# STRAIN AMONG ELDERLY PRIMARY CAREGIVERS

BY

LORNA W. GUSE

A Thesis
Submitted to the Faculty of Graduate Studies
in Partial Fulfillment of the Requirements
for the Degree of

DOCTOR OF PHILOSOPHY

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Throughout the process of doctoral study, I have been fortunate in receiving the support of my family and friends. This dissertation would not have been possible without these special people. My special thanks to my husband Eugene Brokopiw who remained steadfast and supportive throughout my program of study.

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# ABSTRACT

While empirical research on the difficulties or burden of elder caregiving has increased substantially during the past ten years, relatively less effort has been directed toward developing theoretical perspectives on family care of elderly members. This thesis attempts to address theory development by empirically testing a model of caregiving. This model, based on stress theory and social support theory, and consistent with empirical findings from caregiving research is tested with a group of elderly primary caregivers.

Data come from a large survey carried out in 1985 with 1284 community dwelling elderly persons age 60 and older. Secondary analyses are carried out with those elderly respondents who indicated that they were primary caregivers. Multivariate methods are used to examine relationships among caregiver characteristics, role strain, social support and health status. Hypotheses address the direct effects and buffering models of social support. Additional hypotheses address the relationship between caregiver role strain or the appraisal of caregiving as difficult and factors that have been associated with caregiver burden.

Results indicate limited support for the caregiving model. Consistent with the literature, findings point to a direct relationship between caregiver role strain and symptoms of depression. Other findings indicate that women and adult child caregivers are more likely to report caregiver role strain. For adult children, this finding appears partly due to the kind of tasks performed, that is, tasks that are physically and time demanding.

Although the caregiving model adds little to an overall understanding of caregiving, this research suggests future study of elderly adult child caregivers and depression among elderly primary caregivers. Current research has emphasized the middle-aged adult child caregiver. Given the demographic projection that the most rapid growth will occur within the old-old population segment (age 85 and older), elderly children as primary caregivers to their very old parents will likely have an increasing role in the future.

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# CHAPTER 1

# INTRODUCTION

Empirical research on family caregiving of elderly members has increased substantially during the past ten years. An extensive literature on the difficulties experienced by family caregivers exists (Montgomery, 1989). Major emphasis has been on the study of burden, that is, on the negative impact of caregiving on the caregiver's health and well-being. Much attention has been given to exploring the correlates of caregiver burden including characteristics of the caregiver, the care receiver and the caregiving setting. In contrast, a theoretical perspective on family caregiving has not been systematically developed (Zarit, 1989). This thesis attempts to address the gap in theoretical development by empirically testing a model of caregiving based on a stress model developed by Pearlin et al. (1981). The caregiving model links the concepts of caregiver role strain and social support to the stressor and stress reaction relationship. The significance of this thesis rests on current interest in the difficulties of caregiving and the identified need to develop and test theoretical models for a clearer understanding of the process and outcome of caregiving.

## 1.0 SIGNIFICANCE

More than 90% of elderly persons reside in the community and the assistance provided by informal support, that is family and friends, constitutes the majority of care received by elders (Brody, 1985; Chappell et al., 1986; Shanas, 1979b). Primary sources of help within the family are the spouse and adult children, and for the childless person, there is evidence that brothers, sisters and other relatives tend to substitute for the child (Bell, 1973; Cantor, 1979; Shanas, 1979a). When family are absent, friends and neighbours act as replacements (Cantor, 1979; Johnson, 1983).

This compensatory replacement process, known as the "principle of substitution" (Shanas, 1979b) suggests that friends and neighbours assist only when family members are not available. In contrast, it has been suggested that beyond the spouse and adult child, it is siblings and friends who provide assistance rather than other extended kin (Chappell, 1987). To date, however, there has been very little research on non-kin informal caregiving relationships and most research on family caregiving has emphasized the spouse and adult child caregiver.

For most elderly persons, the family becomes the primary provider of care and assistance. The major portion of family support is usually provided by one or two members rather than the family as a whole (Johnson & Catalano, 1983). Research on caregiving for the elderly has tended to focus on the primary caregiver-care receiver dyad rather than on the larger family system (Stull et al., 1988). Primary caregivers traditionally have been women, that is, wives, daughters and daughters-in-law (Frankfather et al., 1981; Horowitz, 1985; Treas, 1977). For the elderly couple, given that women live longer and usually are younger than their husbands, it is often wives who are the primary caregivers for their spouse (Shanas, 1979b).

Informal caregiving for the elderly is significant to the extent that entry into a formal care facility often occurs not because of the elder's failing health but because of the caregiver's inability to continue providing care and support (Colerick & George, 1986; Deimling & Poulshock, 1985). There has been growing concern that caregivers are experiencing great personal difficulty in caregiving. Furthermore, social and demographic trends are expected to have an even greater impact on the ability of informal caregivers to initiate and provide care in the future. Such trends include changes in the size and characteristics of the elderly population and their support network.

Demographers have predicted an increasing number and proportion of elderly in the population, with the most rapid growth occurring among those aged 85 and older (Manton & Soldo, 1985; Stone & Fletcher, 1980). This trend is expected to continue and the implications of an aging society include a growing need within the elderly population for assistance with tasks of daily living. Although chronic disease does not necessarily translate into disability, chronic disease and functional disability are associated with an increasing lifespan and are manifested in an expanding dependence on others for help (Wan et al., 1982). For individuals age 65 and older, approximately 75-85% have at least one chronic condition and approximately 50% report some limitation of normal activity related to chronic health conditions (Shanas & Maddox, 1976; Chappell et al., 1986). Increased disability is reported among those age 75 and older (Ford et al., 1988).

Those persons presently entering the ranks of the elderly are the parents of the "baby boom" generation and the potential pool of informal caregivers is relatively broad. However, currently declining fertility rates will change the size and nature of the family support available to future cohorts of elderly. Geographical mobility, increasing urbanization and rates of divorce and remarriage will affect and likely inhibit family members' ability to provide care to elders. An increasing proportion of women are working outside of the home so that this potential caregiver may be decreasingly available (Treas, 1977). The caregiving children of the very old are the "young-old" and they may be experiencing their own age-related changes in health, family life and lifestyle (Stone et al., 1987). These caregivers are the "sandwich generation" because they experience demands both from their younger and older generations (Miller, 1981).

Caregivers have attributed negative changes in their health status and social well-being to caregiving (Cantor, 1983; Chenoweth & Spencer, 1986; Zarit et al., 1980). The competing demands of caregiving and other responsibilities have become a source of difficulty for some families (Crossman et al., 1975; Fengler & Goodrich, 1979; Johnson, 1983). In attempting to identify and measure the specific problems experienced by caregivers, researchers have adopted the term "burden" from the literature on deinstitutionalized mental health patients. Although burden was not formally defined in this early work, it implicitly referred to the impact or the effect of the member's mental illness in terms of social and emotional "costs" for the family (Grad & Sainsbury, 1963).

Mental health research on burden was empirically-based and a theoretical foundation was lacking. Similarly, while the empirical research base of caregiving for the elderly has grown appreciably, there has not been an accompanying effort directed toward theoretical development (Zarit et al., 1986). Gerontological research on family caregiving has emphasized the study of caregiver burden, that is, the negative effect that providing care has on the caregiver. Research on the correlates and predictors of burden has been predominant in the caregiving literature with relatively less effort being directed toward other aspects such as caregiver coping or caregiver satisfaction. The dominance of burden research within the context of caregiving has lent a negative perspective to the study of family caregiving in general.

Research on caregiver burden has explored a number of factors that are related to or predictive of burden. In particular, it appears that characteristics of the caregiver (such as their age, gender, functional disability and relationship to the care receiver) and the caregiving context (such as living arrangement) are more consistent correlates of burden than characteristics of the care receiver (such as the type of impairment) (Gwyther & George, 1986). While research on the factors associated with burden has expanded in the last ten years, there has been little in the way of theoretical development intended to describe and explain relationships among correlates (Zarit, 1989). Continued research on the health and well-being of the elderly and their caregivers is needed. However, an absence of theoretical work has been evident in this field. This thesis attempts to address the gap in theoretical development in the study of family caregiving.

## 1.1 RESEARCH QUESTIONS

A stress model incorporating concepts of caregiver role strain and social support provides a theoretical perspective on elder caregiving. While research on caregiver burden has emphasized the strain and stress of caregiving, these terms have not been used in gerontology in the same manner in which they are used in social science generally. In gerontology, strain and stress have been treated as synonymous with burden and the more broadly accepted definitions of "role strain" and "stress" have not been extensively examined in the context of family caregiving.

Models based on stress theory emphasize the appraisal process and the place of social support in mediating or modifying the relationship between a difficult situation and the effect that this can have on health status. The condition or situation constitutes a potential stressor and the consequent response to a stressor, the stress reaction is manifested in physical, psychological and emotional health outcomes (Elliot & Eisdorfer, 1982). For elder caregiving research, a potential stressor is caregiving. Within the stress model, role strain, the "...felt difficulty in fulfilling role expectations" (Goode, 1960), represents appraisal of a difficult situation and social support is "information" that a person is cared for, valued and part of a set of personal contacts (Cobb, 1976). While the mechanism that links social support and health status is not clearly understood, empirical study has provided supporting evidence for this association (Minkler, 1981).

For this thesis, the relationship among social support, caregiving and caregiver health status is tested using a caregiving model derived from a social model of stress. This thesis addresses the following questions:

> 1) Does social support mediate the relationship between a difficult caregiving situation and health status of the caregiver?
>
> 2) Is there a direct relationship between social support and health status among caregivers?

In addition, the caregiver burden literature has suggested several correlates and predictors of burden. This thesis examines the relationship between these factors and the appraisal of caregiving as difficult. The thesis addresses the following question:

> 3) What is the relationship between caregiver appraisal of caregiving as difficult and caregiver age, gender, functional disability, living arrangement and relationship to the care receiver?

Data come from a large survey carried out in 1985 involving 1284 community dwelling elderly individuals age 60 and older. The purpose of the original study was to examine the relationship between living arrangement and use of informal and formal care through a sampling design which included stratification by three types of living arrangement, that is, intact marriages, living alone and living with a person(s) other than a spouse. Those in personal care homes and congregate housing arrangements were excluded. Secondary analyses are carried out with those elderly respondents (n= 197) who indicated that they were the primary caregiver for another person.

This thesis, then, empirically tests a caregiving model based on a previously developed stress model (Pearlin et al., 1981). The caregiving model incorporates the concepts of caregiver role strain, social support and health status. To begin, the literature on caregiver burden and health status is reviewed in chapter two. The caregiving model, including discussion of the components of caregiver role strain, stress and social support, is provided in chapter three. Hypothesized relationships between these variables are formulated to guide the research. Chapter four describes the methodology and the results of statistical analysis are presented in chapter five. The final chapter consists of a discussion of findings, including limitations of this thesis and implications for future research.

# CHAPTER 2

# LITERATURE REVIEW: CAREGIVER BURDEN AND HEALTH STATUS

The literature review is presented in two sections. The first section provides an overview of the literature on caregiver burden. This overview includes an examination of the conceptualization and measurement of burden as well as empirical findings. In the second section, caregiver health status is discussed in relation to the concept of burden. Caregiver health status, as measured by self-rated health and depression, is a key variable in subsequent analyses.

## 2.0 CAREGIVER BURDEN

### 2.0.1 Origin of the concept of burden

Original investigations of caregiving and burden are found in the mental health literature. Research was carried out with families whose members had been discharged from mental health facilities. Early studies by Grad and Sainsbury (1963) were carried out in Britain with more than 400 families of deinstitutionalized patients. These studies addressed questions related to the return of mental health patients to the family household and the effect of this return on family functioning. This was empirically-based research of an exploratory nature.

Although burden was not formally defined in this early work, it implicitly referred to the impact or the effect of the member's illness in terms of "costs" for the family. The task of assessing the burden experienced by these families rested with those who carried out the face-to-face interviews. The nearest relative or the person with whom the patient had closest contact was interviewed in the home. Interviewers obtained family-based data, such as household composition and socio-economic status, and recorded whether abnormalities of behaviour likely to trouble families, such as aggressiveness, were present. In addition, interviewers assessed the impact of the patient's illness on: family income and employment; social and leisure activities of the family; domestic routine; children in the home; health of household members and relations with the neighbours. Interviewers rated the effect of the patient's illness on each of these features using a three point scale: 1) "not affected by the patient"; 2) "affected"; and 3) "severely affected".

The three point scale placed emphasis on the neutral or negative impact of the patient on the family as opposed to providing a continuum of responses that included positive outcomes of the patient's return to the family home. The response set excluded the possibility that there might be some improvement or even a positive change to family life. Based on these individual item ratings, the interviewer independently identified the overall burden on the family again, using a three point scale of "none", "some" or "severe" burden.

From their findings, Grad and Sainsbury (1963) concluded that discharge from a mental health facility created "relief" within the institution while creating difficulties for families. In particular, they identified elderly patients (age 65 and over) as presenting families with more than twice the number of "severe" problems compared to younger patients. This was largely due to the fact that more elderly patients were experiencing dementia and/or were bedridden. Grad and Sainsbury (1963) recommended that discharge policy take into account the health and economic circumstances of the family as well as family attitude toward the patient's return. They also noted that a short term admission to hospital, did not solve the family's problems and formal support services did not consistently reduce the burden reported by the family.

Additional research on deinstitutionalization of mental health patients was carried out by Hoenig and Hamilton (1966) in Great Britain and Thompson and Doll (1982) in the United States. This work focused on the dual differentiation of subjective and objective burden (Hoenig & Hamilton, 1966; Doll et al., 1976; Thompson & Doll, 1982). Subjective burden consisted of emotional costs for the family such as feelings of embarrassment and resentment, while objective burden included social costs to the family, such as disruption to daily life or financial problems. While there was a significant association between these two components, one did not predict the other. The objective burden of these families was much greater than their subjective burden (Hoenig & Hamilton, 1966; Thompson & Doll, 1982). In particular, the inconvenience of providing care to patients was identified as burdensome (Thompson & Doll, 1982).

Early work on defining and measuring caregiver burden in gerontology acknowledged previous work in the mental health field (Zarit et al., 1980; Montgomery et al., 1985b). Similarities are evident when comparing research on deinstitutionalized mental health patients with later studies of informal caregiving in gerontology. Common features include: 1) an emphasis on the negative impact of caregiving on the caregiver, 2) a focus on caregiving outcome rather on caregiving process, 3) burden as unidimensional or dichotomous, and 4) lack of theoretical perspective.

First, the approach in both the mental health field and gerontology has focused on the negative impact of the individual on the family. Research on the deinstitutionalization of mental health patients emphasized the neutral or negative effects of their returning presence on the family. Possible positive effects on the family were not explored in addition to the felt difficulties. Similarly, in gerontological research on caregiving, there has been an emphasis on burden, that is, the negative effects of caregiving on the caregiver. This is not to suggest that burden should include positive elements. It is an observation that within elder caregiving, the study of burden has dominated (Zarit, 1989) and therefore tended to promote a negative view of caregiving in general.

Second, in the mental health literature, burden referred to impact or outcome rather than process or interaction. The focus was on the impact of the mentally ill patient on family member's health and lifestyle rather than on the interactive relationship between the patient and the family. Information was not collected from the patient and no assessment was made concerning how deinstitutionalization and return to the family had affected the patient's health and well-being. Clearly, examining adjustment of mental health patients was not the intent of the research. Still, mental health-based burden research placed the family in a position of prominance and neglected interactive components that might in fact, contribute to outcome.

Similarly, in gerontological research on burden, the focus has been on the effects of caregiving on the caregiver rather than on the interaction of caregiver and care receiver, or on the effect of caregiving on the care receiver. An implication of this perspective is that care receivers cannot experience "burden", per se, even if the experience of receiving care is difficult or oppressive. Burden is restricted to the effects felt by caregivers. Very little is known about how elderly persons feel about receiving care (Aronson, 1985).

Third, at least initially in the mental health literature, the construct of burden was unidimensional and families were assigned an overall burden score. Later, it was suggested that burden had two dimensions, objective burden and subjective burden (Hoenig & Hamilton, 1966; Thompson & Doll, 1982). The distinction between subjective and objective burden has been identified in the gerontological literature (for example, Montgomery et al., 1985a) but has not gained widespread acceptance. While there has been increasing discussion of burden as multidimensional (Gwyther & George, 1986; Novak & Guest, 1987; Zarit, 1989), there has been little agreement concerning the substance of the dimensions.

Finally, research on burden in the mental health field lacked theoretical foundation. "Burden" was not formally defined until several years after Grad and Sainsbury's (1963) research when it was dichotomized as emotional and social costs to the family (Thompson & Doll, 1982). The application of the concept of burden to elder caregiving was not accompanied by a theoretically informed explanation. While researchers have referred to possible theoretical models or frameworks when presenting their findings, (for example, Zarit et al., 1986 referred to their findings as being consistent with "general models of stress"), systematic efforts to develop and test theory have not been made. Most recently, Pearlin et al., (1990) have suggested a caregiving stress model but tests of this model have not been reported to date. Although early work in elderly caregiving emerged in the late 1970's, "...there has been little theory to guide research" (Zarit et al., 1986, p. 260). Caregiving research has tended to explore empirically the correlates and predictors of burden rather than to derive variables from a theoretical framework (Schulz, 1990).

### 2.0.2 Conceptualization of burden

Burden as defined in gerontology is difficult to discuss for two reasons. First, several definitions of "burden" exist and while all of them relate to elements or costs of caregiving, distinctions among such definitions make clarification of the concept a challenging undertaking. Sometimes, in reported research, burden is not formally defined (for example, Zarit et al., 1980). Second, other terms such as caregiver strain or caregiver stress have been used to describe similar phenomena, that is, the costs or effects of caregiving. It is difficult to sort out where meanings among such terms overlap or where distinctions rest. This has made cross study comparison difficult (Poulshock & Deimling, 1984). In addressing this second issue, Montgomery (1989) has suggested that for simplicity sake, "burden" be used to encompass all terminology for the negative effects of caregiving. This approach is taken for this review of the caregiving burden literature.

Several definitions of caregiver burden are found in the gerontological literature. Burden has been defined as "...the extent to which caregivers perceive their emotional or physical health, social life and financial situation as suffering as a result of caring for their relative" (Zarit et al., 1986, p. 261). Others have defined it as "...the subjective perceptions of the caregivers relative to the degree of problems experienced in relation to the elder's specific ailment" (Poulshock & Deimling, 1984, p. 238) or generally as enduring problems, costs or strain created by caregiving (Cantor, 1983; Montgomery et al., 1985b; Robinson, 1983).

Development of the conceptualization of burden followed a process in which early work tended to view burden as unidimensional, progressing to burden as dichotomous and then as a multidimensional construct consisting of more than two dimensions. Examples of early work include that of Zarit et al. (1980) and Robinson (1983) and burden was conceptualized as the total sum of caregiver "suffering" and "discomfort" attributable to caregiving. Instrumentation reflected this perspective and a summary score represented the effect of caregiving on the caregiver. The use of summary scores has been critcized because these scores tend to mask or blur the distinctive features of burden that are being measured (Gwyther & George, 1986; Novak & Guest, 1987).

Montgomery and associates were first to describe burden as having two dimensions (for example, Hooyman et al., 1985; Montgomery et al., 1985a; Montgomery & Kamo, 1987). Their work borrowed from the mental health field and "subjective burden" represented emotional costs to the family while "objective burden" represented social costs borne by the family. As presented by Montgomery et al. (1985a), subjective burden was defined as "...[caregiver] attitudes toward or emotional reaction to the caregiving experience" (p. 21), and objective burden was defined as "...disruptions or changes in various aspects of the caregivers' life and household" (p 21). Concrete events such as infringements on caregiver time, money and activities (objective burden) were distinguished from the caregiver feelings and reactions, such as embarrassment and anger, that arose from the caregiving experience (subjective burden).

Earlier work by Zarit et al., (1980) and Robinson (1983) had not distinguished between subjective and objective burden. Instead, burden as a unidimensional construct, that is, as caregiver suffering represented a number of problems attributable to caregiving including "...caregiver's health, psychological well-being, finances, social life and the relationship between the caregiver and the impaired person" (Zarit et al., 1980, p. 651). According to Montgomery and associates, these first four elements, that is, caregiver health, well-being, finances and social life represent objective burden while problems in the relationship between caregiver and care receiver constitute subjective burden. In fact, the dichotomy of objective and subjective burden has not gained widespread acceptance. One of the difficulties cited is that objective burden is no more "objective" or concrete than subjective burden, given that both dimensions are prone to subjectivity of caregiver reports (Schulz, 1990). Currently, greater emphasis is being placed on clarifying the concept of burden (Pruchno & Resch, 1989). Much of what is written supports a multidimensional perspective while not embracing the two dimensions of subjective and objective burden suggested by Montgomery and associates.

Poulshock and Deimling (1984; Deimling & Poulshock, 1985) have argued that the division of subjective and objective burden lacked precision and did not address the multidimensional nature of burden. They suggested that the concept of burden would be meaningful only if it were more closely connected to the reality of the elder's impairment and consequent care needs. Poulshock and Deimling (1984) defined burden as the "...subjective interpretation by caregivers of problems that flow from elders' [physical and mental] impairments" (p. 230). Thus, the multidimensional nature of burden proceeded from the various dimensions of elder impairment. Poulshock and Deimling (1984) further suggested that the term "caregiving impact", including the impact that caregiving had on family relationships, social activities, health and employment, replace objective burden.

Montgomery (1989) has argued that Poulshock and Deimling (1984) merely redefined burden and then took the definition of burden as used by others and renamed it "caregiver impact". This is partly correct. Poulshock and Deimling's definition (and measurement) of burden was aligned with the elder's impairment; burden was the caregiver's appraisal of difficulties emanating from the elder's impairment. This was a redefinition of burden because it did not agree with burden as generalized suffering or with "subjective" burden and the emphasis on feelings and relations with the care receiver. However, the concept of caregiving impact was not as broad as Montgomery and associates' definition of objective burden (which had also included aspects of personal freedom and finances) but it was more specific than burden as suffering (Zarit et al., 1980) so it was not a "renaming" of burden. Montgomery's (1989) criticism also assumed that "burden" had been used consistently in the literature and this was neither the case then nor is this now true.

Poulshock and Deimling's (1984) work represented an early attempt to address the multidimensional nature of burden. George and Gwyther (1986) also examined caregiver burden as a multidimensional construct. They suggested that "... caregiver burden can profitably be measured in terms of discrete dimensions of well-being...[for] it appears that 'caregiver burden' and 'caregiver well-being' are but opposite sides of the same coin" (p. 253). From this perspective, burden is defined and measured by the deficiencies in caregiver well-being, that is, by deficiencies in caregiver physical health, mental health, social participation and financial resources. In essence, this definition is similar to that of "objective" burden (Montgomery et al., 1985a) and "caregiver impact" (Poulshock & Deimling, 1984). However, several researchers have argued that burden is not the opposite of well-being and measurement of burden as a deficiency in well-being neglects the specific link between caregiving and related difficulties (Montgomery, 1989; Poulshock & Deimling, 1984; Schulz, 1990). Instead, it has been suggested that burden is best viewed as an intervening variable that (along with other variables) may contribute to caregiver well-being (Montgomery, 1989).

