not be generalized to all caregivers. Alternatively, the task of future research is to replicate these findings, but with different samples within the caregiving population. The data analyzed indicated that family social network has no relationship to caregiver burden; however, adapting the family social network variable to meet the criteria of the original model developed by Stuckey and Smyth (1997) would allow for fewer methodological limitations and a more accurate replica of the model.

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## Appendix A

## Activities of Daily Living (ADL) for Subjects

\*. Now, I want to ask you about how (\_\_\_\_) manages (her/his) daily life. I will mention a number of common, daily activities, and for each, I want you to say if (\_\_\_\_) can manage this without help, or with some help, or whether he/she cannot do it at all, that is, someone has to do this for them.

\*\*\*\*\*  
 REMEMBER WE ARE INTERESTED IN WHETHER OR NOT THEY ARE ABLE TO  
 PERFORM THE ACTIVITY; AND NOT WHETHER OR NOT THEY ACTUALLY DO IT.  
 \*\*\*\*\*

## ADL's for SUBJECTS

a. Can (\_\_\_\_) eat ...

1	2	3	4	5	8
without any help	some help from device ONLY	some help from person ONLY	some help from person & device	unable to do it	DK

b. Can (\_\_\_\_) dress and undress

1	2	3	4	5	8
without any help (pick out clothes dress, undress)	some help from device ONLY (Zipper pulls)	some help from person ONLY	some help from person & device	unable to do it	DK

## ADL's for Subject (cont'd)

- c. Can ( ) take care of his/her own appearance, for example, combing his/her hair and (for men) shaving

1	2	3	4	5	8
without any help	some help from device ONLY (extenders, long shoe horn)	some help from person ONLY	some help from person & device	unable to do it	DK

- d. Can ( ) walk (not including with a wheelchair)

1	2	3	4	5	8
without any help (except a cane)	some help from device ONLY (walker, crutches or a chair)	some help from person ONLY	some help from person & device	unable to do it	DK

## (IF ANSWER WITHOUT ANY HELP OR WITH SOME HELP)

- dd. Does ( ) walk out of doors (Assisted or Unassisted)

1. 1 mile or more
2. ¼ mile
3. 100 yards
4. 10 yards
0. Does not walk out of doors at all
7. SKIP

- e. Can ( ) get about the house

1	2	3	4	5	8
without any help	some help from device ONLY (walker, crutches or a chair)	some help from person ONLY	some help from person & device	unable to do it	DK

## ADL of Subject (cont'd)

f. Can ( ) go up and down stairs

1	2	3	4	5	8
without any help	some help from device ONLY (handrails, walker, chairlift)	some help from person ONLY	some help from person & device	unable to do it	DK

g. Can ( ) get in and out of bed

1	2	3	4	5	8
without any help	some help from device ONLY (any type lift)	some help from person ONLY	some help from person & device	unable to do it	DK

h. Can ( ) take a bath or shower

1	2	3	4	5	8
without any help	some help from device ONLY (shower seat hand held shower)	some help from person ONLY	some help from person & device	unable to do it	DK

i. Can ( ) go to the bathroom, or toilet (commode or outhouse)

1	2	3	4	5	8
without any help	some help from device ONLY (raised toilet seat, walker)	some help from person ONLY	some help from person & device	unable to do it	DK

## ADL of Subject (cont'd)

j. Can ( ) use the telephone

1	2	3	4	5	8
without any help (look up and dial)	some help from device ONLY (hearing device, special phone, CAN dial operator in emergency)	some help from person ONLY (help getting number, dialing can dial operator in an emergency)	some help from person & device	unable to do it	DK

k. Can ( ) get to places out of walking distance

1	2	3	4	5	8
without any help (can travel alone on bus, taxi; drive car)	some help from device ONLY (motorized scooter)	some help from person ONLY (need someone to go with him/her)	some help from person & device	unable to do it	DK

l. Can ( ) go out of doors in good weather

1	2	3	4	5	8
without any help	some help from device ONLY	some help from person ONLY	some help from person & device	unable to do it	DK

m. Can ( ) go out of doors in any weather

1	2	3	4	5	8
without any help	some help from device ONLY	some help from person ONLY	some help from person & device	unable to do it	DK