A recent development in the conceptualization and measurement of burden has been the Caregiver Burden Inventory, a multidimensional instrument designed to capture the complexity of caregiver burden (Novak & Guest, 1989). The definition of burden that guides this work comes from Ory et al. (1985) and burden is "...the impact of the changes in cognition and behavior of the Alzheimer patient on the family, and the patient's subsequent need for care and supervision" (p. 631). The dimensions of burden that are addressed include: 1) time constraints on the caregiver, 2) caregiving as inhibiting the caregiver's developmental growth, 3) physical health problems, 4) social relations difficulties, and 5) emotional problems (Novak & Guest, 1989). This instrument has been tested with primary caregivers providing care to family members in the community and in institutions. This instrument and the dimensions of burden that it captures currently await further validation.

In general, attempts at clarifying the concept of burden have shown convergence and divergence. It seems clear that what is of interest is the caregiver's evaluation of the caregiving experience and that a number of elements are likely involved. These elements have included caregiver perceived changes in health and well-being as well as the emergence of undesirable feelings such as anger and guilt. What is less clear is whether or not these elements can be meaningfully separated. No uniformly accepted definition of burden exists and while currently there is interest in exploring the multidimensional nature of burden, no clear direction for doing this is evident. Empirical research on caregiver burden is flourishing and will likely continue in the face of ambiguity concerning the concept of burden. In fact, most studies use instruments based on burden as a unidimensional construct and in particular, the burden interview (Zarit et al., 1980) has been used extensively.

### 2.0.3 Measurement of burden

Several instruments have been developed to measure caregiver burden. These instruments have been used among diverse groups of caregivers who provide care to elderly persons possessing varying degrees of physical and/or mental impairment. Caregiving settings vary but most research has been community-based rather than set in hospital or long term care facilities. Concerns related to measurement of burden have centred on instrumentation and sample selection.

Instruments for measuring caregiver burden include: the burden interview (Zarit et al., 1980); the caregiver strain index (Robinson, 1983); objective and subjective burden scales (Montgomery et al., 1985a); the perceived burden scale (Hooyman et al., 1985); and the caregiver burden inventory (Novak & Guest, 1987; 1989) among others. The burden interview (Zarit et al., 1980) was developed early and has become one of the most widely used instruments. This tool originally was designed for use with a sample of caregivers providing care to a family member suffering from dementia. Since then it has been used with both dementia and non-dementia samples (Fitting et al., 1986; Marcus & Jaeger, 1984; Pratt et al., 1985). Other burden measurement instruments postdate the burden interview and items were borrowed from the burden interview tool. Because the burden interview is the archetype and currently in wide use, this instrument is highlighted.

Twenty-one of the twenty-two items in the burden interview (Zarit et al., 1986) are worded negatively, one is worded neutrally and none are worded positively. Items refer to negative changes in the caregiver's health and well-being and ask about caregiver feelings of loss, suffering, embarrassment, anger, strain, stress and uncertainty. This is consistent with Zarit et al.'s (1986) definition of burden as the extent of caregiver perceived suffering as a result of caregiving, and the response set does provide the option of disagreeing with the item. The burden interview is scored by summing the responses of the individual items, with higher scores indicating greater caregiver burden. The potential range of zero to 88 can be translated into "little or no burden" (zero to 20), "mild to moderate burden" (21 to 40), "moderate to severe burden" (41 to 60) and "severe burden" (61-88).

Negatively phrased items are not unique to the burden interview. Kinney et al. (1986)

evaluated six of the most frequently used caregiver burden instruments. They concluded that the six major instruments include only negative aspects of caregiving, rather than satisfactions and positive feelings occcuring in the process of providing care. Again, it is not being suggested that burden tools should measure positive aspects of caregiving but caregiver burden research has predominated and results that indicate at best, "no burden" tend to neglect the possibility that caregiving may have its rewards and gratifications.

Some evidence has indicated that elder caregiving does have rewards of self-satisfaction and feelings of accomplishment (Bailey & Young, 1986; Colerick & George, 1986). Hooyman et al. (1985) reported that while most family caregivers indicated an increase in the amount of burden in their lives, over one-quarter also reported an increase in life satisfaction resulting from caring for an older relative. Fitting et al. (1986) reported the "unexpected" finding that 25% of husbands claimed an improved relationship with the care receiving spouse since assuming the caregiving role. However, there has been little research on positive aspects of caregiving. While there are several instruments to measure caregiver burden, there appears to be no tool to measure caregiver gratification, for example (Motenko, 1989).

The current focus on burden and the lack of attention to positive aspects of caregiving may be traced back to the development of burden measurement items. It is not clear whether items on any of the caregiver burden instruments were directly generated by caregivers themselves and therefore grounded in their experience. For the burden interview, Zarit et al. (1980) reported that the items "were selected based on clinical experience with caregivers and prior studies" (p. 651). It is possible that if items had been derived directly from caregivers (including "nonclinical" samples), a broader view of caregiving, that is, one that depicted difficulties and rewards of caregiving, might have resulted.

A criticism of burden instruments that applies to the burden interview is the inherent confounding of caregiving and its impact when burden is used as predictor of health outcome (Poulshock & Deimling, 1984). George and Gwyther (1986) have indicated that "...because extant measures of caregiver burden explicitly require respondents to relate caregiving to its impact, an unwelcome kind of confounding occurs" so that "...one cannot independently relate caregiving to its impact" (p. 254). For the burden interview, items such as "do you feel your health has suffered because of your involvement with your relative?" require respondents to relate caregiving to its impact, thus intertwining the two so that caregiving and its impact cannot be separated at the analysis phase. Items that tap changes in caregiver health status or feelings of depression attributable to caregiving, contribute to burden scores that are used to predict caregiver health (Kinney et al., 1986).

Selection of caregivers for burden studies has been criticized in terms of sample size and composition. Researchers have acknowledged that recruitment for caregiving studies is difficult (Archbold et al., 1987; George & Gwyther, 1986). Very little has been learned about differences between those caregivers who agree to participate in research and those who do not, and the loss of potential respondents has been reported to vary from 10% to 60% (Zweibel, 1986). Caregivers who do not choose to participate in research possibly are a "more burdened, hidden, subpopulation of caregivers" (Dura & Kiecolt-Glaser, 1990). Horowitz (1989) reported that a poorer response rate for men compared with women caregivers contributes to the relative lack of information on male caregiving. However, implications of response rate and dropout rate for caregiving burden research findings have not been explored.

Measurement of burden has most often been carried out with small sample sizes and convenience samples of caregivers, notably women and those who are providing care to a cognitively impaired care receiver. An exception was the 1982 Informal Caregivers Survey, a component of the National Long-Term Care Survey, and information on a national community-based sample of over 2000 elderly caregivers was collected (Stone et al., 1987). However, this study did not address burden, per se. For the most part, samples of caregivers have been derived from agency or institutional lists and from self-help organization rosters (Barer & Johnson, 1990). Such groups are known to be middle-class, informed and already in need of some form of help. Matthews (1985) has argued that these samples of caregivers represent those families with few social, financial and physical resources and that their need has reinforced the belief that elderly caregiving is not only normative but also normatively burdensome. In addition, organized groups or agencies are used far less by men, suggesting that men may be underrepresented in caregiving research relative to their prevalence as caregivers (Horowtiz, 1989).

Research on family caregiving often has analyzed all caregivers together suggesting that caregiving is a common experience regardless of whether the caregiver is a spouse or an adult child, for example. Alternatively, purposive samples have been selected based on gender and/or generational criteria, usually female caregivers or caregiving daughters, implying that differences exist while not attempting a comparative approach. Women caregivers predominate in relative number for much of the research and the differences between the caregiving experiences of men and women are not well understood. Small sample sizes have not always been sufficient for further breakdown into smaller comparision groups according to age, gender and so on. While there is growing recognition that differences among caregivers such as those based on gender, age and familial relationship influence the caregiving experience (Gwyther & George, 1986), there has been relatively little comparative work.

Related to sample composition is the identity of the respondent and the scope of the information obtained. Several definitions of "primary caregiver" exist (Barer & Johnson, 1990). Much of the research on caregiving has identified the primary caregiver and then elicited information on both the caregiver and care receiver from this person. Except for cognitively impaired elderly, it would seem evident that the best source of data on the care receiver is the care receiver. Empirical evidence has indicated that it may be inappropriate to assume that caregivers are able to speak accurately for care receivers (Treat, 1986). However, burden research has tended to depend exclusively on the caregiver to provide information on caregiving and the care receiver.

Relying solely on the caregiver has meant that the dynamics of the caregiver-care receiver relationship have remained largely unexplored. For example, very little is known about the difficulties felt by care receivers and the quality of the dyadic relationship as perceived by care receivers (Aronson, 1985; Barer & Johnson, 1990). Because burden has been defined as the impact of caregiving <u>on the caregiver</u>, the focus narrows to the caregiver and places his or her needs in prominence. The needs and feelings of the care receiver are addressed less often and usually in the context of how these affect the caregiver. For example, Montgomery et al. (1985a) found that providing personal care to the care receiver is a difficult task for some caregivers because of the intimate contact required, but they do not attend to the probable similar difficulties experienced by the care receiver.

As another example, when the role that affective relations play in the caregiving process is addressed, it most often is from the caregiver's perspective. The idea that affection and compatibility are linked with perceptions of burden has gained support (Cantor, 1983; Marcus & Jaeger, 1984; Horowitz & Shindelman 1983; Robinson, 1983) but longitudinal research has also indicated that the quality of the relations between caregiver and care receiver can deteriorate over time (Johnson & Catalano, 1983). The dynamics of interaction between the caregiver and care receiver and how this may affect caregiving has not received much attention. Focus on the caregiving dyad has tended to exclude others who may be providing some part of caregiving assistance. Recently, more emphasis has been placed on the role of secondary caregivers (Stull et al., 1988; Tennstedt et al., 1989). However, the family caregiving system as a whole has yet to be systematically studied (Horowitz, 1989).

The majority of family caregiving studies have attempted to measure caregiver burden and then relate this measure to specific characteristics of the caregiver, the care receiver and the caregiving context. Data have been collected on elder impairment and functional ability and on the nature of the caregiving tasks performed. Findings from this body of research have indicated several correlates of burden, some of which relate to care receiver characteristics (for example, the type and severity of impairment) while others relate to characteristics of the caregiver such as age, gender and employment status. A third category of correlates of burden can be described as situational or structural factors and include living arrangement, care receiver residence and formal and informal support features. These categories of correlates are examined respectively.

### 2.0.4 Correlates of burden: Care receiver characteristics

Caregiving research has focused primarily on cognitively impaired care receivers rather than those with functional impairment in activities of daily living (ADL) (Silliman &

Sternberg, 1988). A major question for debate has been whether, or to what degree the disability or impairment of the care receiver relates to caregiver burden. It has been suggested that the type of care receiver impairment, either mental or physical may be crucial to caregiver burden (Fitting et al., 1986). Studies of caregivers for the cognitively impaired care receiver have reported both high levels of burden (Pratt et al., 1985; Zarit et al., 1986) and low levels of burden (George & Gwyther, 1986). Other studies have indicated no relationship between the severity of cognitive impairment and caregiver burden (Cohen & Eisdorfer, 1988; Zarit et al., 1980). Findings are inconsistent and while there may be a moderate relationship between burden and type and degree of elder impairment, other factors (such as living arrangement) also likely influence burden (Poulshock & Deimling, 1984; Schulz, 1990).

Fitting et al. (1986) reported in their study of spouse caregivers of elderly dementia patients that increasing severity of illness was associated with greater burden by spouses. However, this was only true for younger wives and older husbands indicating that age and gender might also influence the degree of burden. In contrast, George and Gwyther (1986) found that for caregivers of demented elders, the care receiver illness characteristics were minimally related to caregiver well-being and burden. Characteristics of the caregiving situation and the resources available to the caregiver, rather than the condition of the patient most directly affected caregiver well-being (George & Gwyther, 1986). Similarly, Zarit et al. (1980) reported that the extent of burden reported by caregivers who were providing care to family members with dementia was not related to the elder's mental or physical impairment. Instead burden was associated with the availability of social supports for the care receiver, in particular, the number of visitors to the household other than the primary caregiver. An association between social support for the care receiver and caregiver burden has been reported in other studies (Marcus & Jaeger, 1984; Pratt et al, 1985).

Although there is no clear or direct relationship between impairment and disability (Barer & Johnson, 1990), the types of caregiving tasks required of the caregiver are related to elder disability and need. However, an association between caregiver burden and care receiver functional limitations in basic ADL (such as washing and dressing) and instrumental ADL (such as meal preparation and grocery shopping) has not been consistently observed. Deimling and Bass (1986) reported increased level of caregiver burden with care receiver limitations in basic ADL while other studies have reported no relationship between burden and both basic and instrumental ADL (Pearson et al., 1988; Zarit et al., 1980, Zarit et al., 1986).

The type of caregiving task may be related to the level of burden. Caregiving tasks that tend to restrict or confine the caregiver in time and place, and those tasks that involve the performance of personal care or body contact tasks such as bathing, dressing or toileting have been linked to burden (Hooyman et al., 1985; Montgomery et al., 1985a; Robinson & Thurnher, 1979). Hooyman et al. (1985) have suggested that the strong relationship between performance of personal care tasks and perceptions of burden are a function of family expectations and norms. Assisting an older relative with personal care tasks may violate family norms about the appropriate familial roles and interactions.

Care receiver dependency and needs can translate into substantial time demands on the caregiver and can restrict other outside activities. Changes in the frequency and type of social and personal activities are often reported by caregivers as an outcome of caregiving. Such constrictions may deprive caregivers of needed respite, diversion and social contacts, including opportunities for social support (Miller & Montgomery, 1990). Reported limitations in social activities have varied by gender and relationship to the care receiver with daughters and wives more likely to report limitations than husbands and sons (Horowitz, 1985; Miller & Montgomery, 1990).

While burden has been linked to the length of the caregiving experience (Johnson & Catalano, 1983), the lack of longitudinal research exploring changes in burden over time has inhibited an understanding of this process. Tennstedt et al.'s (1989) panel study of adult child caregivers is one exception and findings indicated improvement rather than deterioration in caregiver adaptation to caregiving. Similarly, Zarit et al.'s (1986) longitudinal spousal caregiver study revealed a decrease in burden scores after a two year interval. Gender differences were also evident and although wife caregivers initially reported greater burden compared with husbands, no differences were found two years later.

### 2.0.5 Correlates of burden: Caregiver characteristics

Research on caregiver burden has reported that the level of burden varies among different groups of caregivers. Cantor (1983) has argued that familial relationship is associated with burden and the closer the bond, (that is, for spouse and then adult children), the more likely that caregiving is burdensome. When spouse and adult child caregivers are compared, spouse caregivers tend to report greater burden than do adult child caregivers (Cantor, 1983; George & Gwyther, 1986; Johnson & Catalano, 1983). However, living arrangement is likely intertwined because the majority of spouse caregivers are living with the care receiver whereas most adult child caregivers do not live with the care receiver. It may be that living arrangement is the crucial factor although research has not been conclusive in this respect.

Differences between spouse and adult child caregivers may be due to differences in caregiving tasks; evidence indicates that spouse and adult child caregivers vary according to caregiving tasks that they perform and assistance that they receive. In Young and Kahana's (1989) study of wife, husband and daughter caregivers, spouses tended to concentrate on more general food and housekeeping needs of the care receiver while child caregivers were significantly more likely to help parents with personal care, toileting and transportation. Within the spousal group, male and female caregivers were more likely to help with gender specific tasks, that is, meal and laundry assistance were linked to care by women while transportation and handywork were associated with male caregivers.

Gender-specific caregiving tasks have been widely reported in the literature and women tend to perform personal or "hands-on" care and indoor chores while men perform household maintenance and business or financial affairs tasks (Horowitz, 1985; Rathbone-McCuan & Coward, 1985; Stoller, 1988). In contrast to much of the research, Young and Kahana's (1989) study found that compared with spouse caregivers, daughters reported greater burden and attributed changes in their health to caregiving.

A second explanation for higher level of reported burden among spouse caregivers compared with adult child caregivers relates to social support factors. Findings have indicated that spouse caregivers receive less help from friends and relatives than adult child caregivers resulting in greater burden (George & Gwyther, 1984). In comparing husband and wives, the data gathered to date have sent mixed messages. Barusch and Spaid (1989) found no significant differences between husband and wife caregivers in the level of family support they received while Johnson and Catalano (1983) reported that husband caregivers tended to receive relatively more support from both formal and informal caregivers. In a comparative study of wife and husband caregivers, Pruchno and Resch (1989) found that men were more likely to receive help with tasks, such as housework, laundry and cooking. Gender may be important along with the relationship to the care receiver. Among adult child and spousal caregivers, male caregivers are more likely to receive family assistance compared to female caregivers (Horowitz, 1985; Noelker & Wallace, 1985). Currently, the extent and dynamics of family support for caregivers is not well understood.

Few studies compare gender and caregiver burden because of small sample sizes and because women predominate in relative number for much of the caregiving research. Relatively little research has focused on male caregiving although men constitute one-third of spousal caregivers (Stone et al., 1987). When gender has been isolated as a variable, findings on the relationship between gender and reported burden are not consistent. This inconsistency might be due to interacting factors such as age and relationship to the care receiver. Some studies have reported no difference between male and female caregivers and the amount of burden they report (Barusch & Spaid, 1989; Fitting et al., 1986; Miller, 1987; Robinson, 1983; Zarit et al., 1980). However, when differences have been found, it is women who report higher levels of burden (Cantor, 1983; George & Gwyther, 1986; Johnson & Catalano, 1983).

It is not clear whether gender differences in level of reported burden represent real differences or an artifact of gender bias in reporting. Socialization of men places high value on the appearance of competence and control and this may be manifested in male caregiver reports of lower burden compared with women caregivers (Horowitz, 1989). Assuming that there are true gender differences in caregiving, it has been suggested that gender-related management style, later life expectations and social support patterns may be factors. Miller (1987) found that women caregivers who reported greater burden tended to focus on their changed relationship with the care receiver, whereas men caregivers who reported less burden focused on caregiver tasks and projects. This suggests management style as an operating factor. In terms of later life expectations, middle-aged women who are leaving child-rearing responsibilities may find that caregiving conflicts with their expectation for greater control of their lives (Brody, 1985). Resultant feelings of conflict and resentment may contribute to feelings of burden (Zarit et al., 1986).

Seeking and receiving help may also be important considerations. Because of their traditional family care roles, women may be more reluctant to seek and utilize outside supports and this lack of support may create feelings of constraint, exhaustion and burden (Morycz, 1985). Compared with women caregivers, men caregivers are more likely to receive outside sources of assistance (Johnson & Catalano, 1983). George and Gwyther (1984) have suggested two other possible explanations for men caregivers reporting less burden than women caregivers. They suggest first that men may be less involved than women, that is, content to do the minimum, and therefore are less burdened. Second, men may take on a caregiving as a positive challenge that substitutes for feelings of accomplishment and productive use of time that formerly were supplied by employment. However, currently, all these explanations are speculative. One clear message is that gender and relationship to the care receiver need to be distinguished because of potential differences in caregiving tasks, social support and burden.

Although age of the caregiver likely has a bearing on burden, findings have been inconsistent, suggesting that associations are dependent upon additional factors. When younger caregivers have reported greater burden, a linkage between age and employment status has been suggested (Johnson & Catalano, 1983). Younger, employed caregivers may have demands that compete with the time required for caregiving and they are therefore apt to experience burden (Montgomery et al., 1985a; Robinson, 1983). Studies have reported that employment status does not translate into reduced amounts of caregiving (Brody, 1981; Cantor, 1980; Scharlach, 1987). However, the demands of caregiving may modify work roles with some caregivers reporting their need to reduce employment hours or quit working entirely in order to accommodate caregiving (Brody, 1985; Scharlach & Boyd, 1989).

The association between advanced age of the caregiver and burden is likely related to caregiver's physical health and functional ability in activities of daily living. Even if they are not chronically ill or disabled, the elderly caregiver likely will find caregiving difficult because of their own age-related decreasing functional capacities (Fengler & Goodrich, 1979; Rathbone-McCuan, 1976). An aged caregiver's own functional limitations may contribute to the difficulty of providing care and hence, to burden. A caregiver who is as disabled as the care receiver has been referred to as the "hidden patient" (Fengler & Goodrich, 1979). Alternatively, changes in caregiver health status may be more directly related to the demands of caregiving than the process of aging. Caregiving may be the cause of health problems for the caregiver (Springer & Brubaker, 1984).

Caregiver mental health, in particular, feelings of depression have been associated with burden (Danis & Silverstone, 1981; Fitting et al., 1986; Poulshock & Deimling, 1984; Pratt et al., 1985; Robinson, 1983). Most studies have been cross-sectional in design, making it difficult to argue for causality but it is plausible that feelings of depression are a product of a difficult caregiving situation. Longitudinal research will provide the strongest evidence of depression as antecedent or outcome of burden. Studies have indicated gender differences in caregiver reports of depression with women reporting greater depression (Cantor, 1983; Fitting et al., 1986; Pruchno & Resch, 1989; Robinson & Thurnher, 1979). Possible interacting factors are living arrangement and relationship to the care receiver (Cohen & Eisdorfer, 1988). Danis and Silverstone (1981) found that caregiver gender and living arrangement were associated with depression, in particular female caregivers living with the care receiver reported higher levels of depression. In contrast, Moritz et al. (1989) reported a significant relationship between caregiver depression and cognitive impairment of the care receiver in shared households but only for caregiving husbands. Several factors appear to be interacting when depression is reported including gender, relationship to the care receiver and living arrangement.

Research on caregiver coping strategies has not been widely reported in the gerontological literature. Pratt et al. (1985) measured individual and family coping strategies with the F-COPES Scale, and Johnson and Catalano (1983) used qualitative analysis to identify caregiver strategies of distancing from the care receiver and intense involvement in the life of the care receiver. Zarit et al. (1986) reported that caregiving husbands tended to adopt an instrumental approach to daily problems while caregiving wives had difficulty maintaining emotional distance and considering alternative strategies. More recently, Barusch (1988) reported on the development of a survey instrument for assessing the training needs of spouse caregivers that attempts to identify coping techniques. Findings indicated one difference, that is, compared with women, men reported significantly greater effectiveness in coping with interpersonal problems with their spouse care receiver (Barusch & Spaid, 1989). Pearlin et al. (1990) has reported on developing caregiver coping measures but this work has been delayed by difficulties in establishing reliability (personal communication). It seems fair to say work on measuring caregiver coping is currently in a developmental stage.

Instead, research on caregiver burden has emphasized the use of coping resources, such as formal services and informal supports for the care receiver. One of the more consistent findings in this body of research has been a low level of burden associated with the presence and support of social network members, particularly the family for the care receiver (Marcus and Jaeger, 1984; Montgomery et al., 1985; Pratt et al., 1985; Zarit et al., 1980). In addition, caregiver well-being may be enhanced by the availability of a second caregiving relative (Stull et al., 1988). Currently, fewer attempts have been made to go beyond the primary or even secondary caregiver and explore the larger family or support network (Barer & Johnson, 1990).

### 2.0.6 Correlates of burden: Situational factors

Sharing a household with the care receiver has been associated with caregiver burden (Danis & Silverstone, 1981; George & Gwyther, 1986) and depression (Cohen &

Eisdorfer, 1988). An underlying assumption has been that intrahousehold caregiving compared with interhousehold caregiving is more intensive and demanding (Soldo & Myllyloma, 1983). Danis and Silverstone (1981) found that caregivers living alone with the care receiver, that is older wives caring for ill husbands and daughters living with an ill parent, were the most vulnerable to depression and poor physical health. In contrast, daughters living with an ill parent plus their husband and/or children have reported relatively better mental and physical health. The presence of other family members may provide a diversion and a source of social support to caregivers and when this is not available, caregivers are more vulnerable to physical health problems and depression (Danis & Silverstone, 1981).

Living arrangement is also intertwined with caregiver gender and relationship to the care receiver; women, spouses and adult daughters more likely to live with the care receiver. The association between burden and living arrangement may be related to limitations on social and family activity that such as arrangement entails. Caregivers who live with the care receiver may be more involved in caregiving and consequently face greater limitations in their personal lives than those who do not live with the care receiver (Schulz, 1990). Kosberg et al. (1989) found that caregivers living with the care receiver reported significantly more restrictions related to receiving friends into the home and to maintaining home routines.

Burden has not been associated with the care receiver's residence, that is, whether the care receiver is living in the community or has entered an institution (George & Gwyther, 1986; Pratt et al., 1985). In a study of caregivers for cognitively impaired care receivers, Pratt et al. (1985) found that levels of burden were generally high and did not differ according to whether the care receiver was living in an institution or at home. They suggested that the high level of burden experienced by caregivers whose relatives are institutionalized may be related to guilt over the placement which was often seen as a personal failure, coming after months or years of caregiving. Bowers (1988) maintained that families perceive institutional care as inadequate and needing to be supplemented by family participation and caregiving. Thus, family members may not experience changes in burden because their involvement with the care receiver continues to be intense even after institutionalization. However, these studies have not compared changes in burden beyond a one year period after the care receiver entered an institution. It is possible that level of burden does decrease as the length of the care receiver's institutionalization increases.

In terms of formal support in the community, the literature has suggested that most caregivers make minimal use of formal supports (Noelker & Wallace, 1985), and formal care is sought only after family resources have been exhausted (Soldo & Manton, 1985; Stone et al., 1987). The level of family care generally does not decrease after the initial use of formal health and social services (Chappell, 1985). In comparing families who were using or not using home-care support, few differences were found in the kind of informal support provided and level of burden (Hooyman et al., 1985). Evidence indicates that while high levels of burden lead to formal support service use, this utilization does not alter the level of burden (Bass & Noelker, 1987; Johnson & Catalano, 1983).

Informal support includes assistance from family, friends and neighbours. As indicated earlier, most caregiving research focuses on informal support, particularly family support for the care receiver. Less attention has been directed toward social support for caregivers, unrelated to care receiver need, and how this might affect burden.

## 2.1 CAREGIVER HEALTH STATUS

Initial impetus for research on caregiver burden arose from concern for family functioning and caregiver health. Caregiver burden research was viewed as providing a knowledge base for further applied research on interventions that could support family caregiving and reduce caregiver burden and subsequent premature institutionalization of the elder (Montgomery, 1989; Zarit et al., 1980). Zarit (1989) has questioned the value of additional research on burden unless such work will lead to the development of models to understand caregiving or to the collaboration of research and agency interests in the evaluation of interventions aimed at family caregivers.

The link between burden research and an applied focus on clinical intervention for caregivers explains to some extent the response that George and Gwyther (1986) received to their suggestion that caregiver burden and caregiver well-being were "two sides of the same coin". Several researchers argued that burden was not the opposite of well-being and that measurement of burden as deficiency in well-being neglected the relationship between caregiving and associated difficulties (Mongomery, 1989; Poulshock & Deimling, 1985; Schulz, 1990). The reluctance to separate caregiving from its impact may relate at least partly to a reluctance to give up caregiving as a referrent when planning caregiving-specific interventions as a secondary or future goal.

In fact, George and Gwyther's (1986) criticism that "an unwelcome kind of confounding" occurs when caregiving is related to its impact is only true when measures of burden are used to predict caregiver health. In that situation, burden instrument items that ask about health changes attributable to caregiving demands that are subsequently used to predict caregiver health, do confound the research question. However, if the purpose of the research is to examine the relationship between caregiving and its outcome or as Montgomery (1989) has suggested, to make comparisons across caregiver groups, then confounding is not an issue.

Depending on the research question, burden could be conceptualized and measured as either the negative impact of caregiving on the caregiver or as a deficiency in caregiver well-being without referring to caregiving per se. George and Gwyther (1986) have argued that a major advantage of measuring burden as a deficiency in caregiver physical health, mental health, social participation and financial resources is that it allows comparison of the well-being of caregivers with non-caregivers, establishing population norms. While this clearly is an advantage at population aggregate levels, this comparative data is much less useful to researchers whose interests lay in caregiver perceived changes in well-being that are attributable to caregiving and amenable to intervention.

The link between caregiver health status and burden and well-being is discernible. The link between caregiver health status and burden is evident as far back as the research on deinstitutionalized mental health patients, when Grad annd Sainsbury (1963) asked about the impact of the family member's return on the health of household members. This measurement item contributed to an overall burden score. Similarly, current instruments for measuring caregiver burden consistently include items or dimensions of caregiver health status. Caregivers are asked to indicate if their health has suffered because of caregiving (Montgomery et al., 1985a; Poulshock & Deimling, 1985; Zarit et al., 1986). Novak and Guest's (1989) instrument has physical health problems and emotional problems as two of the five dimensions of burden within the burden inventory.

In terms of caregiver health status and well-being, George and Gwyther (1986) include physical and mental health as indicators of well-being. For example, in their comparative research on caregiver and non-caregiver samples, George and Gwyther used self-rated health as a measure of physical health and a checklist of psychiatric symptoms (Short Psychiatric Evaluation Schedule) as a measure of mental health. Their findings indicated that caregivers had nearly three times as many stress symptoms as the comparison sample. No differences in self-rated health were evident between caregivers and non-caregivers.

George and Gwyther's (1986) study used global measures of caregiver physical and mental health status, that is, indicators not linked to any specific aspect of caregiving.

For this thesis, global measures of caregiver health status, similiar to those suggested by George and Gwyther (1986) are used to measure caregiving outcome. In particular, caregiver self-rated health and reported symptoms of depression are measures of caregiver health status. This research does not have an applied focus and instead attempts to address theoretical development through testing a model of caregiving. The subsequent section argues that a stress model incorporating the concepts of role strain and social support provides a theoretical perspective on caregiving.

# CHAPTER 3

# THEORETICAL FRAMEWORK

The theoretical framework is presented in three sections followed by formally stated hypotheses. The first section provides a definition of caregiver role strain that is congruent with Goode's (1960) original work on the conceptualization of role strain. Caregiver role strain as the felt difficulty in fulfulling role expectations represents caregiver appraisal. The "stress process model" (Lieberman, 1982; Pearlin et al., 1981; Pearlin et al., 1990), a transactions model of stress that integrates the use of personal and social resources in dealing with difficulties is reviewed in the second section. The application of a social model of stress for caregiving is described and the resultant caregiving model is presented. Key components of the caregiving model are the appraisal of difficulties and the place of social resources in mediating potentially harmful effects of stressors. In the third section, two models (the buffering and direct effects models) proposing possible relationships between social support and caregiver health status are described. Following this section, hypotheses on the relationship among caregiver role strain, social support and caregiver health status are stated. Additional hypotheses address the relationship between caregiver role strain and the caregiver characteristics.

## 3.0 CAREGIVER ROLE STRAIN

Caregiver burden, stress and role strain have used interchangeably in the gerontological literature to describe the negative impact of caregiving on the caregiver (Archbold, 1988;

Montgomery, 1989; Morycz, 1985; Scharlach, 1987). However, both role strain and stress have specific meanings within social science. In particular, the concept of role strain emanates from role theory and refers to "...the felt difficulty in fulfilling role expectations" (Goode, 1960, p. 483). Although frequent reference to the caregiver role has been made in the literature (for example, Crossman et al., 1981; Fengler & Goodrich, 1979; Robinson & Thurnher, 1979), relatively little work focusing on caregiving as a social role has been carried out. Gerontologists refer to the caregiver role in common parlance rather than from a formal theoretical standpoint.

The concept of role strain as defined by Goode (1960) has not received wide attention in the literature on caregiving. Following from Goode's definition, caregiver role strain is the felt difficulty in fulfilling caregiving role expectations. Accordingly, caregiver role strain involves an appraisal of caregiving and an assessment that meeting caregiving expectations is difficult.

Conforming to Goode's definition of role strain means that caregiver role strain is not the same as caregiver burden. Burden as the negative effect of caregiving on the caregiver included decrements in physical health, mental health and social life of the caregiver, and the emergence of undesirable feelings toward the care receiver. Caregiver role strain, as the felt difficulty in fulfilling caregiving role expectations, is an appraisal of the difficulties of caregiving; it does not encompass the caregiving-related physical, mental and social health outcomes. These outcomes are more appropriately viewed as the manifestations of a difficult caregiving situation.

As the felt difficulty in fulfilling caregiver role expectations, caregiver role strain represents an appraisal of caregiving. Individual appraisal of stressors has received key emphasis within social models of stress. Such models also emphasize the place of social support in mediating or modifying the relationship between a stressor and consequential health outcome. A social model based on stress theory and incorporating the concepts of role strain and social support provides a broader theoretical perspective on caregiving. The subsequent section provides a descriptions of stress theory and social models of stress from which a model of caregiving is derived.

## 3.1 CAREGIVING AND STRESS

### 3.1.0 Stress theory

Scientific interest in the impact of stressful conditions and events on health status has spanned disciplines, emanating from the biomedical and social sciences. Perhaps partly because of the multidisciplinary roots of stress-based research, there has been little agreement concerning the concept of stress itself (Depue & Monroe, 1986; Pearlin, 1982). "Stress" has been used in fundamentally different ways, referring to a condition or event that provokes individual response as well as the response itself (Neufeld, 1982). Selye (1956) identified a stressor as that which produces a stress response in the individual.

Currently, there is some agreement that stress should be reserved to describe the field of study, that stressor refers to internal and external environmental events or conditions, and that stress reaction refers to human response, either short-term or long-term that occurs as a consequence of exposure to the stressor (Elliot & Eisdorfer, 1982). Stressor and stress reaction are linked and an event or condition becomes a stressor when there is evidence of a consequent stress reaction.

Less agreement exists on defining criteria for stressors and stress reactions (Kasl, 1984; Pearlin et al., 1981). Depression, for example, can constitute either a stressor or a stress reaction. In general, stress reactions are manifested in physical, mental and social health outcomes and are measured with instruments that tap depression, anxiety or morale (Chiriboga, 1989). No generally accepted instruments to measure stressors are currently available and the selection of tools depends on whether the research question relates to the cumulative effects of stressors or the consequences of a particular stressor (George, 1989).

Based on evidence from animal and human studies, scientists have convincingly argued that stressors contribute to the occurrence of a variety of physical and psychological health disorders (Elliott & Eisdorfer, 1982; Hamburg et al., 1982). However, individuals have had markedly different responses to the same stressor, suggesting the influence of genetic, environmental and social factors (Pearlin, 1985; Rabkin & Struening, 1976). In addition, although this has not been addressed to a great extent, a tenet of stress theory is that stressors need not provoke only negative responses and "...what represents a crisis to one individual may simply be a challenge to another" (Chiriboga, 1989, p. 13). Clearly, the appraisal of the stressor and the resources to deal with it are factors to be considered. Researchers have continued to probe for attentuating factors in the relationship between stressor and stress reaction and have attempted to measure their mediating effects.

### 3.1.1 Stress process model

Social science models of stress take into account the process of appraisal and the potential contribution of mediating factors. A transactions model of stress incorporates individual assessment of stressors and mediating factors such as individual coping strategies and social network resources into the stressor and stress reaction paradigm. The essence of "transaction" within a transactions model is that which occurs between the individual and the stressor. The stressor can evoke changes in the individual and the individual can potentially alter the nature of the stressor. A stress reaction is the consequence of a perceived disparity of demands exceeding resources.

Lazarus and associates (1976; Coyne & Lazarus, 1980) have been prominent in developing the transactions model of stress. In particular, Lazarus and Folkman (1984) have emphasized the key role of appraisal in determining health outcome. Cognitive appraisal refers to evaluation of the demands in the environment and available resources to handle these demands. Appraisal is composed of two parts (Coyne & Lazarus, 1980;

Lazarus & Folkman, 1984). "Primary appraisal" refers to the cognitive process of evaluating an event as irrelevant, beneficial or harmful; "secondary appraisal" is a judgement concerning possible approaches or solutions to the condition.

Lazarus and associates integrated coping strategies as attenuating factors in the stressor and stress reaction paradigm. Coping strategies and not simply demands determined the occurrence and extent of the stress reaction. Coping is not simply a response to an event that has happened, but instead is an active process in shaping what has happened and what will happen (Lazarus, 1976). In Lazarus' model, coping served either to control the problem or the emotional response to it. Thus, individual coping was a reaction to demands and also a determinant of the overall stress experience.

While Lazarus and associates concentrated on individual coping, others have emphasized broader social network resources as mediators in the relationship between stressor and stress reaction. In particular, Pearlin and associates (Lieberman, 1982; Pearlin & Schooler, 1978; Pearlin et al., 1981) developed a transactions model called the stress process model that included both individual coping and social support as mediators in the context of discrete life events and chronic strains or "lifestrains". It should be noted that Pearlin and associates use "stressor" and "strain", and "role strain" and "lifestrain" as interchangeable concepts meaning enduring problems, and in the case of role strain and lifestrains, enduring problems associated with social roles (Pearlin, 1983; Pearlin & Schooler, 1978; Pearlin et al., 1981). For Pearlin and associates, "role strain" is a stressor.

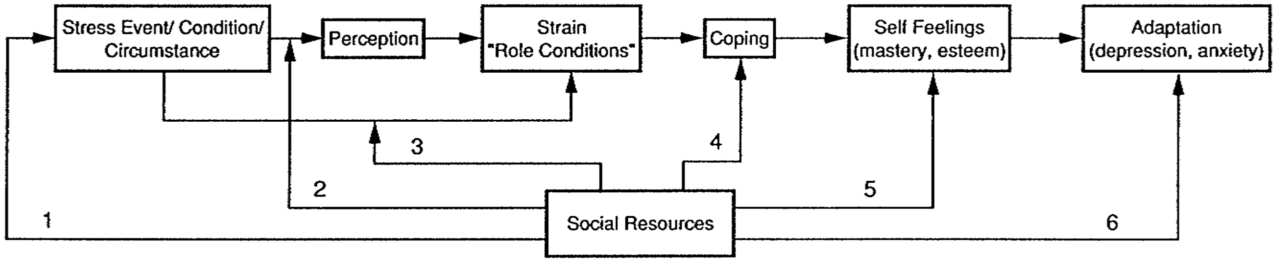
The stress process model consists of three conceptual domains: sources of stress; mediators of stress; and manifestations of stress. These domains conform to concepts of stressor, attentuating factors, and stress reaction as described earlier. For the stress process model, enduring lifestrains along with discrete life events compose the sources of stress or "stressors". Mediating resources consist of individual coping behaviour and social supports. Manifestations of stress, the "stress reaction", are health status outcomes and in particular, Pearlin and associates have studied depression symptoms as a stress reaction.

In the stress process model, the occurrence of life events (for example, losing a job) intensifies preexisting lifestrains or creates new strains within various roles such as parent and spouse. Lifestrains singly or in combination with difficult life events provide evidence of inability and lead to a diminishment of self, particularly to feelings of decreased "mastery" and "self-esteem". Sources of stress in combination with lowered self-esteem and perceived competence lead to the manifestation of stress symptoms including feelings of depression and other health disorders. This process is interrupted or altered by individual coping behaviour and/or social support resources. According to Pearlin et al. (1981), there are several junctures at which mediators can intervene in the stressor-stress reaction process, that is, "prior to an event, between the event and the lifestrains that it stimulates, between the strain and the diminishment of self-concept, or prior to the stress outcome" (p. 341).

Lieberman (1982) has diagrammed the stress process model to illustrate the junctures at which social supports or social resources influence the occurrence and effects of stressor (see figure 3.2.1). Social resources operate to: 1) reduce the likelihood of occurrence of stressful events; 2) modify the individual's perception of the event and hence mitigate the stress potential; 3) alter the relationship between role strain and the stress event; 4) influence coping strategies and thus, modify the linkage between the stressor and the stress reaction; 5) counteract the erosion of self-esteem and feelings of personal mastery; and 6) influence the adaptation or stress reaction directly (Lieberman, 1982, p. 77).

Figure 3.2.1

The Stress Process Model



Note. From "The effects of social supports on responses to stress" by M.A. Lieberman, 1982. In L. Goldberger & S. Breznitz (Eds.), Handbook of Stress: Theoretical and Clinical Aspects (p. 777). New York: The Free Press.

Lieberman's stress process model indicates less emphasis on the appraisal component compared with the Lazarus transactions model. In fact, Pearlin and associates do not address stressor appraisal in their writing except to refer briefly to individual "perception" or "meaning" of the event (Lieberman, 1982). However, empirical evidence supports the position that subjective appraisal of stressors plays a central role in determining health outcome (Meichenbaum & Turk, 1982; Snow et al., 1987). In her literature review of stress, social support and depression, George (1989) indicated that "...subjective assessment of stress...is more predictive of health and mental health outcome than is the simple occurrence of experience defined as stressful by external observers" (p. 244).

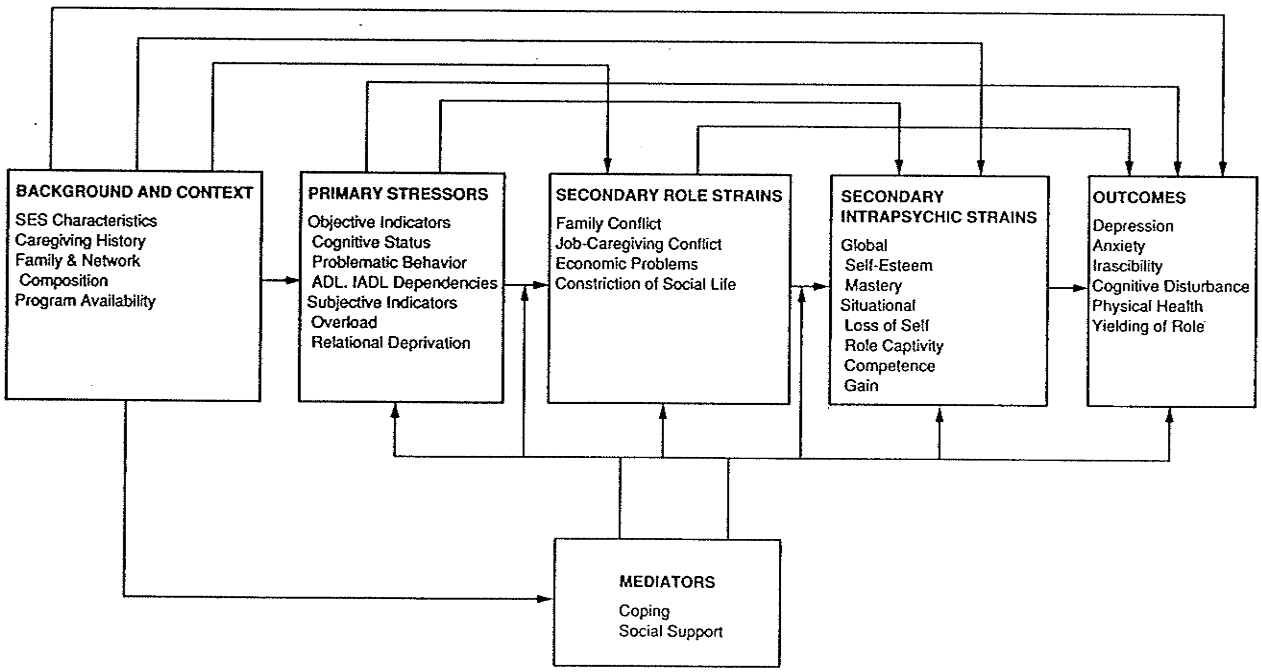
### 3.2.2 Stress process model and caregiving

Recently, Pearlin et al. (1990) have adapted the stress process model for elder caregiving (see figure 3.2.2). In addition to the three original domains of: sources of stress, mediators of stress; and manifestations of stress, a fourth domain has been identified, that is, the background and context of stress. This fourth domain represents four categories of information including: 1) sociodemographic characteristics of the caregiver; 2) aspects of caregiving history (including caregiver-care receiver family relationship; care receiver illness and care demands); 3) informal support resources; and 4) formal support resources. In essence, the fourth domain consists of those caregiver and care receiver characteristics as well as contextual or situational factors that have been associated with caregiver burden.

Within the sources of stress or stressor domain, Pearlin et al. (1990) identify primary and secondary stressors. Primary stressors "...stem directly from the needs of the patient and the nature and magnitude of the care demanded by these needs" (as indicated by care receiver cognitive status) while secondary stressors refer to "..other problems and hardships" that follow from the primary stressors. Secondary stressors are of two types, role strains and intrapsychic strains. The use of the term, role strain in this recent model follows closely from the original model (Pearlin et al., 1981) and role strains represent problems associated with social roles. In the recent model, role strain refers to problems with social roles (not including the caregiver role) that represent stressors for the caregiver. The second type of secondary stressor, intrapsychic strains includes diminished self-concept and mastery.

Figure 3.2.2

Caregiving and the Stress Process



Note: From "Caregiving and the stress process: An overview of concepts and measures" by L.I. Pearlin et al., 1990, The Gerontologist 30(5), p. 586.

In the domain of mediating conditions, Pearlin et al. (1990) include coping and social support and for the domain of manifestations of stress, physical, mental and social health outcomes are included. On the whole, these domains are expanded but are not essentially different from the original stress model (Pearlin et al., 1981). Currently, the stress process model is being tested with caregivers who are providing care to care receiver's suffering from Alzheimer's Disease. Pearlin et al. (1990) do not explain all of the relationships that are indicated by the several arrows connecting various domains and this likely reflects the developmental stage of the model. In fact, Pearlin et al. (1990) state that this model should be used as a "...heuristic device rather than as a literal reflection of realities and the pathways that join them, many of which are still unclear" (page 591).