## ADL of Subject (cont'd)

- n. Can (\_\_\_\_) go shopping for his/her groceries or clothes  
(assuming they have transportation)
- |  |                                  |  |                                      |                    |    |
|--|----------------------------------|--|--------------------------------------|--------------------|----|
| 1  | 2                                | 3  | 4                                    | 5                  | 8  |
| without<br>any help<br>(take care<br>of all shopping | some help<br>from device<br>ONLY | some help<br>from person<br>ONLY<br>(needs someone<br>to go with him/her on all trips) | some help<br>from person<br>& device | unable to<br>do it | DK |
- o. Can (\_\_\_\_) prepare his/her own meals
- |  |                                  |  |                                      |                    |    |
|--|----------------------------------|--|--------------------------------------|--------------------|----|
| 1  | 2                                | 3  | 4                                    | 5                  | 8  |
| without<br>any help<br>(plan and<br>cook full meals) | some help<br>from device<br>ONLY | some help<br>from person<br>ONLY<br>(not full meals) | some help<br>from person<br>& device | unable to<br>do it | DK |
- p. Can (\_\_\_\_) do his/her housework  
(eg, scrub floors, vacuum, windows, and walls)
- |  |                                  |  |                                      |                    |    |
|--|----------------------------------|--|--------------------------------------|--------------------|----|
| 1  | 2                                | 3  | 4                                    | 5                  | 8  |
| without<br>any help<br>(scrub<br>floors, etc.) | some help<br>from device<br>ONLY | some help<br>from person<br>ONLY<br>(can do light<br>but not heavy work) | some help<br>from person<br>& device | unable to<br>do it | DK |
- q. Can (\_\_\_\_) do light housework  
(dusting, dishes, etc.)
- |                     |                                  |                                  |                                      |                    |    |
|---------------------|----------------------------------|----------------------------------|--------------------------------------|--------------------|----|
| 1                   | 2                                | 3                                | 4                                    | 5                  | 8  |
| without<br>any help | some help<br>from device<br>ONLY | some help<br>from person<br>ONLY | some help<br>from person<br>& device | unable to<br>do it | DK |
- r. Can (\_\_\_\_) do his/her yard work and/or gardening
- |                     |                                  |                                  |                                      |                    |    |
|---------------------|----------------------------------|----------------------------------|--------------------------------------|--------------------|----|
| 1                   | 2                                | 3                                | 4                                    | 5                  | 8  |
| without<br>any help | some help<br>from device<br>ONLY | some help<br>from person<br>ONLY | some help<br>from person<br>& device | unable to<br>do it | DK |

## ADL of Subject (cont'd)

s. Can ( ) take his/her own medicine

1	2	3	4	5	8
without any help (in the right doses at the right time)	some help from device ONLY (pill counter)	some help from person ONLY (someone prepares it and reminds him/her to take it	some help from person & device	unable to do it	DK

t. Can ( ) handle his/her own money  
(THIS QUESTION REFERS TO DAY-TO-DAY SPENDING)

1	2	3	4	5	8
without any help (write checks, pay bills, etc.)	some help from device ONLY	some help from person ONLY (can manage day-to-day buying but need help with check book and paying bills)	some help from person & device	unable to do it	DK

u. Can ( ) handle planning his/her long-term finances  
(ie. Investments, banking)

1	2	3	4	5	8
without any help	some help from device ONLY	some help from person ONLY	some help from person & device	unable to do it	DK

Appendix B

SOCIAL NETWORK OF INFORMAL CAREGIVERS

We are also interested in finding out about YOUR family and friends.

16a. (SKIP IF CAREGIVER LIVES WITH ( ) > GO TO Q. 16b)

I would like to ask about your household. Aside from yourself, do any other people live with you?

Yes: How Many? \_\_\_\_\_ 00 No

How are they related to you?

Names

(Relationship)

_____	( )
_____	( )
_____	( )
_____	( )

16b. (IF CAREGIVER IS SPOUSE > GO TO Q. 20)

Do you have any other children, who do not live with you?