The caregiving stress process model proposed by Pearlin et al. (1990) awaits testing. For the most part, the domains of the model reflect earlier work that linked stressor and stress reaction with factors that might mediate this relationship. The inclusion of the "background and context" domain and the identification of primary and secondary stressors represent an attempt to tailor the model for the caregiving context. This recent model like the original (Pearlin et al., 1981) does not emphasize the individual appraisal component, and it uses role strain interchangebly with stressor. Thus, the recent model suggested by Pearlin et al. (1990) does not represent a conceptual refinement of the earlier model. In fact, the lack of explanation of the relationships among concepts inhibits the the model's current wider application beyond that of Pearlin and his associates.

### 3.2.3 Caregiving model

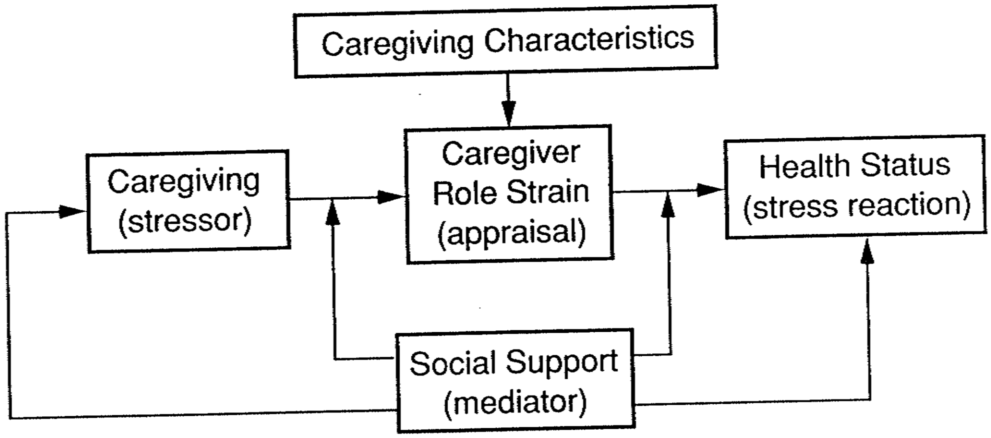
For this thesis, a model emanating from the stress process model (Pearlin et al., 1981) provides a framework for caregiving. Like the stress process model, this caregiving model incorporates concepts of stressor, stress reaction and mediators of the stressor-stress reaction. In addition, the concept of appraisal is clearly evident in the caregiving model. Caregiving is the source of stress or stressor, and caregiver role strain is the appraisal of caregiving as difficult. The definition of caregiver role strain follows from Goode's (1960) original definition and it is congruent with the concept of primary appraisal for the Lazarus transactions model of stress. While primary appraisal involves the evaluation of a stressor as irrelevant, beneficial or harmful, the definition of caregiver role strain is more restricting and does not include the possibility that caregiving is beneficial.

Health outcomes in the form of caregiver health status constitute the manifestations of stress or stress reaction. Stress reactions include changes in physical, mental and social health and well-being. The burden literature has indicated an association between caregiving and caregiver health status, in particular, between caregiving and depression. In the stress process model, social resources in the form of individual coping strategies and social supports are mediators in the relationship between stressor and the stress reaction (health outcome). In caregiving research, individual coping strategies have not been widely reported, however findings have indicated that burden and social support for the care receiver are inversely associated.

The caregiving model suggested here indicates a number of points where mediators can operate. Mediators can intervene prior to caregiving, between caregiving and the role strain role it invokes, prior to the stress outcome and after the stress outcome. Social resources will affect whether or not an individual becomes a caregiver and the nature of caregiving experience and whether or not it will become a a source of role strain. In addition, after appraisal of the difficulties of caregiving is made, social resources can influence whether or not this leads to changes in health status, and if so, social resources can come into play after this change occurs. Figure 3.2.3 provides a visual representation.

Figure 3.2.3

Caregiving Model



Caregiving characteristics represent caregiver, care receiver and the situational characteristics that have been identified as correlates of burden in the gerontological literature. This model suggests that these characteristics are integral in the appraisal of caregiving as difficult, that is, in appraising caregiving as a stressor. Emphasis on individual appraisal in the caregiving model is based on a body of research that has demonstrated the key role of appraisal in predicting health outcome (George, 1989; Meichenbaum & Turk, 1982).

Research based on variants of this type of model for caregiving research are few and relatively recent. Stull et al. (1988) found support for the hypothesis that having a second family caregiver would increase the well-being of the primary caregiver at higher levels of burden. This hypothesis was based on a stress model but what Stull et al. (1988) referred to as "stress" is more accurately "stressor" and it was measured using some items from the objective and subjective burden scale developed by Montgomery et al. (1985a). Stull et al. (1988) do not identify particular items so it may be that burden instrument items linking caregiving to well-being are confounded with well-being as an outcome measure. In addition, the model suggested by Stull et al. (1988) does not include an appraisal component.

Bass et al. (1988-89) used a stress model to encompass the simultaneous effects of elder impairment and social support on caregiver distress. The appraisal component of the model was identified as "...caregivers' perceptions of their relatives' impairments and the care support given by others [to the care receiver]" (p. 92). This definition of appraisal differs from the definition of primary appraisal offered by Lazarus and associates (1984; Coyne & Lazarus, 1980) and from the appraisal component of the caregiving model suggested here. Primary appraisal represents an evaluation of of a stress as irrelevent, beneficial or harmful. For the caregiving model, caregiver role strain is the appraisal of caregiving as difficult.

Another example comes from published work on developing a scale to measure caregiving as a stressor by Kinney and Stephens (1989). The scale is the caregiving hassles scale. In order to assess construct validity, this new scale was compared with instruments measuring three health outcomes: functioning in social life; morale; and somatic health. Five categories of caregiving stressor were represented on the scale including hassles associated with assisting the care receiver with basic and instrumental ADL; and hassles with the care receiver's cognitive status, behaviour and support network. For this study, social support was not conceptualized as a mediator between stressor and stress reaction. Instead, lack of social support was a potential stressor. In fact, while Kinney and Stephens (1989) referred to Lazarus' concept of appraisal, their purpose was not to explore or develop a model. Their aim was to provide validation for the caregiving hassles scale.

Although recent work by Pearlin et al. (1990) represents an attempt to place empirical findings from caregiving research into a conceptual framework, it is fair to say that social models of stress have not been systematically presented in caregiving research. While stress models have implicitly guided research, there has been very little formal theoretical development. In social science generally, a great deal of research has been carried out examining the modifiers of stressors and stress reactions, in particular the role of social supports. Empirical research supports the claim that social support can buffer the relationship between stressor and stress reaction/health outcome (Israel, 1983; Pilisuk & Froland, 1978). In addition, a direct association between social support and health status has been demonstrated (Berkman, 1985; Berkman & Syme, 1979). The relationship between social support and health status and the potential mediating role of social support within a stress model can be explored within the caregiving model. Examination of the concept and measurement of social support precedes a discussion of caregiving and social support models.

## 3.2 CAREGIVING AND SOCIAL SUPPORT

### 3.2.0 Social support

"Social support" has encompassed a host of diverse definitions (Depner et al., 1984). Definitions of social support have reflected the multidimensional nature of the construct and the specific purposes of the research. Measurement of this construct has been equally diverse. A dominant, well-validated measure of social support is absent and most researchers have developed scales as appropriate to their area of study (House & Kahn, 1985). Research on social support has expanded rapidly but the use of varying definitions and measures has meant that findings are difficult to compare and integrate (Depner et al., 1984; Procidano & Heller, 1983).

Several typologies have been developed to clarify the dimensions of social support. Caplan (1974) described social support in terms of informal and formal relationships. Informal support is provided by family, friends, and neighbours while formal support is provided by health care workers within agencies and institutions. Others have approached the subjective or objective dimensions of social support (Cohen & Willis, 1985; George, 1989). "Objective" social support refers to quantitative aspects of contact and interaction while "subjective" social support refers to individual assessment of the quality of social ties or interaction.

Another approach to the dimensions of social support has been suggested by Barrera (1986). In an attempt to clarify the social support concept, Barrera (1986), proposed three dimensions: 1) social embeddedness; 2) enacted support; and 3) perceived social support. Social embeddedness referred to individual ties with significant others. Enacted social support referred to the actual assistance individuals receive from their network members and perceived social support referred to the individual's assessment of the availability and adequacy of supportive ties. Each of these dimensions has been linked with measures of health and well-being.

Social embeddedness has typically been measured by indicators of participation in community activities such as number of support providers or amount of social contact. Such measures have equated marital status, church membership or participation in voluntary associations with social support without regard to whether or not these linkages actually provide support (Israel, 1981). Marital status has been consistently related to lower morbidity and mortality (Berkman & Syme, 1979) and the reported benefits of marriage have been greater for men than for women (Gove & Hughes, 1979). Membership and attendance in church and participation in other voluntary organizations have shown relatively consistent positive relationships to well-being (Berkman & Syme, 1979; Schoenbach et al., 1986).

Enacted social support referred to the actual assistance individuals receive from their network members. Enacted social support has commonly been measured by asking individuals to indicate the kinds of help (for example, emotional support) that they receive, either from formal or informal support resources. Investigators have categorized the kinds of help provided, usually classifying them as emotional, cognitive and material.

Emotional support referred to behaviour that lead the individual to believe that he or she is valued, respected and loved. Cognitive support referred to the provision of information and/or advice that assists the individual to assess accurately and to adjust appropriately to a situation. Material or tanglible support referred to provision of goods and services that help the individual to solve practical problems. These components may be independently provided by different persons (Israel, 1981). Research findings have indicated the primacy of emotional support over material support in reducing stress-related symptoms (Cohen et al., 1985) and in rating self health (Krause, 1987). However, it is difficult to separate these types of support because material support, especially if it is provided by a socially significant person often implies emotional support (Thoits, 1982).

Measures of enacted social support typically have included indicators such as the total number of persons in the individual's social network or the frequency of interactions with these persons. Findings linking these indicators with well-being have been inconsistent, suggesting that quality rather than quantity of interaction may be a crucial element (Israel, 1981; Pilisuk & Froland, 1978). Overall, quality of social support has been found to be the stronger predictor of health outcome (Antonucci, 1985; Blazer, 1982).

The third dimension of social support proposed by Barrera (1986) was perceived support. Perceived social support referred to the individual's assessment of the availability and adequacy of supportive ties. Cobb's (1976) conceptualization of social support typifies this dimension. Social support is "information" that leads the person to believe that he or she is cared for and loved (emotional support), esteemed and valued (esteem support) and belongs to a network of communication and mutual obligation (Cobb, 1976). Measures of perceived social support have focused either on confidence that, if requested, social support would be forthcoming or on satisfaction with support and support providers.

Research findings have indicated that perceived support is an important factor in mediating effects of stressors on psychological health (Wethington & Kessler, 1986; Kessler & McLeod, 1985). While the reasons for this are unclear, studies have indicated that actually receiving support is not always a positive experience, due at times to the inherent inequality or dependency status of being a recipient (Fisher et al., 1983; Ingersoll & Antonucci, 1983). Fisher et al. (1983) observed that receipt of assistance contains a mixture of supportive qualities (that is, evidence of caring and concern) as well as threatening qualities (that is, evidence of failure, inferiority and dependence). Perceiving that help is available when needed may be a more positive experience than actually accepting that help. Depending on the circumstances, accepting help may be an additional stressor rather than a mediator of the stress experience (Lieberman, 1982; Wethington & Kessler, 1986).

From his review of studies, Barrera (1986) concluded that indices of social embeddedness, enacted social support, and perceived social support were only modestly interrelated. He also hypothesized that stress mediating effects were more likely to occur when measures of perceived social support as compared with measures of social embeddedness and enacted social support were used. Similarly, George (1989) reported that subjective assessments of social support have been more strongly related to health outcome than objective assessments.

Regardless of the dimension of social support considered, research in this field has clearly focused on neutral or positive aspects of social interaction. Negative aspects of social support have not been emphasized. Much research on social support has assumed that social relations are supportive rather than examining which components are supportive and which are not (Depner et al., 1984). The cross-sectional design of most studies has prohibited an understanding of the causal relationship between social support and health and well-being (House, 1981). Questions about social support have not separated how the feeling of being supported, that is, the affective component of social support, influences general states of health and well-being and vice versa (Berkman, 1984). The underlying reason for the linkage between social support and well-being has not been clearly demonstrated. Social support could influence well-being or, decreased well-being could influence the perception of social support. In addition, depressed individuals may behave in a manner that leads to a reducton of social support behaviours from friends and family. When viewed at one point in time, social support and well-being are correlates without a clear causal direction.

### 3.2.1 Two models of social support

Based on empirical research, it has been argued that social support has a direct effect and a mediating effect on physical, mental and social health (Brownell & Schumaker, 1984; Dean & Lin, 1977). However, very little has been learned concerning the mechanism by which social ties and support influence health and well-being (Heller & Mansbach, 1984; Israel, 1983). According to the specificity model of social support, the type of support provided must be congruent with the type of need, that is, emotional support for emotional need (Cohen & McKay, 1986). While this seems intuitively obvious, very little work has been carried out to explore or develop the specificity model of social support.

Several hypotheses have been suggested to explain the relationship between social support and health status as delineated by Minkler (1981). First, the existence of a supportive network may mean that an individual is being encouraged by social contacts to take preventive action or to seek needed medical treatment. Second, the support provided by social networks may increase individual coping ability. By providing resources to deal with life's difficulties, the stressor reaction is curtailed. Social ties may act in a supportive manner by providing resources for coping with life problems and this in turn, may increase the individual's resistance to health problems.

Third, the perceived sense of support from others may lead to a more generalized sense of control. This theoretical approach has been taken by Pearlin and associates (Pearlin et al., 1981; Lieberman, 1982). They have suggested that social support may bolster feelings of mastery and self-esteem and thus mediate the potential deleterious effects of stressors. Similarly, Krause (1987b) suggested that social support operates by enhancing internal locus of control beliefs. However, his research indicated that the relationship between social support and perceived control is curvilinear, at least for emotional support (Krause, 1987b). An increase in emotional support tended to increase feelings of control up to a certain point, and beyond this point, additional support decreased feelings of control. These relatively global feelings of control and confidence may be the missing link between social support and health outcome (Minkler, 1981).

While there has been no clear agreement on the mechanism linking social support and health status, two models have become prevalent in the literature. The two models are the "direct effects" model and the "buffering" model. The direct effects model proposes that social resources have beneficial effects independent of stressors, that is, the relationship between social support and health status is direct. The buffering model suggests that social support buffers or protects individuals from the harmful effects of stressors (Cobb, 1976; 1979; Cassel, 1979). For individuals who possess low levels of social support, the model predicts that stressors will have a negative effect on health and well-being (Dean & Lin, 1977). However, for individuals who possess high levels of social support, the model predicts that stressors will have little impact on their health and well-being. The stress buffering model suggests an interaction between level of stressor and level of support. At its most stringent, the buffering model proposes a buffering effect for high support and high stressor level.

Several studies have examined the stress buffering function of social support and results have been mixed (Cohen & Willis, 1985). While findings from some studies have lent support to the buffering hypothesis (for example, Dean & Lin, 1977; Gore, 1978; Pearlin et al., 1981;) others have found no evidence of social support as a mediator (for example, Lin et al., 1979; Schaefer et al., 1981). Support for the direct effects model has come from community-based studies that have emphasized social ties such as marital status, contact with close friends and relatives, and membership in formal groups (Berkman & Syme, 1979; Schoenbach et al., 1986; Snow & Gordon, 1980). Longitudinal research has indicated that these factors are associated with lower morbidity and mortality (Berkman, 1985).

Although empirical research is far from conclusive, support has been indicated for both of these models. In fact, these models are not in direct opposition and support for each may depend on the conceptualization of social support as being linked to stressful events or as a measure of overall social integration (Cohen & Willis, 1985). Social support could have a positive effect on health status independent of stress and furthermore could ameliorate the effects of stress, that is, both models could be correct (Aneshensel & Stone, 1982). George (1989) has suggested further that some dimensions of social support may be important primarily because of their direct effects on health outcome whereas other dimensions are important largely during time of crisis.

The stress process model (Pearlin et al., 1981) is a buffering-type model and it proposes that the relationship between stressor and stress reaction can be mediated by individual coping strategies and the use of social supports but it does not preclude the direct effects of social support on health outcome. Similarly, the caregiving model that provides the framework for this research (figure 3.2.3) indicates several junctures where social support can mediate the relationship between stressor of caregiving and caregiver health outcome. In addition, there may be a direct link between social support and health outcome that reflects the direct effects model. Both the buffering and the direct effects of social support are included within the caregiving model.

### 3.2.2 Caregiving and social support models

Several studies of caregiving have examined the relationship between social support for the care receiver and burden (for example, Pratt et al., 1985; Zarit et al., 1980), reporting an inverse relationship between burden and social support. The definition and measurement of social support has been diverse within caregiving research. More often, social support is defined and measured as informal support (that is, support emanating from family members) rather than formal support (from agencies and institutions) for the care receiver.

Informal social support has been measured as the number of visitors to the care receiver's household (Marcus & Jaeger, 1984; Zarit et al., 1980) or as family members assisting the caregiver (Montgomery et al., 1985a; Pratt et al., 1985). Snow et al. (1987) measured social support as the caregiver's perceived availability of help from family and friends. The salience of perceived availability of informal support for well-being was found for spouses but not for adult child caregivers, reinforcing the importance of factors such as relationship to the care receiver and living arrangement. Most of the caregivers were living alone with their spouse (Snow et al, 1987).

In terms of formal support from agencies and institutions, the caregiving literature supports the notion that families provide the majority of care to elderly members and that this caregiving does not stop after the introduction of formal services. In their longitudinal study, Johnson and Catalano (1983) found that when burden was high, families utilized formal support but that this utilization did not decrease burden. They did not explore the relationship between formal support and changes in caregiver health status. Montgomery et al. (1985a) have suggested that formal care services must address specific and unique problems that caregivers are facing. Without phrasing it in the context of the specificity model, Montgomery et al. (1985a) suggested that formal agencies may only be able to assist caregivers with some but not all of the problems contributing to their feelings of burden. For example, if a caregiver feels constrained by constant surpervision of the care receiver, then providing housekeeping will not address the caregiver need for respite from supervision.

The caregiving model (figure 3.2.3) allows testing of both the direct effects and the buffering models of social support for elderly primary caregivers. The direct effects model suggests a direct relationship between social support and health whether or not caregiving is appraised as a stressor. This relationship should hold regardless of the level of reported caregiver role strain. Support for the buffering model is indicated when social support and health status are correlates in the presence of high caregiver role strain but not for low or no caregiver role strain.

## 3.3 RESEARCH HYPOTHESES

Hypotheses on the relationship among caregiver role strain, social support and health status among primary caregivers for the elderly are based in the caregiving model (figure 2.2.3). Additional hypotheses address the relationship between caregiver role strain or the appraisal of caregiving as difficult and factors that have been associated with caregiver burden. Caregiver characteristics including age, gender, functional ability, living arrangement and relationship to the care receiver have been associated with burden. These secondary hypotheses are grounded within the appraisal component of the caregiving model.

Hypotheses addressing the direct effects and buffering models of social support are stated first. In order to test the relationship among caregiver role strain, social support and caregiver health status, the hypotheses are stated in the context of level of caregiver role strain. A second set of hypotheses addressing the correlates of caregiver role strain follows.

### 3.3.0 Buffering and direct effects: Hypotheses #1, #2 and #3

The direct effects model posits a direct relationship between social support and health status regardless of the level of reported caregiver role strain. The following hypothesis addresses the direct relationship between social support and health status among those who indicated no caregiver role strain (n=109):

> 1) For caregivers indicating no caregiver role strain, there is a direct positive relationship between social support and health status.

The buffering model posits that social support acts as a buffer when caregiver role strain is high but does not act as a buffer when caregiver role strain is low or absent. The following hypotheses address the relationship between social support and health status for those who have indicated low caregiver role strain (n=42) and for those who have indicated high caregiver role strain (n=46):

> 2) For caregivers indicating low caregiver role strain, there is no relationship between social support and health status.
>
> 3) For caregivers indicating high caregiver role strain, there is a direct positive relationship between social support and health status.

These first three hypotheses address the relationship between social support and caregiver health status among elderly primary caregivers who report three different levels of caregiver role strain. The direct effects model proposes a direct relationship regardless of level of reported caregiver role strain. Thus, support for the direct effects model exists when for each caregiver group, there is a direct and positive relationship between social support and caregiver health status. The buffering model specifies the relationship between social support and caregiver health status only for high caregiver role strain. Thus, support for this model exists when the relationship between social support and caregiver health status holds only for the high caregiver role strain group but does not hold for the low and no caregiver role strain groups.

### 3.3.1 Correlates of caregiver role strain: Hypotheses #4 to #8

Drawing upon previous caregiver research findings on the correlates of burden, additional hypotheses are stated.

> 4) Female caregivers compared with male caregivers are more likely to indicate caregiver role strain and among those with role strain, females will indicate more strain than males.
>
> 5) Caregivers who co-reside with the care receiver compared with those do not, are more likely to indicate caregiver role strain and among those with strain, those who co-reside with the care receiver will indicate more strain than those who do not.
>
> 6) Spouse and adult child caregivers compared with other caregivers are more likely to indicate caregiver role strain and among those with role strain, spouse and adult child caregivers will indicate more strain than other caregivers.
>
> 7) Older caregivers compared with younger caregivers are more likely to indicate caregiver role strain and among those with role strain, older caregivers will indicate more strain than younger caregivers.
>
> 8) Caregivers with functional disability compared with caregivers who do not have functional disability are more likely to indicate caregiver role strain and among those with role strain, caregivers with functional disability will indicate more strain than caregivers who do not have functional disability.

# CHAPTER 4

# METHODOLOGY

The methodology used in this research is presented in four sections. In the first section, the advantages and disadvantages of secondary research are examined in general and for this research. Sample characteristics of the entire group of caregivers are presented in the second section. (Sample characteristics for subgroups of caregivers are presented in Appendix B.) Section three contains a description and discussion of the selected measures. The fourth section outlines the procedure for data analyses.

## 4.0 SECONDARY DATA ANALYSIS

Secondary analysis consists of any further analysis of one or more datasets that yields findings or knowledge additional to or different from those intended in the original research (Boruch & Reis, 1980; Hakim, 1982). Simply stated, it is the analysis of data after the original purposes (Walizer & Wienir, 1978). Secondary analysis has a long history in social science research and Durkheim's study of suicide has often been cited as a classic example. An examination of articles in the American Sociological Review and the American Journal of Sociology for 1979 indicated that two-thirds of the articles were based on secondary analysis (Hakim, 1982).

Secondary analysis encompasses several strategies. It may rely entirely on an existing dataset or it may involve some additional data collection to augment the dataset. The entire dataset or a portion of it may be used. The focus of the secondary analysis most often is different from the original analysis but development of new analytic techniques may spur a second analysis of a primary dataset. An existing dataset may be reanalyzed with more sophisticated statistical techniques with a view to challenge the conclusions of the original researchers (Hakim, 1982). Similarly, a primary dataset may be reanalyzed within the framework of an alternative theory or a newly developed model (Bryant & Wortman, 1978).

Few books have addressed secondary analysis as methodology; survey research texts tend to pay cursory attention to it. Overall, the literature on secondary analysis emphasizes its relative advantages and disadvantages. Although no evidence exists to support the assumption that collecting new data produce more significant contributions to social science than secondary analysis (Boruch & Reis, 1980), this notion has permeated discussions of advantages and disadvantages. The emphasis seems to be on defending the use of secondary analysis.

Clearly, advantages and disadvantages exist. The argument for secondary data analysis of existing datasets is based both on the cost-effectiveness of such research and its contribution to the social and behavioural sciences (Fortune & McBee, 1984). Secondary analysis eases the demands that might be placed on individuals who are selected as participants for a number of studies. Disadvantages are related to the availability and validity of measures from the primary research for the purposes of secondary analysis.

The cost advantage has predominated and secondary analysis offers economies of time, money and personnel that are particularly attractive when funds for new research are scarce (Boruch, 1978; Kiecolt & Nathan, 1985). Data collection represents the major cost in most behavioural science research, and the cost and complexity of large-scale data collection have been deterrents to the conduct of generalizable research in the social sciences (Fortune & McBee, 1984). The alternative of selecting a small, narrowly defined sample or a convenience sample may not be an acceptable or viable approach for addressing the research question, making secondary analysis a compelling choice.

Secondary analysis provides opportunities for several researchers to carry out empirical research, facilitating the generating of ideas and critical assessments, without inordinate increase in cost (Boruch & Reis, 1980; Hakim, 1982). Demands placed on secondary analysts to be different from or go beyond the primary analysis can encourage creativity and innovation. Secondary analysis permits the researcher to think more about the theoretical aims and substantive issues of the study rather than the practical and methodological problems of collecting new data (Hakim, 1982). It preserves time for pursuit of methodological innovation and for testing, refining and retesting theoretical models that were not part of the original research, the "old data for new research" approach (Boruch & Reis, 1980).

Demands placed upon the general public and upon particular groups within society can be limited through secondary analysis. The survey method has become widespread for many purposes including academic research, marketing and polling. As individuals are increasingly called upon to be respondents, they may become reticent about agreeing to participate. Declines in response rates have been noted in the 1970's and secondary analysis of existing surveys might provide a reasonable alternative for some topics (Hakim, 1982). Primary datasets that are large, possessing a breadth and depth of information provide the greatest potential for secondary analysis.

Major limitations involve availability and completeness of the data; secondary analysis is limited to the available measures (Kiecolt & Nathan, 1985). The question arises, were variables in the original study defined and operationalized appropriately in view of the current research interest? Typically, the secondary analyst will find that the original researcher asked a question that comes close to measuring the current topic of interest but is not the ideal question. Or the secondary analyst will find that the original researcher did not ask a needed question for the secondary analysis. The concerns are: was the question that was asked a valid measure of the current variable, and is the secondary analysis worthwhile given that not all desired variables are available? The onus rests on the secondary analyst to argue that the primary study's measures are reasonable measures for the ones needed.

This study of elderly primary caregivers is a secondary analysis of data collected for a large community-based study (n=1284). Data collection was completed in 1985. The design was cross-sectional and quantitative survey data were collected using interviewer administered questionnaires. The purpose of this research is not the purpose of the original study and a portion of the total original sample is used (n=197) for this analysis.

For this research, both the direct effects and the buffering hypotheses of social support and health are tested with elderly primary caregivers. Tests of buffering and direct effects of social support were not planned or examined within the original study. For the caregiving model (figure 3.2.3) suggested here, the potential stressor is caregiving. Caregiver role strain, the felt difficulty in fulfilling caregiver role expectations represents the appraisal of caregiving as difficult. The stress reaction is caregiver health status and the buffer or mediator is perceived social support. The caregiving model does not include individual coping behaviors as mediators although this was a component of the mediator domain in the stress process model (Pearlin et al., 1981). In the original study, no data were collected on individual coping strategies so this variable cannot be addressed. A limitation of this elderly primary caregiver study is that it cannot take individual coping behaviours into account.

A second limitation involves the conceptualization of caregiver role strain and the lack of information on the sources of strain for caregivers. Respondents were asked if they were the main person providing help for someone else and about the amount of interference such help had placed on them in the last six months. This single "interference item" forms the basis for grouping elderly primary caregivers into the three groups of "no caregiver role strain", "low caregiver role strain" and "high caregiver role strain". While the appraisal of caregiving as interference implies difficulty in fulfillment of role expectations, the measure does not directly address expectations. There is some information elicited on the impact of caregiving on employment, education and residence, no questions were asked concerning aspects of caregiving that constituted the "interference" or "expectation". Except for the caregiving tasks performed, there was no information on care receiver impairment. While links between care receiver impairment and burden have been inconsistent, suggesting the importance of other factors, (Poulshock & Deimling, 1985), it would have been useful to examine care receiver impairment as a correlate of caregiver health and role strain. In addition, the caregiver burden literature has suggested that certain aspects of caregiving, such as time inconvenience, may contribute to burden.

While not all desirable information was available, measures of social support and health status (self-rated health and depression) from the original study do reflect currently acceptable definitions and measurement in social social science research. Despite limitations of availability of information on caregiver coping and sources of caregiver role strain, this research has a major advantage related to the community sample base. This study of elderly primary caregivers provides an unusual opportunity to learn about a range of caregiving experience. A recognized weakness of previous research on burden is convenience sampling of caregivers from agency listings or from self-help organizations that has tended to favor selection of caregivers who are relatively distressed (Matthews, 1985). This research affords an uncommon opportunity to examine and compare caregivers who report a range of experience from no caregiver role strain to considerable caregiver role strain. This range permits testing the buffering and directs effects models of social support and allows an exploration of the relationships among caregiver characteristics and caregiver role strain.

## 4.1 SAMPLE CHARACTERISTICS

Interviews for the original study took on average, ninety minutes to complete. This was a stratified random sample of persons age 60 and older living in Winnipeg, Manitoba. The purpose of the original project was to study the relationship between living arrangement and informal and formal care through a sampling design which included stratification by three types of living arrangement, that is, intact marriages (n=301), living alone (n=423) and living with a person(s) other than a spouse (n=506). Those in personal care homes and congregate living arrangements were excluded. Names for the sample were randomly generated by the Manitoba Health Services Commission, the organization responsible for provincial health care claims. The overall refusal rate was 29%.

A copy of the questionnaire schedule is appended (Appendix A). Detailed information was obtained from respondents on their sociodemographic characteristics, residence relocations, life satisfaction, recreation, social relationships and interactions, health status and utilization of health care services. This group of 1284 individuals ranged in age from 60 to 101 (mean age of 71 years) and the majority were women (69%). Most were married (25%) or widowed (50%). Most reported no functional disability (60%) and good (48%) or fair (22%) health.

A group of 258 persons in this "living arrangements" study responded positively to an item addressing whether they were the main person providing help to another. Respondents were asked, "Are you the main person providing help for someone else at the present time?" Information was collected on the identity of the recipient of this help, where this care receiver lived, and what type of help was provided. After eliminating those respondents who were providing daycare support for a grandchild, and those who were providing "room and board" support for an adult child, a group of 197 primary caregivers remained. Table 4.1 provides information on caregiving characteristics for this group of elderly primary caregivers (n=197) .

The care receiver was identified as spouse, parent, sister, brother, friend, neighbour, in-law or family. The largest group of care receivers was the spouse (28%), followed by parent (18%) and sister (16%). Information was collected on the living arrangement of caregiver and care receiver, that is, in the same household, within walking distance, in the same city or outside the city. The majority of caregivers (65%) resided with the care receiver.

### TABLE 4.1
### CAREGIVING CHARACTERISTICS (n=197)

| | n | % |
|---|---|---|
| Relationship of care receiver to caregiver | | |
| Spouse | 55 | 28 |
| Parent | 36 | 18 |
| Sister | 31 | 16 |
| Friend | 27 | 14 |
| Neighbour | 20 | 10 |
| Other Family | 19 | 9 |
| Brother | 7 | 4 |
| In-Law | 2 | 1 |
| | 197 | 100 |
| Caregiver living arrangement with care receiver | | |
| Same household | 116 | 65 |
| Walking distance | 33 | 18 |
| Same city | 29 | 16 |
| Outside city | 1 | 1 |
| | 179 | 100 |
| Changes in lifestyle attributable to caregiving (more than one response) | | |
| Provided housing | 16 | 8 |
| Moved yourself | 13 | 7 |
| Quit work totally | 12 | 6 |
| Moved others | 8 | 4 |
| Quit work partially | 6 | 3 |
| Altered education plan | 3 | 3 |
| Not started working | 3 | 2 |
| Caregiving as interference | | |
| No interference | 109 | 55 |
| Not much | 42 | 21 |
| Noticeable interference | 21 | 11 |
| Considerable interference | 25 | 13 |
| | 197 | 100 |
| Tasks performed by caregivers (more than one response) | | |
| Emotional support | 139 | 71 |
| Grocery shopping | 119 | 60 |
| Eye on things | 114 | 58 |
| Emergencies | 109 | 55 |
| Housekeeping | 109 | 55 |
| Personal business | 108 | 55 |
| Food preparation | 102 | 52 |
| Transportation | 83 | 42 |
| House maintenance | 80 | 41 |
| Taking medications | 35 | 18 |
| Walking | 33 | 17 |
| Dressing | 33 | 17 |
| Cut toenails | 32 | 16 |
| Reading/Writing | 32 | 16 |
| Washing | 28 | 14 |
| Telephoning | 24 | 12 |
| Feeding | 16 | 8 |
| Toileting | 11 | 6 |

Note: Totals may not equal 197 because of missing values

Respondents were asked to identify the caregiving tasks within the categories of: 1) basic activities of daily living (that is, walking, dressing, feeding, washing and using the toilet); 2) instrumental activities of daily living (that is, housekeeping, household maintenance, transportation, food preparation, grocery shopping and personal business); and 3) other activities (that is, using the telephone, cutting toenails, taking medication, reading/writing, providing emotional support, keeping an eye on things and helping in emergencies). These activities of daily living represent the kinds of tasks that define caregiving in the gerontological literature. The caregiving task most frequently cited by caregivers was emotional support (71%). More than 50% of caregivers reported giving assistance with grocery shopping, housekeeping, food preparation, personal business and keeping an eye on things. More physically demanding caregiving tasks such as washing, toileting, walking and feeding the care receiver were reported by a smaller percentage of caregivers (6% to 17%).

Information was gathered on the interference that helping had entailed. Respondents were asked, "Considering the help you gave in the last 6 months, how much of an interference would you say it placed on you?" Slightly more than half of the caregivers (55%) indicated that the help they gave had not caused an interference. Of those caregivers who indicated that giving help had been an interference (n=88), three levels of interference were reported: 1) not much interference (48%); 2) noticeable interference (24%); and 3) considerable interference (28%).

Respondents were queried regarding the impact of caregiving on their employment status, residence relocation, education plans and modifications in housing. Generally speaking, these items did not elicit many affirmative replies. It may be that these items did not address pertinent areas of change for this group of elderly caregivers. For example, although caregiving-invoked changes in employment status have been reported in the literature (Brody, 1981; Cantor, 1980; Scharlach, 1987), the majority of these elderly primary caregivers were not employed (see table 4.2).

Table 4.2 provides a summary of selected sociodemographic characteristics . Caregiver age ranged from 60 to 91 with an average age of 69 years. Approximately two-thirds were women. Those who were married or had been widowed made up almost two-thirds of the sample. Caregiver income is indicated in table 4.2 and in terms of satisfaction with income, more than 80% reported that their income adequately or very well satisfied their needs. The past occupations of the majority of caregivers were in unskilled to skilled crafts and trades. This tends to reflect sample characteristics of years of schooling with the majority reporting the completion of high school or less. Sixty percent of respondents indicated no ethnic group membership or Canadian as their ethnic group and for religious preference, the two largest categories were Protestant (60%) and Catholic (23%).

Health status was measured by several items and is reported in table 4.3 . Respondents were asked to rate their health as "excellent", "good for your age", "fair for your age", "poor for your age" or "bad for your age". Most caregivers (73%) reported excellent or

TABLE 4.2
SELECTED SOCIODEMOGRAPHIC CHARACTERISTICS (n=197)

| | n | % |
|---|---|---|
| Employment status | | |
| Not employed | 158 | 80 |
| Employed full-time | 27 | 14 |
| Employed part-time | 10 | 5 |
| Employed occasionally | 2 | 1 |
| | 197 | 100 |
| Age | | |
| 60 to 64 | 59 | 30 |
| 65 to 69 | 54 | 27 |
| 70 to 74 | 39 | 20 |
| 75 to 79 | 27 | 14 |
| 80 to 84 | 13 | 7 |
| 85 and older | 6 | 3 |
| | 197 | 101 |
| Gender | | |
| Male | 69 | 35 |
| Female | 128 | 65 |
| | 197 | 100 |
| Marital status | | |
| Married | 77 | 39 |
| Widowed | 52 | 26 |
| Single | 42 | 21 |
| Divorced/Separated | 17 | 9 |
| Common law | 9 | 5 |
| | 197 | 100 |
| Average monthly income | | |
| No income | 3 | 2 |
| <$250 | 3 | 2 |
| $250-499 | 23 | 12 |
| $500-749 | 44 | 22 |
| $750-999 | 24 | 12 |
| $1000-1249 | 32 | 16 |
| $1250-1499 | 11 | 6 |
| $1500-1749 | 13 | 7 |
| $1750-1999 | 9 | 5 |
| $2000-2249 | 9 | 4 |
| $2250+ | 13 | 7 |
| | 184 | 101 |

| | n | % |
|---|---|---|
| Income satisfying needs | | |
| Very well | 60 | 31 |
| Adequately | 105 | 53 |
| With some difficulty | 21 | 11 |
| Not very well | 6 | 3 |
| Totally inadequate | 4 | 2 |
| | 196 | 100 |
| Previous occupation | | |
| Semi-skilled | 74 | 38 |
| Skill crafts/trades | 54 | 27 |
| Housewife | 27 | 14 |
| Professional | 19 | 10 |
| High level management | 16 | 8 |
| Farmer | 6 | 3 |
| | 197 | 100 |
| Years of schooling | | |
| None to six years | 13 | 7 |
| Seven to twelve years | 142 | 72 |
| More than thirteen years | 42 | 21 |
| | 197 | 100 |
| Ethnic group membership | | |
| No ethnic group | 75 | 38 |
| Canadian | 43 | 22 |
| British | 21 | 11 |
| German/Austrian | 12 | 6 |
| Ukrainian | 9 | 5 |
| French | 8 | 4 |
| Other | 29 | 16 |
| | 197 | 102 |
| Religious preference | | |
| Protestant | 118 | 60 |
| Catholic | 45 | 23 |
| No preference | 22 | 11 |
| Jewish | 7 | 4 |
| Eastern Orthodox | 5 | 3 |
| | 197 | 101 |

Note: Due to rounding, percentage exceeds 100%
Totals may not equal 197 because of missing values

good health with only a few reporting poor or bad health. In addition, respondents were asked to report on the number of days spent in hospital and spent sick in bed at home during the past twelve months. The vast majority reported no days in hospital (85%) and no bedridden days at home (80%). While a number of chronic conditions were reported, more than two-thirds reported no functional disability, that is, more than two-thirds reported that they required no assistance with their own activities of daily living.

The characteristics of these elderly caregivers reflect what might be expected from individuals who are able to provide care for another person. Most caregivers were no longer formally employed and the majority were women. Generally speaking, they reported good health and satisfaction with income. A little more than half reported that caregiving was not an interference. Reported caregiving tasks do not appear to be overly demanding in terms of physical exertion for most caregivers. For the vast majority, caregiving has currently not necessitated changes in employment, education and housing.

Note:

Tables illustrating caregiving, sociodemographic and health characteristics for the subgroups of primary caregivers (n=109; n=88; n=42; and n=46) are available in Appendix B.

## TABLE 4.3
## SELECTED HEALTH CHARACTERISTICS (n=197)

| | n | % |
|---|---|---|
| Self-rated health | | |
| Excellent | 48 | 25 |
| Good | 93 | 48 |
| Fair | 46 | 24 |
| Poor/Bad | 8 | 4 |
| | 195 | 101 |
| Days in hospital | | |
| None | 166 | 85 |
| 2 to 7 days | 16 | 8 |
| 10 to 21 days | 9 | 5 |
| 35 to 90 days | 4 | 2 |
| | 195 | 100 |
| Bedridden days | | |
| None | 156 | 80 |
| 1 to 7 days | 30 | 15 |
| 10 to 20 days | 6 | 3 |
| 30 to 50 days | 3 | 2 |
| | 195 | 100 |
| Functional disability | | |
| No disability | 134 | 68 |
| Some disability | 63 | 32 |
| | 197 | 100 |
| Chronic conditions (more than one response) | | |
| Arthritis and Rheumatism | 102 | 52 |
| Heart and circulation | 82 | 42 |
| Stomach troubles | 49 | 25 |
| Ear problems | 43 | 22 |
| Foot trouble | 38 | 19 |
| Nerves/emotional | 35 | 18 |
| Skin problems | 35 | 18 |
| Chest problems | 33 | 17 |
| Dental problems | 32 | 16 |
| Eye problems | 29 | 15 |
| Kidney problems | 20 | 10 |
| Diabetes | 9 | 5 |
| Cancer | 9 | 5 |
| Stroke | 4 | 2 |
| Palsy | 2 | 1 |

Note: Due to rounding, percentage exceeds 100%
Totals may not equal 197 because of missing values

## 4.2 MEASUREMENT

### 4.2.0 Caregiver health status

The dependent variable for the buffering and direct effects hypotheses is caregiver health status. Two measures of health status are used, that is, self-rated health and depression. Data for self-rated health was provided when respondents rated their own health as excellent, good, fair, poor or bad compared with others their own age. Although the measure of self-rated health is often found in gerontological research, except for George and Gwyther (1986) it has not been commonly used in caregiving studies. Self-rated health has been used as an indicator of physical health (for example, Liang et al, 1989), mental health (for example, Wan et al., 1982) and functional ability (for example, Fillenbaum, 1979), reflecting the three dimensions of physical, mental and social health. In particular, several studies support the association between self-rated health and activity, mobility and functional ability (Graney & Zimmerman, 1981; Maddox, 1962; Tissue, 1972) suggesting that an older person's conceptualization of health may be grounded in their perceived ability to function in everyday activities and tasks. However, because most research is cross-sectional, it is not possible to determine whether functional disability results in poor health ratings or whether perception of poor health leads to decreased functional ability (Linn & Linn, 1980).

Construct validity for self-rated health and physician assessments has been documented (Garrity et al., 1978; Kaplan et al., 1988). Disagreements between self-rated health and clinical medical evaluation tend to reflect a more favorable report from the elderly person (LaRue et al., 1979; Maddox & Douglass, 1973). Empirical research has consistently found optimism on the part of elderly persons who have been asked to rate their own health. Older people tend to report favorable health despite chronic illness and reduced functional ability that might provide the basis for more pessimistic reports (Mossey & Shapiro, 1982). Evidence suggests that this health optimism increases with age and the very old (age 75 years and older) rate their health higher than younger persons (age 65 to 74 years). Linn and Linn (1980) reported data indicating that the non-institutionalized very old persons, except for having had more surgery during their lifetime, had no more indications of pathology than those in the younger groups and in fact, reported taking significantly fewer medications. It has been suggested that the very old may represent a biologically elite group and that they are in fact, as healthy or healthier than younger persons (Linn & Linn, 1980; Mossey & Shapiro, 1982).

Self-rated health has been strongly correlated with objective measures of health and it has predicted subsequent mortality better than either medical records or physician generated data (Kaplan et al., 1988; LaRue et al., 1979; Mossey & Shapiro, 1982;). In particular, Mossey and Shapiro (1982) have suggested that those who rate their health as fair or poor should be considered high risk and should be followed with greater clinical diligence. Maddox and Douglass (1973) reported satisfactory stability for self-rated health status and physician rated health with repeated measures of an elderly sample during a fifteen year period. In his review of health measures, Stahl (1983) has suggested that self-rated health is an ideal indicator of general levels of health and an exellent tool for survey work.

Maddox and Douglass (1973) have argued that self-rated health is not a random reporting but persists in a positive relationship with more objective physician generated evaluations of health status. Garrity et al. (1978) further suggested that self-rated health is a useful proxy for clinically measured health status. Self-rated heath has not been extensively used as a measure of caregiver health status in the caregiving literature. However, given widespread use in gerontological research and the demonstrated relationship between self-rated health and other evaluations of health status, it was selected as a measure of caregiver health status within the caregiving model. In view of the small number of caregivers who reported poor or bad health and the higher risk associated with those who indicate fair or poorer health (Mossey and Shapiro, 1982), self-rated health was reduced to a three point scale (fair/poor/bad=1; good=2; and excellent=3).

For the second measure of caregiver health status, the 20-item Center for Epidemiological Studies Depression Index (CES-D) (Radloff, 1977) of depression symptoms was used. Items for this scale were previously selected from validated depression scales including those of Zung (1965), Beck et al. (1961) and the Minnesota Multiphasic Inventory (1960). The CES-D scale is widely used in community surveys for assessing levels of depressive symptoms. Respondents are asked the frequency with which they have experienced each of a list of symptoms or feelings during the previous week. Somatic symptoms include loss of appetite and sleep disturbance (seven items) and the list of feelings includes those of loneliness, sadness and failure (seven items). Four items are stated with a positive perspective, referring to happiness and hopefulness, and were designed to interrupt a possible response set tendency as well as to assess positive affect (Radloff, 1977). Finally, two items refer to interpersonal difficulties, that is, the respondent's perception of unfriendliness and dislike from others.

Item response categories for the CES-D range from zero (for less than one day) up to three (for five to six days). The potential range is from zero to sixty. For this group of elderly primary caregivers, the range was zero to forty-two, with a mean of 7.2. A cut-off score of sixteen has been used to distinguish depressed from non-depressed persons (Boyd et al., 1982). A score of sixteen or higher indicates a high level of depressive symptoms and has been correlated with other indices of depression (Goldberg et al., 1985). For this group of caregivers, approximately 12% achieved a score of sixteen or higher. This prevalence is similar to previous findings of 10% and 15% in community samples (Goldberg et al., 1985; Blazer & Williams, 1980).

Content, criterion and construct validity, and test-retest and internal consistency reliability for the CES-D scale have been reported (Radloff, 1977). This scale does not measure clinically defined depression; it measures the current level of depressive symptoms (Boyd et al., 1983). As such, it is an appropriate measure for a community-based sample. The CES-D has been tested and shown to be valid and reliable across age groups (younger than 25, 25 to 64 and older than 64 years of age) (Radloff, 1977). Although further study is required, it has been suggested that the CES-D is valid cross-culturally (Liang et al., 1989). For this research, coefficient alpha is .83, indicating adequate internal consistency.