Yes: How Many? \_\_\_\_\_ Sons

\_\_\_\_\_ Daughters

00 No

17. Of your sons, how many do you have contact with.....

(CONTACT INCLUDES: SEEING, PHONING, LETTER WRITING. EXCLUDING THOSE LIVING IN HOUSEHOLD)

- |                         |  |
|-------------------------|--|
| ___ Everyday            | ___ Less often than once a month<br>but at least once a year |
| ___ Once a week or more | ___ Less than once a year                                    |
| ___ A few times a month | ___ Never  |
| ___ Once a month        |  |



**SOCIAL NETWORK OF INFORMAL CAREGIVERS (cont'd)**

**18 Of your daughters, how many do you have contact with.....**  
 (CONTACT INCLUDES: SEEING, PHONING, LETTER WRITING. EXCLUDING THOSE LIVING IN HOUSEHOLD)

- |  |   |
|--|---|
| <input type="checkbox"/> Everyday            | <input type="checkbox"/> Less often than once a month<br>but at least once a year |
| <input type="checkbox"/> Once a week or more | <input type="checkbox"/> Less than once a year                                    |
| <input type="checkbox"/> A few times a month | <input type="checkbox"/> Never  |
| <input type="checkbox"/> Once a month        |   |

**19. Do you have any other close relatives who live within a 1 hour drive?**  
 (Do not mention those already listed above. Close Relatives = siblings, nephews, nieces, adult grand children)

Yes: How Many? \_\_\_\_\_ 000 No

**20a. Are either of your parents still living?**

- 1 = Neither ----- GO TO Q. 21
- 2 = Mother ----- GO TO Q. 20c.
- 3 = Father ----- GO TO Q. 20b.
- 4 = Both

**20b. (ASK FOR EACH LIVING PARENT NOT LIVING IN HOUSEHOLD)**

How often do you have contact with ....  
 (CONTACT INCLUDES: SEEING, PHONING, LETTER WRITING)

.... your father

- |                       |  |
|-----------------------|--|
| 1 Everyday            | 5 Less often than once a month<br>but at least once a year |
| 2 Once a week or more | 6 Less than once a year                                    |
| 3 A few times a month | 7 Never  |
| 4 Once a month        | 0 Father deceased  |

**20c. .... your mother**

- |                       |  |
|-----------------------|--|
| 1 Everyday            | 5 Less often than once a month<br>but at least once a year |
| 2 Once a week or more | 6 Less than once a year                                    |
| 3 A few times a month | 7 Never  |
| 4 Once a month        | 0 Mother deceased  |

**SOCIAL NETWORK OF INFORMAL CAREGIVERS (cont'd)**

21a. How many bothers do you have not including those living with you?  
(LIVING ONLY)

\_\_\_\_\_

21b. Of your bothers, how many do you have contact with ....  
(CONTACT INCLUDES: SEEING, PHONING, LETTER WRITING. EXCLUDING THOSE LIVING IN HOUSEHOLD)

- |  |   |
|--|---|
| <input type="checkbox"/> Everyday            | <input type="checkbox"/> Less often than once a month<br>but at least once a year |
| <input type="checkbox"/> Once a week or more | <input type="checkbox"/> Less than once a year                                    |
| <input type="checkbox"/> A few times a month | <input type="checkbox"/> Never  |
| <input type="checkbox"/> Once a month        |   |

22a. How many sisters do you have not including those living with you?  
(LIVING ONLY)

\_\_\_\_\_

22b. Of your sisters, how many do you have contact with ....  
(CONTACT INCLUDES: SEEING, PHONING, LETTER WRITING. EXCLUDE THOSE LIVING IN HOUSEHOLD)

- |  |   |
|--|---|
| <input type="checkbox"/> Everyday            | <input type="checkbox"/> Less often than once a month<br>but at least once a year |
| <input type="checkbox"/> Once a week or more | <input type="checkbox"/> Less than once a year                                    |
| <input type="checkbox"/> A few times a month | <input type="checkbox"/> Never  |
| <input type="checkbox"/> Once a month        |   |

23a. How many relatives do you have not including those living with you?  
(LIVING ONLY)

\_\_\_\_\_

23b. Thinking of your other relatives, how OFTEN do you have contact with them?  
(CONTACT INCLUDES: SEEING, PHONING, LETTER WRITING. EXCLUDING THOSE LIVING IN HOUSEHOLD)

- |                       |  |
|-----------------------|--|
| 1 Everyday            | 5 Less often than once a month<br>but at least once a year |
| 2 Once a week or more | 6 Less than once a year                                    |
| 3 A few times a month | 7 Never  |
| Once a month          | 0 No other relatives                                       |

Appendix C

Zarit Burden Scale, Interview Items

Here is a list of ways that people sometimes feel when caring for another person.