### 4.2.1 Social support

The major independent variable of interest for the buffering and direct effects hypotheses is social support. While social support can be conceptualized in several ways, only perceived social support measures were selected for this research. Perceived social support measures provide information on sources of help if needed, indicating availability and implying aspects of individual choice. Limitations existed for available embedded and enacted social support measures from the original research for the purposes of this secondary analysis. Embedded social support measures such as marital status, and club membership were present in the original study but such measures do not specify whether support was actually available. For enacted support, as measured in the original study by assistance with activities of daily living, concerns involved the limitation of this measure in view of the fact that approximately two-thirds of the caregivers reported no functional disability.

Two measures of perceived social support were selected. These measures focus on the respondent's assessment of potential support that would be available and forthcoming when needed. Respondents were asked, "If you were not feeling well, for whatever reason, among your family, friends and neighbours, who if anyone, would call you regularly?" For this question, respondents were asked to identify up to two individuals who would provide this emotional support (see table 4.4). In addition, respondents were asked to identify who would get groceries or essentials for them if they were ill. This question on material support asked, "If you were not feeling well, for whatever reason, among your family, friends and neighbours, who, if anyone would get groceries, essentials, etc. for you?" Again, respondents were asked to identify up to two individuals who would provide this support (see table 4.4).

Table 4.4
Caregiver Perceived Support (n=197)

| | n | % |
|---|---|---|
| Number of persons who would get groceries/ essentials if caregiver was ill | | |
| No informal supports | 19 | 10 |
| One person | 115 | 58 |
| Two persons | 63 | 32 |
| | 197 | 100 |
| Number of persons who would call regularly if caregiver was ill | | |
| No informal supports | 18 | 9 |
| One person | 85 | 43 |
| Two persons | 94 | 48 |
| | 197 | 100 |

Scores for both of the perceived social support measures were developed by counting the number of persons identified by the respondent. The possible values were zero (no informal support), one person or two persons. For perceived emotional support, almost half (48%) indicated that two persons would call regularly if needed, 43% indicated one person, and 9% indicated that no informal support was available to them (see table 4.4). For perceived material support, that is, for the provision of groceries and essentials, the same values were possible: no informal support or one or two informal supporters. The majority of caregivers (58%) indicated that one person would be available if needed, 32% indicate two persons, and 10% indicated that no family or friends would be available for instrumental support in time of illness. These two measures appear to address different dimensions of support, that is, material versus emotional support, and in view of the low correlation (+.16), the measures were left separate and were not combined into a single score.

### 4.2.2 Caregiver role strain

Caregiver role strain was measured with the item addressing appraisal of the interference that caregiving had placed upon the caregiver. The response set for this item was "no interference", "not much of an interference", "a noticeable interference" and "considerable interference". Two dichotomous variables were created. First, a dichotomous variable addressing presence or absence of caregiver role strain was created; caregivers who indicated no interference were labelled "no caregiver role strain" and caregivers who indicated not much, noticable or considerable interference were labelled "yes caregiver role strain". A little more than half (55%) indicated no caregiver strain (see table 4.5).

Table 4.5
Caregiver Role Strain

| | n | % |
|---|---|---|
| Presence of caregiver role strain | | |
| No caregiver role strain | 109 | 55 |
| Yes caregiver role strain | 88 | 45 |
| | 197 | 100 |
| Level of caregiver role strain | | |
| Low caregiver role strain | 42 | 48 |
| High caregiver role strain | 46 | 52 |
| | 88 | 100 |

The second dichotomous variable was created within the "yes caregiver role strain" group to indicate level of reported caregiver role strain. Caregivers indicating noticeable and considerable interference were combined because they appeared closer to each other relative to degree of interference compared with those who indicated not much of an interference. Caregivers indicating noticeable or considerable interference were labelled "high caregiver role strain"; caregivers who indicated not much interference were labelled "low caregiver role strain" (see table 4.5). Slightly less than half of these elderly primary caregivers (48%) indicated low caregiver role strain compared with 52% who indicated high caregiver role strain.

### 4.2.3 Caregiver characteristics

Age, gender, functional ability, living arrangement with the care receiver and relationship to the care receiver are the selected caregiver characteristics. Caregiver age is a continuous variable with a range of 60 to 91 years of age. A dummy variable was created for gender (male=0; female=1). Functional ability is usually assessed with measures of self care and daily living activities (Ernst & Ernst, 1984). These activities have been categorized into "basic", "instrumental" and "other" ADL and several tools have been developed to address one or all of these categories (for a review of measures, see Ernst & Ernst, 1984; Kane & Kane, 1981).

Respondents were asked about their ability to perform tasks including basic ADL (that is, walking or transfers, dressing, feeding or eating, washing, bathing or grooming and using the toilet), instrumental ADL (that is, housekeeping, household maintenance, transportation, grocery shopping and personal business affairs) and other ADL (that is, using the telephone, cutting toenails, taking medication or treatment and reading or writing). The response set for these items was dichotomous, that is, "yes" or "no". For this research, overall functional disability was summarized as a dichotomous variable indicating either disabled or not disabled (0=no disability; 1=disability). This dichotomization of older persons according to functional ability is not uncommon in the literature (Blazer & Williams, 1980; Moritz et al., 1989; Katz, 1963). However, categorizing persons with a limitation in at least one of the ADL activities as "functionally disabled" produces a relatively larger number of disabled persons than if a more liberal approach were taken.

In order to address the caregiver's relationship to the care receiver, two dummy variables were created to separate spouse, child and other caregivers (0=not a spouse caregiver; 1=spouse caregiver and 0=not a child caregiver; 1=child caregiver). Living arrangement focused on whether or not the caregiver and the care receiver live together (0=caregiver and care receiver do not share the same household; 1=caregiver and care receiver do share the same household).

## 4.3 PROCEDURE FOR DATA ANALYSIS

### 4.3.0 Testing of Assumptions

Multiple linear regression analysis provides information on relationships between a dependent variable and two or more independent variables concurrently. The use of multivariate analytic techniques, necessary for testing the research hypotheses, is predicated on a set of assumptions. These assumptions relate to issues of normality, linearity and independence. In addition, multicollinearity or the greater correlation among independent variables than between independent and dependent variables must be addressed.

Violation of assumptions necessary for regression analysis are assessed using several procedures. The analysis of residuals and graphic methods are often helpful in identifying breaches in assumptions (Cohen & Cohen, 1983). In linear regression, the residual is the difference between the observed and predicted values of the dependent variable. Computer software packages provide the output of residuals and these residuals can be plotted in scatterplots and histograms. When assumptions are violated, data can be transformed but the type of transformation depends on the circumstances (Sjoquist et al., 1974).

Multicollinearity is a high degree of linear relationship among independent variables. The presence of highly correlated independent variables in a regression model may cancel the statistical effects of the variables. When taken separately, each variable might have been significant but in combination, none achieve significance. Multicollinearity can be avoided by careful choice of variables, that is, if several variables are known to measure the same factors, not more than one should be selected. Multicollinear relationships may be detected with bivariate and multivariate techniques. Two highly correlated independent variables (coefficients of .80 or larger) may be revealed in a preliminary correlation matrix (Lewis-Beck, 1980).

However, multicollinearity cannot be accurately assessed until the relationship among independent variables is examined in the regression procedure. Each independent variable is regressed on all the other independent variables. When the r-squared from these equations is near 1.0, high multicollinearity is evident (Lewis-Beck, 1980; Norusis, 1985). An additional test involves observed changes in stability of parameter estimates as each independent variable is entered in a stepwise procedure. When multicollinearity is suspected, one of the highly correlated variables typically is omitted from the regression (Sjoquist et al., 1974).

### 4.3.1 Buffering and Direct Effects: Hypotheses #1, #2 and #3

Hypotheses #1, #2 and #3 address the buffering and direct relationship between social support and health status among elderly primary caregivers reporting varying levels of caregiver role strain. The direct effects model proposes a direct relationship between social support and caregiver health status, regardless of the level of caregiver role strain. The buffering model posits an interaction between the level of social support and the level of caregiver role strain. High level of social support in the presence of high caregiver role strain buffers negative effects on health status. According to the buffering model, when caregiver role strain is low, the relationship between social support and health is not meaningful.

Currently, two approaches exist for studying this interaction between social support and caregiver role strain. An interaction term (support x strain) can be placed in the regression model. Alternatively, a subgroups approach can be taken and groups are divided according to high and low levels of strain, and the effect of social support on health status is measured directly. Arguments supporting and criticizing each approach have been made. Krause (1989) has argued for the subgroups approach, suggesting that the creation of an interaction term compounds the measurement error of the component parts leading to biased estimates of any relationships involving this variable. On the other hand, George (1989) has argued that while the subgroup comparison "...can generate evidence supporting interactive effects,...the statistical significance of the differences across subgroups is not directly tested" (George, 1989, p. 256). Given that each approach has limitations, no clear preference is evident. For this research, both approaches were taken. Data were analyzed first, by using the subgroup approach and second, by creating an interaction term for the entire sample.

Three subgroups were created including: 1) caregivers (n=109) who indicated that caregiving was not a stressor ("no caregiver role strain"), 2) caregivers (n=42) who indicated low caregiver role strain, and 3) caregivers (n=46) who indicated high caregiver role strain. Identical regression equations are tested for all three subgroups of caregivers. While social support is the independent variable of primary interest, age, gender and functional disability, often associated with self-rated health and depression are included in the analyses. Functional disability or limitations in the ability to perform activities of daily living (ADL) has been shown to be associated with both depressive symptoms (Berkman, 1985) and self-rated health (Ferraro, 1980; Stewart et al., 1977). Age and gender have been correlated with self-rated health and social support measures

(Antonucci, 1985), and with depression. Women indicate higher depression scores compared with men at every age (Chaisson-Stewart, 1985). Belonging to the "old-old" group, that is, those persons age 75 and older has also been linked with a higher level of depression (Blazer & Williams, 1980). The relationship between age and depression may be secondary to increasing functional disability among the old-old (Blazer & Williams, 1980). Association between level of depression and social support characteristics has been reported but the causal direction is uncertain (Goldberg et al., 1985).

Although the interrelationship between age, gender and functional ability has not been precisely determined (Ernst & Ernst, 1984), data indicate a direct association between age and functional disability (Branch & Jette, 1981; Jette & Branch, 1981; Shanas & Maddox, 1976) and women tend to report greater functional disability (Branch & Jette, 1981a; Shanas & Maddox, 1976).

For each subgroup, the relationship of social support, age, gender and functional disability on health status was tested. Separate regression analyses were carried out for each measure of health status (that is, self-rated health and depression). Results would indicate support or lack of support for the buffering and direct effect of social support among elderly primary caregivers' health status as measured by their own ratings of health and by level of depression. A significant relationship between social support and health status across all subgroups, would support the direct effects model. However, a significant association between social support and health status restricted to the high caregiver role strain group would provide support for the buffering model.

To test the relationship between social support and health status, while controlling for age, gender, and functional disability, separate hierarchical regressions were run with dependent variables of depression and self-rated health. Age, gender and functional disability were entered as a block followed by the social support variables. An integral part of the subgroup approach for testing the relationship among social support, caregiver roel strain and health status, is a statistical comparison of slopes. The formula provided by Ferraro (1987) was used for this comparison of slopes:

$$t = \frac{b_1 - b_2}{\sqrt{SE_1^2 + SE_2^2}}$$

where b refers to the unstandardized coefficient and SE refers to the standard error of b.

Taking the second approach, an interaction term (support x strain) was created for each of perceived emotional support and perceived material support with caregiver role strain. Age, gender and functional disability were entered first in the regression model, followed by the component terms, support and strain. Following the suggestion by Cohen and Cohen (1983), the interaction terms were forced in after the component terms. Separate regression analyses were carried out for each measure of health status, that is, self-rated health and depression. Results from the subgroup and interaction term approaches were subsequently compared.

### 4.3.2 Correlates of caregiver role strain: Hypotheses #4 to #8

Hypotheses #4 to #8 test caregiver age, gender, functional disability, living arrangement and relationship to the care receiver as correlates of the presence or absence of caregiver role strain, and of the level of reported caregiver role strain (high or low). The gerontological literature on caregiver burden suggested these correlates. Women caregivers compared with men, and caregivers residing with the care receiver tend to report caregiving as burdensome. Caregivers with a closer family bond such as spouse and adult child caregivers also report greater burden compared with other caregivers. The relationship between burden and caregiver age has been inconsistent and may be related to additional factors such as employment (in the young) and functional disability (in the old).

For hypotheses #4 to #8, regarding the reported presence or absence of caregiver role strain, the entire group of caregivers (n=197) was dichotomized into those who report no caregiver role strain (n=109) and those who report some caregiver role strain (n=88). Bivariate relationships between each of the independent and dependent variables were tested. Then, a logistic regression model was applied, that is, a regression of the selected caregiver characteristics on the binary outcome of reported presence or absence of caregiver role strain was carried out. In logistic regression, the probability of falling into one of two categories is a function of the values of the independent variables in the equation. The use of logistic regression in social science has been relatively recent but for regression equations with dichotomous dependent variables, opinion has favored logistic regression as the most theoretically correct procedure (Cleary & Angel, 1984; Harrell, n.d.).

Hypotheses #4 to #8 also addressed the level of reported caregiver role strain among those who indicated strain. The binary dependent variable was reported level of caregiver role strain, that is, high caregiver role strain (n=46) and low caregiver role strain (n=42). An identical model of independent variables, including age, gender, functional ability, living arrangement and relationship to the care receiver was tested. Bivariate and logistic regression procedures were carried out.

# CHAPTER 5

# RESEARCH FINDINGS

Research findings are presented in four sections. First, a description of the procedure for testing assumptions is provided. Second, the results of testing hypotheses #1, #2 and #3, relating to the buffering and direct effects models of social support and health status are reported and discussed. Third, the results of testing hypotheses #4 to #8, addressing correlates (age, gender, functional disability, relationship with the care receiver and living arrangement) of caregiver role strain (presence or absence; high or low) are presented and discussed. Finally, correlates of reported caregiver role strain are examined in relation to types of caregiving tasks performed.

## 5.0 TESTING OF ASSUMPTIONS

The distribution assumptions of linearity, normality, homogeneity of variance and multicollinearity of variables for each of the groups involved in testing hypotheses were assessed. For the first set of hypotheses (#1, #2 and #3) relating to the buffering and direct effects of social support on health status, four groups were involved:

1) combined no, low and high caregiver role strain (n=197);
2) no caregiver role strain (n=109);
3) low caregiver role strain (n=42); and
4) high caregiver role strain (n=46).

The three groups of "no", "low" and "high" caregiver role strain allowed a "subgroup" approach for examining the potential interaction of strain and support on health status. The combined group of all caregivers (n=197) enabled a further testing of the buffering or direct effects of social support on health status through use of an interaction term (strain x support) in the regression model.

The second set of hypotheses (#4 to #8) were related to the correlates of caregiver role strain. For the dependent variable, presence or absence of caregiver role strain, the entire sample of caregivers was used (n=197). For the dependent variable, high or low caregiver role strain, the high caregiver strain group (n=46) and the low caregiver strain group (n=42) were combined (n=88).

To test the assumption of linearity between independent and dependent variables, the breakdown procedure in SPSSX ("test of linearity") was employed. The values of r-squared and eta-squared were compared for a difference of greater than .05. According to Blalock (1972), r-squared subtracted from eta-squared indicates the proportion of variation explained by a non-linear relationship. If the difference between r-squared and eta-squared is greater than what might be expected by chance (that is, 5%), then a nonlinear relationship is indicated. The linearity assumption held for all relationships except those involving caregiver age, a continuous variable with a range of 60 to 91. To address this violation of assumption, truncation of the extreme values of age was carried out but this proved ineffective.

A decision was made to dichotomize age into those age 60 to 74 years old and those 75 to 91 years old. The categorization of elderly persons as young-old and old-old (75 years and older) is common in gerontological literature. Categorization into two and sometimes more groups underlies recognition of the different historical and social experiences of cohorts within the elderly population as well as differences in health status. Those age 75 years and older represent a group within the elderly segment who are more likely experiencing greater declines in health compared with those elderly persons less than 75 years old (Ford et al., 1988).

Assumptions of normality and constant variance were tested by examining histograms and scatterplots of residuals as outlined by Norusis (1986). Residuals represent the difference between an observed value and the value predicted by the model. The distribution of residuals should appear approximately normal when plotted. When the assumption of homogeneity of variance is met, the scatterplot should present no observable pattern of relationship. Examination of histograms and scatterplots did not indicate need for further variable transformation.

Multicollinearity is a high degree of linear relationship among independent variables. Interpretation of individual partial regression coefficients assumes the absence of a multicollinear relationship. Multicollinearity was assessed using bivariate analysis and by examining the stability of parameter estimates in stepwise regression analysis. Changes in unstandardized coefficients, standard error and significance level were noted as each independent variable was entered in a stepwise procedure. Large changes in these parameter estimates is indicative of a linear relationship between the last entered variable and those already in the equation.

A multicollinear relationship was detected for the interaction terms ("strain x perceived emotional support" and "strain x perceived material support") when the dependent variable was caregiver depression. Separate regression analyses were carried out with each of the terms included respectively. Multicollinearity was also detected for living arrangement (that is, living with or not living with the care receiver) and having the spouse as care receiver. For the majority of spouse caregivers, the living arrangement is with the care receiver. Living arrangement was deleted from the regression model.

## 5.1 BUFFERING AND DIRECT EFFECTS: HYPOTHESES #1, #2 and #3

Hypotheses #1, #2 and #3 address the buffering and direct effects models of social support and health status. The hypotheses tested were:

> 1) For caregivers indicating no caregiver role strain, there is a direct positive relationship between social support and health status.
>
> 2) For caregivers indicating low caregiver role strain, there is no relationship between social support and reported health status.
>
> 3) For caregivers indicating high caregiver role strain, there is a direct positive relationship between social support and health status.

A relationship between health status and social support for all groups of caregivers would support the directs effects model. If the the relationship between health status and social support only held for the high caregiver role strain group, the buffering model would gain support. Two measures of self reported health status were used, caregiver self-rated health and caregiver depression. The independent variables of primary interest were perceived emotional support and perceived material support. Other independent variables were caregiver age (60 to 74 versus 75 to 91 years old), gender and functional disability (presence or absence). Regression analyses used the identical model with the each of the three subgroups, that is, with the groupings of caregivers who reported no, low and high caregiver role strain. A second regression model incorporating an interaction term for strain and support was used with the entire group of caregivers.

### 5.1.0 Results: Self-rated health as dependent variable

Results for the dependent variable, self-rated health are described first. Hypothesis #1 tested the direct effects model of social support and health status with caregivers who reported no caregiver role strain (n=109). As indicated in chapter three, the direct effects model proposes that social support will be positively related to health status regardless of the level of caregiver role strain while the buffering model specifies the role of social support in situations of high caregiver role strain. Empirical evidence for hypothesis #1 would indicate support for the direct effects model.

For caregivers reporting no caregiver role strain, bivariate relationships between self-rated health and the independent variables were computed before proceeding to the regression analyses. Table C.1 in Appendix C provides the results of bivariate analyses. For age, gender and functional disability, chi-square analyses indicated nonsignificant relationships with self-rated health. For the two social support variables, only perceived emotional support and self-rated health were statistically significant (F=3.25; p<.05). However, when placed in a regression model, none of the independent variables were statistically significant correlates of self-rated health (see table 5.1). For the no caregiver role strain group, data were not consistent with the direct effects model and hypothesis #1 was not supported.

**Table 5.1**

**Correlates of Self-rated Health: No Caregiver Role Strain Group (n = 109)**

| Independent variables | b | SE | Beta | t | $r^2$ | p |
|---|---|---|---|---|---|---|
| Female | .18 | .14 | .13 | 1.30 | .01 | .20 |
| Older (75+) | .11 | .16 | .07 | .70 | .00 | .49 |
| Functional disability | -.23 | .15 | -.15 | -1.51 | .01 | .14 |
| Perceived emotional support | .14 | .10 | .13 | 1.30 | .02 | .20 |
| Perceived material support | -.17 | .12 | -.15 | -1.51 | .02 | .13 |

R-squared = .06; Adjusted R-squared = .02
F = 1.41; df = 5 and 102; p = .23

Hypothesis #2 stated that for those reporting low caregiver role strain, there would be no relationship between social support and self-rated health status. Bivariate analysis indicated no significant relationships between the dependent and independent variables (see table C.2 in Appendix C.). Regression analysis corroborated this finding (see table 5.2). Data did not indicate a significant relationship between social support and self-rated health for those reporting low caregiver role strain. Although perceived material support was not a statistically significant correlate of self-rated health, this variable did explain 7% of the variance.

An inconsistency of 7% explained variance and nonsignificant correlation suggested possible "suppression" of the relationships within the model due to the relationship between independent variables. According to Cohen and Cohen (1983), an independent variable that is not correlated to the dependent variable but is correlated to another independent variable may add irrelevant variance, reducing its relationship to the dependent variable. For the low strain group, it may be that relationships among independent variables acted to "suppress" by decreasing the relationship of perceived material support to self-rated health. When suppression is suspected a common procedure is to delete variables and examine change in the significance level of the variable of interest. However, this procedure did not change the "t value" of perceived material support to a level of significance.

A more plausible explanation for a non-significant correlate explaining 7% of the variance relates to sample size and size of the standard error. For a given level of significance, the size of the t-statistic is influenced by the size of the sample. The t-statistic depends on the degrees of freedom defined as the number of observations minus the number of coefficients estimated (Schroeder et al., 1986). It seems likely that for a regression model with five independent variables, a sample size of 42 is insufficient to detect a relationship. In addition, it has been suggested that r-squared can be large in the face of weak correlation (small slope) and large standard error of the estimate (Achen, 1982). Large standard error contributes to small "t value" and nonsignificant relationships. According to Achen (1982), interpretation of causal strength is best measured by the slopes and the goodness of fit is best captured by the standard error.

**Table 5.2**

**Correlates of Self-rated Health: Low Caregiver Role Strain Group (n = 42)**

| Independent variables | b | SE | Beta | t | $r^2$ | p |
|---|---|---|---|---|---|---|
| Female | -.04 | .29 | -.02 | -.14 | .00 | .89 |
| Older (75+) | -.07 | .27 | -.04 | -.26 | .00 | .80 |
| Functional disability | -.20 | .34 | -.10 | -.58 | .01 | .57 |
| Perceived emotional support | -.06 | .21 | -.05 | -.27 | .00 | .79 |
| Perceived material support | .38 | .24 | .28 | 1.57 | .07 | .13 |

R-squared = .08; Adjusted R-squared = .04
F = .62; df = 5 and 36; p = .69

Hypothesis #2 was supported as there was no relationship between either perceived emotional support or perceived material support and health status. These findings do not completely test the buffering model which at its most stringent posits a relationship between support and health at high level of strain but not at low level of strain. Hypothesis #2 tested the relationship between health status and social support for those reporting low level of caregiver role strain.

Hypothesis #3 addressed the relationship between support and health for those reporting high caregiver role strain. For the high caregiver role strain group, bivariate analyses once again indicated no significant relationship between self-rated health status and the independent variables (see table C.3 an Appendix C.). Regression analysis indicated functional disability as the only significant correlate of self-rated health, explaining 10% of the variance (see table 5.3). In addition, caregiver age explained 7% of the variance. Both measures of perceived social support failed to reach significance and contributed almost nothing to the explained variance of the dependent variable, self-rated health status.

A correlation between self-rated health status and functional disability has been reported in the literature (Graney & Zimmerman, 1981; Maddox, 1962; Tissue, 1972). An inverse relationship between functional disability and self-rated health is not unexpected. Although caregiver age does not achieve a level of statistical significance, this direct relationship between age and self-rated health status has also been widely reported in the literature (Linn & Linn, 1980). This finding supports the paradox of relatively older persons rating ther health higher compared with those who are younger.

For this group of caregivers reporting high strain, as with the low caregiver role strain group, a nonsignificant correlate (caregiver age) explained a fair amount of variance. Again, to address the possibility of suppression, variables were deleted from the model. This failed to effect a significant change in the "t-value" of caregiver age. Following from the earlier discussion, it is plausible that sample size and size of standard error were operating to produce a fairly respectable explained variance with nonsignificant correlation.

**Table 5.3**

**Correlates of Self-rated Health: High Caregiver Role Strain Group (n = 46)**

| Independent variables | b | SE | Beta | t | $r^2$ | p |
|---|---|---|---|---|---|---|
| Female | .28 | .26 | .16 | 1.08 | .02 | .29 |
| Older (75+) | .49 | .25 | .29 | 1.94 | .07 | .06 |
| Functional disability | -.61 | .24 | -.39 | -2.53 | .10 | .02 |
| Perceived emotional support | -.10 | .16 | -.09 | .62 | .01 | .54 |
| Perceived material | .13 | .17 | .12 | .78 | .01 | .44 |

R-squared = .20; Adjusted R-squared = .10
F = 2.02; df = 5 and 39; p = .10

The lack of relationship between perceived emotional support and perceived material support with self-rated health did not support hypothesis #3 and the buffering model. Findings from analyses using caregiver groupings based on level of caregiver role strain failed to uphold either the direct effects or the buffering hypotheses of social support and self-rated health status. However, an integral part of the subgroup approach to the potential interaction of social support and health is a statistical comparison of slopes. As indicated by Ferraro (1987), the following formula was used to assess the difference of slopes for each combination of the possible group comparisons:

$$t = \frac{b_1 - b_2}{\sqrt{SE_1^2 + SE_2^2}}$$

where b refers to the unstandardized coefficient and SE refers to the standard error of b.

The only statistically significant difference in slopes was for perceived material support when comparing the no caregiver role strain group with the low caregiver role strain group ($t = -2.05$; $p < .05$). This indicated that health optimism among the no caregiver role strain group was different from the low caregiver role strain group relative to the level of perceived material support. For the low caregiver role strain group, the relationship was direct, that is high perceived material support was positively related to self-rated health. However, it should be noted that within the no caregiver role strain group, the relationship between perceived material support and self-rated health was inverse, that is, higher reported level of perceived material support was associated with lower self-rated health.

As indicated in chapter three, positive aspects of social support have received the greatest attention in the literature with limited attention given to the negative aspects of social support (Depner et al., 1984). However, explanation of social support as a negative experience has focused on enacted support, that is, support that is actually received, rather than on perceived support. The underlying assumption has been that the actual receipt of support can be damaging to self-esteem (Fisher et al., 1983; Ingersoll & Antonucci, 1983). For this research, perceived social support rather than enacted social support was measured.

To examine the three groups for differences in values of the independent and dependent variables, a post-hoc multiple comparison procedure was carried out using the Scheffe statistic. This conservative test compares means across three or more groups and is the test of choice when groups vary in size (Huck et al., 1974). Results indicated no difference among mean values for self-rated health, age, gender, functional disability, and perceived emotional support. For perceived material support, the low strain group (n=42) and the high strain group (n=46) were significantly different at the .05 level, with the high strain group reporting relatively less support.

The subgroups approach for testing direct and buffering models of social support and self-rated health did not provide evidence for either of these models. Comparison of slopes did not add to understanding the relationship between social support and health status. The sole significant correlate of self-rated health was functional disability and this relationship was found only for the high caregiver role strain group. The next step was to create an interaction term for social support and strain that could be tested along with the component terms in a regression equation using the entire sample (n=197). It was anticipated that results from this procedure would corroborate findings from the subgroup approach.

Creation of interaction terms was complicated by the small cell sizes created from strain x support interaction. It became clear that cells would have to be collapsed. The ideal approach would have been to collapse categories of those who had one or two support persons compared with those who had no one. This would be consistent with the literature on confidants that emphasizes the importance of having at least one intimate friendship (Powers and Bultena, 1976). However, this approach was not practical because it did not address the problem of small numbers. Given that the buffering model at its most stringent proposes a buffering effect for high strain and high support, four cells of no and low strain, and none and one support person were collapsed into one group (see table C.4 in Appendix C). This served to maintain the high strain x high support group as well as the component high strain and high support groups.

An interaction term (high strain x high support) was created for each measure of support, that is, for perceived emotional support and perceived material support. A statistically significant association between high strain x high support and self-rated health would be consistent with the buffering model. A positive relationship between support and self-rated health would be consistent with the direct effects model. As discussed by Cohen and Cohen (1983), the interaction terms were forced in after the component terms of strain and support in the regression model.

**Table 5.4**

**Correlates of Self-rated Health for all Caregivers (n = 197)**

| Independent variables | b | SE | Beta | t | $r^2$ | p |
|---|---|---|---|---|---|---|
| Female | .16 | .12 | .11 | 1.41 | .03 | .16 |
| Older (75+) | .16 | .13 | .09 | 1.26 |  | .21 |
| Functional disability | -.27 | .12 | -.17 | -2.32 |  | .02 |
| Strain (high) | -.26 | .18 | -.15 | -1.43 | .02 | .15 |
| Perceived emotional support | -.09 | .12 | -.06 | -.76 |  | .44 |
| Perceived material support | .05 | .12 | .04 | .44 |  | .66 |
| Strain x perceived material support | .40 | .27 | .13 | 1.48 | .01 | .14 |
| Strain x perceived emotional support | -.24 | .25 | -.10 | -1.02 | .00 | .31 |

R-squared = .07; Adjusted R-squared = .03
F = 1.79; df = 8 and 186; p = .08

Table 5.4 indicates that functional disability remained the sole significant correlate of self-rated health and the relationship was inverse, as expected. A regression model including component and interaction terms for strain and support did not provide information to uphold the direct effects or the buffering model of social support. Perceived emotional support and perceived material support were not statistically significant correlates of self-rated health for this sample of elderly caregivers.

The lack of relationship between social support and self-rated health might be attributable to several factors including the meaning of health that underlies a self-rating. Among older persons, self-rated health is likely anchored in self assessment of physical health and related functional ability (Graney & Zimmerman, 1981; Maddox, 1962; Tissue, 1972). The mean score for self-rated health was not significantly different across caregiver groups perhaps reflecting their high level of physical health and low functional disability. These caregivers were uniformly optimistic in rating their health, with the majority reporting good or excellent health, no days in hospital (85%) and no bedridden days at home (80%) during the past twelve months. In addition, more than two thirds reported no functional disability in performing their own activities of daily living. In a study of satisfaction with social support and self-rated health among older adults, Krause (1987a) reported that both the frequency of support and satisfaction with support had a greater effect on self-rated depressive symptoms than on self-rated health. It is plausible that the buffering or direct effects of social support are not reflected in self-rated health in the absence of physical health problems or functional disability.

### 5.1.1 Results: Depression as dependent variable

The direct effects and buffering models (hypotheses #1, #2 and #3) were also tested with caregiver depression as the dependent variable. The steps taken were the same as the procedure used in examining the relationships between caregiver role strain, self-rated health and social support. Bivariate and multivariate analyses were carried out. The identical regression model was used across no, low and high caregiver role strain groups with caregiver reported depression as the dependent variable and age, gender, functional disability, perceived emotional support and perceived material support as the independent variables.

Bivariate findings for the no caregiver role strain group are reported in table C.5 in Appendix C. Multivariate findings are reported in table 5.5. For the group reporting no caregiver role strain, there were no significant correlations at the bivariate or multivariate level of analyses. Hypothesis #1 was not supported and data were not consistent with the direct effects model.

### Table 5.5

### Correlates of Depression: No Caregiver Role Strain Group (n = 109)

| Independent variables | b | SE | Beta | t | $r^2$ | p |
|---|---|---|---|---|---|---|
| Female | -.63 | 1.16 | -.06 | -.55 | .00 | .60 |
| Older (75+) | .67 | 1.32 | .05 | .51 | .00 | .58 |
| Functional disability | -1.20 | 1.24 | -.10 | -.97 | .01 | .34 |
| Perceived emotional support | .24 | .86 | .03 | .28 | .00 | .77 |
| Perceived material support | -.37 | .95 | -.04 | -.40 | .00 | .69 |

R-squared = .02; Adjusted R-squared = .00
F = .44; df = 5 and 102; p = .82

Similarly, for caregivers reporting low role strain, bivariate and multivariate findings indicated no significant relationships between the dependent and independent variables (see table C.6 in Appendix C and table 5.6). Hypothesis #2 was not rejected by the data but this was not definitive support for the buffering model. If perceived emotional support and perceived material support were nonsignificant correlates for the low and no caregiver role strain groups, but achieved significance with the high caregiver role strain group, then this would constititute evidence for the buffering model.

**Table 5.6**

**Correlates of Depression: Low Caregiver Role Strain Group (n = 42)**

| Independent Variables | b | SE | Beta | t | $r^2$ | p |
|---|---|---|---|---|---|---|
| Female | -.17 | 2.53 | -.01 | -.07 | .00 | .95 |
| Older (75+) | -.82 | 2.93 | -.05 | -.28 | .00 | .78 |
| Functional disability | 2.42 | 2.33 | .17 | 1.04 | .02 | .31 |
| Perceived emotional support | 1.30 | 1.79 | .13 | .73 | .01 | .47 |
| Perceived material support | -2.63 | 3.56 | -.23 | -1.26 | .03 | .22 |

R-squared = .07; Adjusted R-squared = .00
F = .51; df = 5 and 36; p = .76

Hypothesis #3 addressed the relationship between support and health for those reporting high caregiver role strain. Bivariate analysis indicated a significant relationship between perceived material support and depression (F=4.68; p=.02) (see table C.7 in Appendix C). Findings from the regression analysis supported hypothesis #3 for perceived material support but not for perceived emotional support (see table 5.7). Perceived material support was a significant correlate of caregiver depression in the expected direction. A higher level of depression was significantly associated with a lower level of perceived material support. Although perceived emotional support accounted for 7% of the variablity in the dependent variable, statistical significance was lacking. Again, to address possible suppression of the relationship between perceived emotional support and depression, other independent variables were deleted. This procedure did not change the t-value to a level of significance.

**Table 5.7**

**Correlates of Depression: High Caregiver Role Strain Group (n = 46)**

| Independent variables | b | SE | Beta | t | $r^2$ | p |
|---|---|---|---|---|---|---|
| Female | 1.53 | 3.46 | .06 | .44 | .04 | .66 |
| Older (75+) | 4.40 | 3.28 | .19 | 1.34 | .01 | .19 |
| Functional disability | 1.60 | 3.17 | .07 | .50 | .00 | .62 |
| Perceived emotional support | 3.59 | 2.12 | .24 | 1.70 | .07 | .10 |
| Perceived material support | -5.91 | 2.17 | -.38 | 2.71 | .14 | .01 |

R-squared = .27; Adjusted R-squared = .17
F = 2.91; df = 5 and 40; p = .02

The results of grouping caregivers by level of strain and then subsequently testing the relationship between support and depression was consistent with a buffering model. Social support was not a significant correlate of depression except for those reporting high level of caregiver role strain. Comparison of slopes indicated a significant difference for perceived material support when comparing the no caregiver role strain group with the high caregiver role strain group (t=2.02; p < .05). The level of depression among the no caregiver role strain group was different from the high caregiver role strain group relative to the level of perceived material support. In particular, for the high caregiver role strain group, the mean value of depression drops as the level of support increases. For the no caregiver role strain group, the level of depression drops initially and then rises so that within this group, the "most depressed" are also reporting the highest perceived material support.

Post-hoc multiple comparison procedure using the Scheffe statistic indicated differences in mean values for depression between the low and high caregiver role strain groups (p=.05), and between the no and high caregiver role strain groups (p=.05). The high caregiver role strain group is relatively depressed (mean=11.85; sd=10.53) compared with both the low caregiver role strain group (mean=7.14; sd=6.39) and the no caregiver role strain group (mean=5.26; sd=5.49).

The three groups were combined and an interaction term (strain x support) was forced in after the components of strain and support in the regression model. It was anticipated that results of this analysis would confirm findings from the grouping approach. For caregiver depression, the interaction terms for strain x perceived emotional support, and for strain x perceived material support were mulitcollinear and so were entered in separate regression models. Following recommendations from Cohen and Cohen (1983), the interaction term was forced into the regression model after the component terms of strain and support were entered as a block. Tables 5.8 and 5.9 indicate that level of strain was the only significant correlate of caregiver depression for the combined groups of no, low and high caregiver role strain (n=197). Within the block of strain and support, 11% of explained variance is attributable to strain while 1% is attributable to support for a total of 12% explained variance.

**Table 5.8**

**Correlates of Depression for all Caregivers (n = 197)**

| Independent variables | b | SE | Beta | t | p | $r^2$ |
|---|---|---|---|---|---|---|
| Female | .58 | 1.14 | .04 | .51 | .61 | .02 |
| Older (75+) | 1.73 | 1.25 | .10 | 1.39 | .17 | |
| Functional disability | .55 | 1.15 | .04 | .48 | .63 | |
| Strain (high) | 6.64 | 1.44 | .37 | 4.62 | .00 | .12 |
| Perceived material support | -1.42 | 1.24 | -.09 | -1.16 | .25 | |
| Strain x perceived material support | -3.55 | 2.70 | -.11 | -1.32 | .19 | .01 |

R-squared = .15; Adjusted R-squared = .12
F = 5.66; df = 6 and 190; p = .00

### Table 5.9

### Correlates of Depression for all Caregivers (n = 197)

| Independent variables | b | SE | Beta | t | p | $r^2$ |
|---|---|---|---|---|---|---|
| Female | .46 | 1.13 | .03 | .40 | .69 | .02 |
| Older (75+) | 1.60 | 1.25 | .09 | 1.29 | .20 | |
| Functional disability | .33 | 1.15 | .02 | .28 | .78 | |
| Strain (high) | 3.98 | 1.63 | .22 | 2.44 | .02 | .12 |
| Perceived emotional support | .85 | 1.17 | .06 | .72 | .47 | |
| Strain x perceived emotional support | 4.45 | 2.42 | .18 | 1.84 | .07 | .02 |

R-squared = .16; Adjusted R-squared = .13
F = 5.86; df = 6 and 190; p = .00

Analysis using an interaction term ("strain x support") for the combined group of caregivers did not corroborate findings from the grouping approach. Data in tables 5.8 and 5.9 were not consistent with the direct effects or the buffering model of the relationship between social support and health (as measured by caregiver depression). Neither the direct effects of support nor the interaction of support and strain were significant correlates of caregiver depression. Instead, level of strain was the sole significant correlate of depression, accounting for 11% of the variance. It should be recalled that the creation of the interaction term necessitated the collapsing of categories of no and low strain and of no one and one support person. Findings from analysis involving the interaction term therefore cannot be directly compared to findings from the grouping approach.

For the dependent variable, caregiver depression, findings from the grouping approach were consistent with the buffering model of social support. Perceived material support was a significant correlate only for the high caregiver role strain group, and the interaction between high strain and high support is the essence of the buffering model. Comparison of slopes indicated a significant difference in perceived material support between the no and high caregiver role strain groups. This is not surprising. The relationship between caregiver depression and reported burden has been established in the gerontological literature (Danis & Silverstone, 1981; Fitting et al., 1986; Poulshock & Deimling, 1984; Pratt et al., 1985; Robinson, 1987). Social support research has indicated the linkage between feelings of depression and low social support (Wethington & Kessler, 1986; Kessler & McLeod, 1985).

However, combining groups and testing with an interaction term did not confirm the grouping approach findings. Instead, level of strain was the only significant correlate of caregiver depression. The relationship between strain and health has been widely supported in stress theory research and this finding is consistent with that literature. The lack of statistical significance for the interaction of strain x support (that had been indicated in the grouping approach) is likely related to the collapsing of categories that took place in the formulation of the interaction term. Nevertheless, findings from the two approaches are not congruent.

## 5.2 CORRELATES OF CAREGIVER ROLE STRAIN: HYPOTHESES #4 TO #8

The literature has suggested caregiver characteristics including age, gender, functional disability, living arrangement and relationship to the care receiver as correlates of burden. Hypotheses #4 to #8 tested the relationship between these characteristics and caregiver reports of the absence or presence of strain for the entire sample of caregivers (n=197). It was expected that women, those who reside with the care receiver, spouse and child caregivers, those who declare themselves as functionally disabled, and those who are older (age 75 and older) would be more likely to report caregiver role strain. In addition, hypotheses state that among those who indicate strain (n=88), the same characteristics will be correlates of high caregiver role strain. It was expected that among those with role strain, women, those who reside with the care receiver, spouse and child caregivers, those who declare themselves as functionally disabled, and those who are older (age 75 and older) would indicate more strain.

The hypotheses tested were:

> 4) Female caregivers compared with male caregivers are more likely to indicate caregiver role strain and among those with role strain, females will indicate more strain than males.

5) Caregivers who co-reside with the care receiver compared with those who do not, are more likely to indicate caregiver role strain and among those with strain, those who co-reside with the care receiver will indicate more strain than those who do not.

6) Spouse and adult child caregivers compared with other caregivers are more likely to indicate caregiver role strain and among those with role strain, spouse and adult child caregivers will indicate more strain than other caregivers.

7) Older caregivers compared with younger caregivers are more likely to indicate caregiver role strain and among those with role strain, older caregivers will indicate more strain than younger caregivers.

8) Caregivers with functional disability compared with caregivers who do not have functional disability are more likely to indicate caregiver role strain and among those with role strain, caregivers with functional disability will indicate more strain than caregivers who do not have functional disability.

Bivariate analyses (see table 5.10) preceded multivariate analyses. Findings indicated that caregiver gender and relationship to the care receiver were significantly related to the likelihood of reporting caregiver role strain. Female caregivers were more likely to report the presence of caregiver role strain. Relationship to the care receiver was also a significant correlate. Findings suggested that child caregivers were more likely to report caregiver role strain.

Preliminary testing of assumptions had indicated a multicollinear relationship between living with the care receiver and spouse relationship to the care receiver. In fact, more than 90% of spouse caregivers reside with the care receiver for enitre group of caregivers (n=197). Living arrangement was deleted from the regression model. Logistic regression was used to test the hypotheses that being female, older (aged 75 and older), functionally

TABLE 5.10
CORRELATES OF CAREGIVER ROLE STRAIN (n=197)

| | AGE | | | | GENDER | | | | FUNCTIONAL DISABILITY | | | | LIVING ARRANGEMENT | | | | RELATIONSHIP | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 60 - 74 | | 75 - 91 | | Male | | Female | | Yes | | No | | Shared | | Other | | Spouse | | Child | | Other | |
| | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % |
| Caregiver Role Strain | | | | | | | | | | | | | | | | | | | | | | |
| Absence | 83 | 55 | 26 | 57 | 47 | 68 | 62 | 48 | 33 | 52 | 76 | 57 | 68 | 59 | 30 | 48 | 35 | 64 | 11 | 31 | 63 | 59 |
| Presence | 68 | 45 | 20 | 43 | 22 | 32 | 66 | 52 | 30 | 48 | 58 | 43 | 48 | 41 | 33 | 52 | 20 | 36 | 25 | 64 | 43 | 41 |
| | 151 | 100 | 46 | 100 | 64 | 100 | 128 | 100 | 63 | 100 | 134 | 100 | 116 | 100 | 63 | 100 | 55 | 100 | 36 | 100 | 106 | 100 |
| | Chi-square = 0.00<br>df = 1;p = .99 | | | | Chi-square = 6.25<br>df = 1;p = .02 | | | | Chi-square = 0.17<br>df = 1;p = .68 | | | | Chi-square = 1.58<br>df = 1;p = .21 | | | | Chi-square = 11.20<br>df = 2;p = .01 | | | | | |

disabled, and being a child or spouse to the care receiver would be associated with the presence of caregiver role strain. In logistic regression, the probability of falling into one of two categories (that is, presence or absence of caregiver role strain) is a function of the values of the independent variables in the equation. Results are presented in table 5.11.

**Table 5.11**

**Correlates of Caregiver Role Strain (n = 197)**

| Independent variables | b | SE | Odds Ratio | Confidence Intervals | Chi-Square | $r^2$ | p |
|---|---|---|---|---|---|---|---|
| Child caregiver | 1.24 | .43 | 3.5 | 1.5, 8.0 | 8.27 | .02 | .01 |
| Female | .71 | .34 | 2.0 | 1.0, 4.0 | 4.32 | .01 | .04 |
| Age (75+) | .30 | .37 | 1.4 | .7, 2.8 | .65 | .00 | .42 |
| Functional disability | .10 | .34 | 1.1 | .6, 2.2 | .09 | .00 | .77 |
| Spouse | -0.03 | .36 | 1.0 | .5, 2.0 | .01 | .00 | .93 |

R-squared = .03
Chi-square = 16.89; 5 df; p = .01

Findings from multivariate analyses confirmed bivariate results, that child caregivers compared with other caregivers were more likely to report caregiver role strain, when controls were added. This finding provided partial support for hypothesis #6. Being female was also a significant correlate, providing support for hypothesis #4. Odds ratio tabulation indicated that child caregivers were more than three times as likely to report caregiver role strain compared with other caregivers. Women were twice as likely to report caregiver role strain. (The 95% confidence intervals for odds ratio are also presented in table 5.11). The relationship between gender and providing care to a parent was further examined for independence. Results indicated a significant relationship between these two variables with 80% of child caregivers being female (Chi-square=3.90; p=.05).

These findings are not unexpected in view of the caregiving literature. The traditional and current role of women as caregivers has been widely reported in caregiver burden research (Aronson, 1985; Brody, 1985; Cantor, 1983). When differences in burden are reported, it has been women who have reported greater caregiver burden (George & Gwyther, 1986; Johnson & Catalano, 1983). Greater burden experienced by child caregivers rather than spouse or other caregivers has not been widely researched or reported in the literature. This is likely due, in part, to small sample sizes and the aggregation of caregivers regardless of their relationship with care receivers in much of the research.