After I read each question, please indicate how often you have felt that way: Never, Rarely, Sometimes, Frequently, or Nearly Always. Remember, there are no right or wrong answers.

- |                   |  |
|-------------------|--|
| 0 = NEVER         | 6 = NA - NOT ALLOWED TO DO THIS/<br>NOT APPLICABLE |
| 1 = RARELY        | 7 = SKIP (FORMAL CAREGIVER)                        |
| 2 = SOMETIMES     | 8 = DK - DON'T KNOW                                |
| 3 = FREQUENTLY    | 9 = MISSING  |
| 4 = NEARLY ALWAYS |  |

HOW OFTEN...	NEV	RARE	SOME	FREQ	ALWAYS	DK	NA
1. Do you feel that ( ) asks for more help than he/she needs?	0	1	2	3	4	8	6
2. Do you feel that because of the time you spend with ( ) that you don't have enough time for yourself?	0	1	2	3	4	8	6
3. Do you feel stressed between caring for ( ) and trying to meet other responsibilities for your family or work?	0	1	2	3	4	8	6
4. Do you feel embarrassed over ( )'s behaviour?	0	1	2	3	4	8	6
5. Do you feel angry when you are around ( )?	0	1	2	3	4	8	6
6. Do you feel that ( ) currently affects your relationship with other family members friends in a negative way?	0	1	2	3	4	8	6
7. Are you afraid of what the future holds for ( )?	0	1	2	3	4	8	6
8. Do you feel ( ) is dependent upon you?	0	1	2	3	4	8	6
9. Do you feel strained when you are around ( )?	0	1	2	3	4	8	6

## Zarit (cont'd)

- |  |   |   |   |   |   |   |   |
|--|---|---|---|---|---|---|---|
| 10. Do you feel your health has suffered because of your involvement with ( )?   | 0 | 1 | 2 | 3 | 4 | 8 | 6 |
| 11. Do you feel that you don't have as much privacy as you would like because of ( )?                                      | 0 | 1 | 2 | 3 | 4 | 8 | 6 |
| 12. Do you feel that your social life has suffered because you are caring for ( )?   | 0 | 1 | 2 | 3 | 4 | 8 | 6 |
| 13. (Only where respondent lives with Subject)<br>Do you feel uncomfortable about having friends over, because of ( )?     | 0 | 1 | 2 | 3 | 4 | 8 | 6 |
| 14. Do you feel that ( ) seems to expect you to take care of him/her as if you were the only one he/she could depend upon? | 0 | 1 | 2 | 3 | 4 | 8 | 6 |
| 15. Do you feel that you don't have enough money to care for ( ) in addition to the rest of your expenses?                 | 0 | 1 | 2 | 3 | 4 | 8 | 6 |
| 16. Do you feel that you will be unable to take care of ( ) much longer?   | 0 | 1 | 2 | 3 | 4 | 8 | 6 |
| 17. Do you feel you have lost control of your life since ( )'s condition?  | 0 | 1 | 2 | 3 | 4 | 8 | 6 |
| 18. Do you wish you could just leave the care of ( ) to someone else?  | 0 | 1 | 2 | 3 | 4 | 8 | 6 |
| 19. Do you feel uncertain about what to do about ( )?  | 0 | 1 | 2 | 3 | 4 | 8 | 6 |
| 20. Do you feel you should be doing more for ( )?  | 0 | 1 | 2 | 3 | 4 | 8 | 6 |
| 21. Do you feel you could do a better job in caring for ( )?   | 0 | 1 | 2 | 3 | 4 | 8 | 6 |

22. Overall, how burdened do you feel in caring for ( )?

- |   |             |
|---|-------------|
| 0 | Not at all  |
| 1 | A little    |
| 2 | Moderately  |
| 3 | Quite a bit |
| 4 | Extremely   |

## Appendix D

## Analysis of Variance for Burden

The family social network (FSN) of males, females, offspring, spouses, living together, living separately, 0 ADL/IADLs, 1-2 ADL/IADLs, 3-5 ADL/IADLs, 6 or more ADL/IADLs, cognitive impairment, and no cognitive impairment were each tested independent of each other on burden. Family social network was divided into three categories: (1) 0 people in caregivers family social network; (2) 1-3 people in caregivers family social network and; (3) four or more people in caregivers family social network. The follow analysis of variance correspond to hypotheses 6 to 10, respectively.

Analysis of Variance for Burden on Family Social Network for Males (n=8 for no FSN, n=54 for 1-3 FSN, and n=46 for 4 or more FSN)

Source	SS	df	MS	F	p
Between groups	297.267	2	148.634	2.673	.074
Within groups	5839.057	105	55.610		
Total	6136.324	107			

Analysis of Variance for Burden on Family Social Network for Females (n=15 for no FSN, n=115 for 1-3 FSN, and n=86 for 4 or more FSN)

Source	SS	df	MS	F	p
Between groups	64.997	2	32.498	.450	.638
Within groups	15391.374	213	72.260		
Total	15456.370	215			

Analysis of Variance for Burden on Family Social Network for Offspring (n=7 for no FSN, n=92 for 1-3 FSN, and n=88 for 4 or more FSN)

Source	SS	df	MS	F	p
Between groups	27.944	2	13.972	.207	.813
Within groups	12415.243	184	67.474		
Total	12443.187	186			

Analysis of Variance for Burden on Family Social Network for Spouses (n=16 for no FSN, n=77 for 1-3 FSN, and n=44 for 4 or more FSN)

Source	SS	df	MS	F	p
Between groups	108.429	2	54.214	1.119	.330
Within groups	6492.506	134	48.452		
Total	6600.934	136			

Analysis of Variance for Burden on Family Social Network for Living Together (n=19 for no FSN, n=93 for 1-3 FSN, and n=48 for 4 or more FSN)

Source	SS	df	MS	F	p
Between groups	91.829	2	45.914	.465	.465
Within groups	9378.115	157	59.733		
Total	9469.944	159			

Analysis of Variance for Burden on Family Social Network for Living Separately (n=4 for no FSN, n=76 for 1-3 FSN, and n=84 for 4 or more FSN)

Source	SS	df	MS	F	p
Between groups	49.154	2	24.577	.382	.683
Within groups	10356.00	161	64.324		
Total	10405.244	163			

Analysis of Variance for Burden on Family Social Network for 0 ADL/IADLs (n=7 for no FSN, n=31 for 1-3 FSN, and n=40 for 4 or more FSN)

Source	SS	df	MS	F	p
Between groups	56.964	2	28.482	.946	.393
Within groups	2256.997	75	30.093		
Total	2313.962	77			

Analysis of Variance for Burden on Family Social Network for 1 to 2 ADL/IADLs (n=8 for no FSN, n=48 for 1-3 FSN, and n=30 for 4 or more FSN)

Source	SS	df	MS	F	p
Between groups	282.556	2	141.278	3.012	.055
Within groups	3892.979	83	46.903		
Total	4175.535	85			

Analysis of Variance for Burden on Family Social Network for 3 to 5 ADL/IADLs (n=6 for no FSN, n=40 for 1-3 FSN, and n=31 for 4 or more FSN)

Source	SS	df	MS	F	p
Between groups	56.959	2	28.480	.449	.640
Within groups	4689.846	74	63.376		
Total	4746.805	76			

Analysis of Variance for Burden on Family Social Network for 6 or more ADL/IADLs (n=2 for no FSN, n=50 for 1-3 FSN, and n=31 for 4 or more FSN)

Source	SS	df	MS	F	p
Between groups	430.577	2	215.289	.018	.018
Within groups	4073.977	80	50.925		
Total	4504.554	82			

Analysis of Variance for Burden on Family Social Network for Cognitive Impairment

(n=3 for no FSN, n=57 for 1-3 FSN, and n=44 for 4 or more FSN)

Source	<u>SS</u>	<u>Df</u>	<u>MS</u>	<u>F</u>	<u>p</u>
Between groups	53.574	2	26.787	.370	.692
Within groups	7313.041	101	72.406		
Total	7366.615	103			

Analysis of Variance for Burden on Family Social Network for No Cognitive Impairment

(n=20 for no FSN, n=112 for 1-3 FSN, and n=88 for 4 or more FSN)

Source	<u>SS</u>	<u>df</u>	<u>MS</u>	<u>F</u>	<u>p</u>
Between groups	75.840	2	37.920	.663	.516
Within groups	12416.755	217	57.220		
Total	12492.595	219			