Age and functional disability were not significant correlates of caregiver role strain and this may reflect the relationship between age and disability for this group of elderly persons. The literature has suggested that the association between advanced age of the caregiver and reported burden is related to functional disability that also increases with age (Fengler & Goodrich, 1979). The older caregiver is more disabled and therefore more likely to feel burdened. However for this group of elderly caregivers, although approximately one-quarter are age 75 and older, the majority 66% reported no functional disability. Findings failed to support hypotheses #7 and #8; older caregivers and those with functional disability were not more likely to report caregiver role strain. Finally, bivariate findings indicated that residing with the care receiver was not significantly related to reporting caregiver role strain and hypothesis #5 was not supported.

Hypotheses #4 to #8 also posited relationships between caregiver characteristics and the level of reported caregiver role strain, that is high or low strain. It was expected that women, those who reside with the care receiver, spouse and child caregivers, those who declare themselves as functionally disabled, and those who are older (age 75 and older) would be more likely to report high caregiver role strain. However, findings from bivariate analyses indicated that none of the selected characteristics were significantly related to the level of reported caregiver role strain (see table 5.12).

Preliminary analysis had suggested a mulitcollinear relationship between living with the care receiver and spouse relationship to the care receiver. Living arrangement was deleted from the regression model. Logistic regression was used to test the hypotheses that being female, older (aged 75 and older), functionally disabled, living with the care receiver and being a child or spouse to the care receiver would be associated with reporting high

## TABLE 5.12

## CORRELATES OF CAREGIVER ROLE STRAIN (n=88)

| | **AGE** | | | | **GENDER** | | | | **FUNCTIONAL DISABILITY** | | | | **LIVING ARRANGEMENT** | | | | **RELATIONSHIP** | | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 60 - 74 | | 75 - 91 | | Male | | Female | | Yes | | No | | Shared | | Other | | Spouse | | Child | | Other | |
| | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % |
| Caregiver Role Strain | | | | | | | | | | | | | | | | | | | | | | |
| Low | 35 | 51 | 7 | 35 | 11 | 50 | 31 | 47 | 12 | 40 | 30 | 52 | 20 | 42 | 19 | 56 | 9 | 45 | 13 | 52 | 20 | 47 |
| High | 33 | 49 | 13 | 65 | 11 | 50 | 35 | 53 | 18 | 60 | 28 | 48 | 28 | 58 | 14 | 42 | 11 | 55 | 12 | 48 | 23 | 53 |
| | 68 | 100 | 20 | 100 | 22 | 100 | 66 | 100 | 30 | 100 | 58 | 100 | 48 | 100 | 33 | 100 | 20 | 100 | 25 | 100 | 43 | 100 |
| | Chi-square = 1.09<br>df = 1;p = .30 | | | | Chi-square = 0.00<br>df = 1;p = 1.0 | | | | Chi-square = 0.67<br>df = 1;p = .41 | | | | Chi-square = 1.40<br>df = 1;p = .24 | | | | Chi-square = 0.27<br>df = 2;p = .87 | | | | | |

caregiver role strain. Multivariate findings indicated no significant correlates (see table 5.13). Although being female and a child of the care receiver increased the likelihood of belonging to the group reporting caregiver role strain, these characteristics were not statistically significant for the level of reported caregiver role strain reported.

**Table 5.13**

**Correlates of Caregiver Role Strain (Low versus High) (n = 88)**

| Independent variables | b | SE | Odds Ratio | Confidence Intervals | Chi-Square | $r^2$ | p |
|---|---|---|---|---|---|---|---|
| Female | .15 | .53 | 1.2 | .4, 3.3 | .08 | .00 | .78 |
| Age (75+) | .59 | .57 | 1.8 | .6, 5.5 | 1.05 | .00 | .30 |
| Functional disability | .33 | .49 | 1.4 | .5, 3.6 | .46 | .00 | .50 |
| Child caregiver | -.04 | .52 | 1.0 | .4, 2.7 | .01 | .00 | .93 |
| Spouse caregiver | .04 | .57 | 1.0 | .3, 3.2 | .01 | .00 | .93 |

R-squared = .00
Chi-square = 2.38; 5 df; p = .80

## 5.3 CAREGIVER ROLE STRAIN AND CAREGIVING TASKS

For hypotheses #4 to #8, findings had indicated that women and adult child caregivers were more likely to report caregiver role strain. The literature on caregiver burden has shown that when men and women are compared and differences are found, it is women who report greater burden. As discussed earlier, there has been a great deal of speculation regarding the underlying reason for this difference. Explanations have been based on gender-related management style, social support patterns, previous socialization, degree of involvement, perception of caregiving, and caregiving expectations (George & Gwyther, 1984; Miller, 1989; Morycz, 1985; Pruchno & Resch, 1989). For the adult child caregivers, the literature suggests that their caregiving difficulties are often based on competing time demands from jobs, younger family members and the care receiver (Brody, 1985; Scharlach, 1987).

For this research, it was possible to examine the types of caregiving tasks performed and reported caregiver role strain relative to differences in caregiver characteristics of gender and relationship to the care receiver. The literature on caregiving has suggested a relationship between caregiving tasks and burden (Hooyman et al., 1985; Montgomery et al., 1985; Robinson & Thurnher, 1979). Initially, the relationship between caregiving tasks and reported presence or absence of caregiver role strain was examined and then this same relationship was examined while controling first, for gender and second, for relationship with the care receiver. In the gerontological literature, caregiving tasks are organized into basic and instrumental activities of daily living (ADL) and those that fall outside of these two categories, referred to here as "other" activities.

Basic activities include assisting the care receiver with walking, dressing, feeding, washing and toileting. These tasks tend to be physically demanding and therefore likely difficult. In addition, tasks such as washing may be more difficult for some caregivers because of the physical contact involved (Hooyman et al., 1985). When these basic ADL tasks were examined in relation to reported presence or absense of caregiver role strain, three of the five tasks were statistically significant in relation to the reporting of caregiver role strain (see table 5.14). Assisting the care receiver with walking, dressing and washing were related to the presence of caregiver role strain. The relationship between feeding and toileting tasks with caregiver role strain, although reported here, cannot be interpreted because cell frequencies were not sufficient.

Instrumental activities of daily living include housekeeping, household maintenance, transportation, food preparation, grocery shopping and assistance with personal business affairs. None of these tasks were significantly related to caregiver role strain except for "assistance with personal business affairs" (see table 5.14). Caregivers who provided help with personal business were more likely to report caregiver role strain. The reason for this is not clear but it may be related to the weight of responsibility, the amount of time involved, the inconvenience of scheduling or the tedium involved. Caregiving tasks that restrict or confine the caregiver in time and space have been linked to burden (Montgomery et al., 1985a; Robinson & Thurnher, 1979). Personal business affairs might include tasks related to financial (for example, banking) or legal transactions that require the caregiver to be at a certain place at a certain time (bank or law firm hours). In addition, some of these tasks may be perceived as dull, tiresome or picayune. On the other hand, some personal affairs may require difficult and complex decision making,

TABLE 5.14

CORRELATES OF CAREGIVER ROLE STRAIN: CAREGIVING TASKS PERFORMED (n=197)

| Basic ADL Tasks | Walking | | | | Dressing | | | | Feeding | | | | Washing | | | | Toilet | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | |
| | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % |
| Caregiver Role Strain | | | | | | | | | | | | | | | | | | | | |
| Absence | 11 | 33 | 98 | 60 | 7 | 21 | 102 | 62 | 1 | 6 | 108 | 60 | 7 | 25 | 102 | 60 | 1 | 9 | 108 | 58 |
| Presence | 22 | 67 | 66 | 40 | 26 | 79 | 63 | 38 | 15 | 94 | 73 | 40 | 21 | 75 | 67 | 40 | 10 | 91 | 78 | 42 |
| | 33 | 100 | 164 | 100 | 33 | 100 | 165 | 100 | 16 | 100 | 181 | 100 | 28 | 100 | 169 | 100 | 11 | 100 | 186 | 100 |
| | Chi-square = 6.73<br>df = 1; p = .01 | | | | Chi-square = 17.05<br>df = 1; p = .00 | | | | Chi-square = 14.88<br>df = 1; p = .00 | | | | Chi-square = 10.76<br>df = 1; p = .00 | | | | Chi-square = 8.19<br>df = 1; p = .00 | | | |

| Instrumental ADL Tasks | Housekeeping | | | | Household Maintenance | | | | Transportation | | | | Food Preparation | | | | Grocery Shopping | | | | Personal Business | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | |
| | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % |
| Caregiver Role Strain | | | | | | | | | | | | | | | | | | | | | | | | |
| Absence | 60 | 55 | 49 | 56 | 48 | 60 | 61 | 52 | 42 | 51 | 67 | 59 | 52 | 51 | 57 | 60 | 62 | 52 | 47 | 60 | 49 | 42 | 64 | 72 |
| Presebce | 49 | 45 | 39 | 44 | 32 | 40 | 56 | 49 | 41 | 49 | 47 | 41 | 50 | 49 | 38 | 40 | 57 | 48 | 31 | 40 | 63 | 58 | 25 | 28 |
| | 109 | 100 | 88 | 100 | 80 | 100 | 117 | 110 | 83 | 160 | 114 | 100 | 102 | 100 | 95 | 100 | 119 | 100 | 78 | 100 | 108 | 100 | 89 | 100 |
| | Chi-square = .00<br>df = 1; p = 1.00 | | | | Chi-square = .89<br>df = 1; p = .35 | | | | Chi-square = .99<br>df = 1; p = .32 | | | | Chi-square = 1.27<br>df = 1; p = .26 | | | | Chi-square = .96<br>df = 1; p = .33 | | | | Chi-square = 16.85<br>df = 1; p = .00 | | | |

involving greater responsibility on the part of the caregiver compared with tasks such as grocery shopping or housekeeping.

"Other" caregiving tasks include assisting with using the telephone, cutting toe nails, giving medication or treatment, reading/writing, providing emotional support, keeping an eye on things and assisting in the event of emergency or crisis. Results for "assisting with the telephone", although reported here, cannot be interpreted because minimum cell frequency was not achieved. All other caregiving tasks were significantly related to the reporting of caregiver role strain (see table 5.15). Again, the reasons why these tasks are associated with reported presence of caregiver role strain are not clear. Cutting toenails might be unpleasant and therefore associated with caregiver role strain. Giving medications and treatment may be confining in terms of scheduling or time-demands. Giving medications or treatments likely requires daily contact and at specific times creating difficulty particularly for caregivers who do not share the care receiver's household. Reading/writing might also be time consuming task and therefore associated with strain.

It is difficult to interpret "keeping an eye on things" or "assisting in the event of emergencies" because the range of activities is potentially broad and not further defined on the questionnaire. However, these two tasks suggest ongoing responsibility and availability of the caregiver and this may be the source of strain. Providing emotional support also implies a broad range of more specific activities and reported caregiver role

## TABLE 5.15

## CORRELATES OF CAREGIVER ROLE STRAIN: CAREGIVING TASKS PERFORMED (n=197)

| "Other" Tasks | Telephoning | | | | Cutting Toenails | | | | Giving Medications | | | | Reading/Writing | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | |
| | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % |
| Caregiver Role Strain | | | | | | | | | | | | | | | | |
| Absence | 4 | 17 | 109 | 61 | 8 | 25 | 101 | 61 | 10 | 29 | 99 | 61 | 9 | 28 | 100 | 61 |
| Presence | 20 | 83 | 68 | 39 | 24 | 75 | 64 | 39 | 25 | 71 | 63 | 39 | 23 | 72 | 65 | 39 |
| | 24 | 100 | 173 | 100 | 32 | 100 | 165 | 100 | 35 | 100 | 162 | 100 | 32 | 100 | 165 | 100 |
| | Chi-square = 14.80<br>df = 1; p = .00 | | | | Chi-square = 12.80<br>df = 1; p = .00 | | | | Chi-square = 11.05<br>df = 1; p = .00 | | | | Chi-square = 10.16<br>df = 1; p = .00 | | | |

| "Other" Tasks | Emotional Support | | | | "Eye on Things" | | | | Emergencies | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Yes | | No | | Yes | | No | | Yes | | No | |
| | n | % | n | % | n | % | n | % | n | % | n | % |
| Caregiver Role Strain | | | | | | | | | | | | |
| Absence | 68 | 49 | 41 | 71 | 54 | 47 | 55 | 66 | 52 | 48 | 57 | 65 |
| Presence | 71 | 51 | 17 | 29 | 60 | 53 | 28 | 34 | 57 | 52 | 31 | 35 |
| | 137 | 100 | 58 | 100 | 114 | 100 | 83 | 100 | 109 | 100 | 88 | 100 |
| | Chi-square = 6.99<br>df = 1; p = .01 | | | | Chi-square = 6.20<br>df = 1; p = .02 | | | | Chi-square = 5.07<br>df = 1; p = .03 | | | |

strain may be based on excessive demands for emotional support. The response categories for questions on the kinds of caregiving tasks provided was dichotomous (that is, "yes" or "no"). No information was gathered on the source of difficulty for these tasks. However, it seems clear that for this group of elderly primary caregivers, caregiving tasks are related to reported presence or absence of caregiver role strain.

Next, reported caregiver role strain and these same caregiving tasks were examined while controlling for gender. The aim was to test whether or not the greater likelihood of women reporting caregiver role strain was based on the types of tasks they performed. The question focused on whether or not the original relationship between a caregiving task and reported caregiver role strain stayed the same or disappeared. If the initial relationship between task and reported caregiver role strain remained after controlling for gender, there was evidence to reject the suggestion that caregiver role strain among women was related to the tasks they performed. If the initial relationship between task and reported caregiver role strain disappeared when controlling for gender, there was support for the notion that the greater likelihood of women reporting caregiver role strain was based on the tasks they performed. This same process was carried out for caregiver role strain and caregiving tasks while controlling for relationship to the care receiver.

Findings indicated that the initial relationship between caregiving task and reported caregiver role strain remained while controlling for gender (see tables 5.16 and 5.17). The

## TABLE 5.16

## CORRELATES OF CAREGIVER ROLE STRAIN: CAREGIVING TASKS PERFORMED CONTROLLING FOR GENDER (n=128)

| Basic ADL Tasks | Walking | | | | Dressing | | | | Feeding | | | | Washing | | | | Toilet | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | |
| | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % |
| Caregiver Role Strain | | | | | | | | | | | | | | | | | | | | |
| Absence | 6 | 26 | 56 | 53 | 4 | 15 | 58 | 57 | 0 | 0 | 62 | 54 | 5 | 21 | 57 | 55 | 1 | 11 | 61 | 51 |
| Presence | 17 | 74 | 49 | 47 | 22 | 85 | 44 | 43 | 13 | 100 | 53 | 46 | 19 | 79 | 47 | 45 | 8 | 89 | 58 | 49 |
| | 23 | 100 | 105 | 100 | 26 | 100 | 102 | 100 | 13 | 100 | 115 | 100 | 24 | 100 | 104 | 100 | 9 | 100 | 119 | 100 |
| | Chi-square = 4.58<br>df = 1; p = .03 | | | | Chi-square = 12.66<br>df = 1; p = .00 | | | | Chi-square = 11.52<br>df = 1; p = .00 | | | | Chi-square = 7.70<br>df = 1; p = .01 | | | | Chi-square = 8.19<br>df = 1; p = .05 | | | |

| Instrumental ADL Tasks | Housekeeping | | | | Household Maintenance | | | | Transportation | | | | Food Preparation | | | | Grocery Shopping | | | | Personal Business | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | |
| | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % |
| Caregiver Role Strain | | | | | | | | | | | | | | | | | | | | | | | | |
| Absence | 40 | 51 | 22 | 44 | 19 | 43 | 43 | 51 | 19 | 40 | 43 | 54 | 36 | 47 | 26 | 50 | 35 | 44 | 27 | 55 | 25 | 35 | 37 | 66 |
| Presence | 38 | 49 | 28 | 56 | 25 | 57 | 41 | 49 | 29 | 60 | 37 | 46 | 40 | 53 | 26 | 50 | 44 | 56 | 22 | 45 | 47 | 65 | 19 | 34 |
| | 109 | 100 | 88 | 100 | 80 | 100 | 117 | 110 | 83 | 160 | 114 | 100 | 102 | 100 | 95 | 100 | 119 | 100 | 78 | 100 | 108 | 100 | 89 | 100 |
| | Chi-square = .39<br>df = 1; p = .53 | | | | Chi-square = .46<br>df = 1; p = .50 | | | | Chi-square = 1.88<br>df = 1; p = .17 | | | | Chi-square = 1.27<br>df = 1; p = .91 | | | | Chi-square = 1.01<br>df = 1; p = .31 | | | | Chi-square = 11.17<br>df = 1; p = .00 | | | |

## TABLE 5.17

## CORRELATES OF CAREGIVER ROLE STRAIN: CAREGIVING TASKS PERFORMED CONTROLLING FOR GENDER (n=128)

| "Other" Tasks | Telephoning | | | | Cutting Toenails | | | | Giving Medications | | | | Reading/Writing | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | |
| | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % |
| Caregiver Role Strain | | | | | | | | | | | | | | | | |
| Absence | 4 | 19 | 589 | 54 | 5 | 20 | 57 | 59 | 8 | 27 | 54 | 55 | 6 | 24 | 56 | 54 |
| Presence | 17 | 81 | 49 | 46 | 20 | 80 | 46 | 49 | 22 | 73 | 44 | 45 | 19 | 76 | 47 | 46 |
| | 21 | 100 | 107 | 100 | 25 | 100 | 103 | 100 | 30 | 100 | 98 | 100 | 25 | 100 | 103 | 100 |
| | Chi-square = 7.34 | | | | Chi-square = 8.69 | | | | Chi-square = 6.34 | | | | Chi-square = 6.24 | | | |
| | df = 1; p = .01 | | | | df = 1; p = .00 | | | | df = 1; p = .01 | | | | df = 1; p = .01 | | | |

| "Other" Tasks | Emotional Support | | | | "Eye on Things" | | | | Emergencies | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Yes | | No | | Yes | | No | | Yes | | No | |
| | n | % | n | % | n | % | n | % | n | % | n | % |
| Caregiver Role Strain | | | | | | | | | | | | |
| Absence | 42 | 43 | 20 | 65 | 29 | 38 | 33 | 64 | 29 | 40 | 33 | 60 |
| Presence | 55 | 57 | 11 | 35 | 47 | 62 | 19 | 36 | 44 | 60 | 22 | 40 |
| | 97 | 100 | 31 | 100 | 76 | 100 | 52 | 100 | 73 | 100 | 55 | 100 |
| | Chi-square = 3.43 | | | | Chi-square = 6.93 | | | | Chi-square = 4.38 | | | |
| | df = 1; p = .06 | | | | df = 1; p = .01 | | | | df = 1; p = .04 | | | |

data do not support the notion that the greater likelihood of women reporting caregiver role strain is grounded in the kinds of tasks they perform.

The relationship between caregiving task and caregiver role strain, controlling for relationship to the care receiver was examined next. The initial relationship between caregiving task and caregiver role strain disappeared for basic ADL, personal business and "other" tasks, providing some support for the notion that the greater likelihood of adult children reporting caregiver role strain is related to the tasks that they perform (see tables 5.18 and 5.19). Although care receiver impairment is not known, it seems likely that the care receivers of these elderly adult child caregivers (60 years of age and older) are very old and may require a great deal of assistance. This assumption is supported to some extent by the tasks performed by adult child caregivers.

## TABLE 5.18

## CORRELATES OF CAREGIVER ROLE STRAIN: CAREGIVING TASKS PERFORMED CONTROLLING FOR RELATIONSHIP TO THE CARE RECEIVER (n=36)

| Basic ADL Tasks | Walking | | | | Dressing | | | | Feeding | | | | Washing | | | | Toilet | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | |
| | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % |
| Caregiver Role Strain | | | | | | | | | | | | | | | | | | | | |
| Absence | 2 | 22 | 9 | 33 | 1 | 10 | 10 | 39 | 0 | 0 | 11 | 38 | 1 | 10 | 10 | 39 | 1 | 20 | 10 | 32 |
| Presence | 7 | 78 | 18 | 67 | 9 | 90 | 16 | 61 | 7 | 100 | 18 | 62 | 9 | 90 | 16 | 61 | 4 | 80 | 21 | 68 |
| | 9 | 100 | 27 | 100 | 10 | 100 | 26 | 100 | 7 | 100 | 29 | 100 | 10 | 100 | 26 | 100 | 5 | 100 | 31 | 100 |
| | Chi-square = .04<br>df = 1; p = .83 | | | | Chi-square = 1.58<br>df = 1; p = .21 | | | | Chi-square = 2.24<br>df = 1; p = .13 | | | | Chi-square = 1.58<br>df = 1; p = .21 | | | | Chi-square = .00<br>df = 1; p = .98 | | | |

| Instrumental ADL Tasks | Housekeeping | | | | Household Maintenance | | | | Transportation | | | | Food Preparation | | | | Grocery Shopping | | | | Personal Business | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | |
| | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % |
| Caregiver Role Strain | | | | | | | | | | | | | | | | | | | | | | | | |
| Absence | 4 | 22 | 7 | 39 | 5 | 31 | 6 | 30 | 5 | 28 | 6 | 33 | 2 | 14 | 9 | 41 | 7 | 29 | 4 | 33 | 9 | 28 | 2 | 50 |
| Presence | 14 | 78 | 11 | 61 | 11 | 69 | 14 | 70 | 13 | 72 | 12 | 67 | 12 | 86 | 13 | 59 | 17 | 71 | 8 | 67 | 23 | 72 | 2 | 50 |
| | 18 | 100 | 18 | 100 | 16 | 100 | 20 | 110 | 18 | 160 | 18 | 100 | 14 | 100 | 22 | 100 | 24 | 100 | 12 | 100 | 32 | 100 | 4 | 100 |
| | Chi-square = .52<br>df = 1; p = .47 | | | | Chi-square = .00<br>df = 1; p = 1.00 | | | | Chi-square = .00<br>df = 1; p = 1.00 | | | | Chi-square = 1.74<br>df = 1; p = .19 | | | | Chi-square = .00<br>df = 1; p = 1.00 | | | | Chi-square = .10<br>df = 1; p = .75 | | | |

TABLE 5.19

## CORRELATES OF CAREGIVER ROLE STRAIN: CAREGIVING TASKS PERFORMED CONTROLLING FOR RELATIONSHIP TO THE CARE RECEIVER (n=36)

| "Other" Tasks | Telephoning | | | | Cutting Toenails | | | | Giving Medications | | | | Reading/Writing | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Yes | | No | | Yes | | No | | Yes | | No | | Yes | | No | |
| | n | % | n | % | n | % | n | % | n | % | n | % | n | % | n | % |
| Caregiver Role Strain | | | | | | | | | | | | | | | | |
| Absence | 1 | 10 | 10 | 39 | 0 | 0 | 11 | 44 | 1 | 8 | 10 | 44 | 1 | 8 | 10 | 42 |
| Presence | 9 | 90 | 16 | 61 | 11 | 100 | 14 | 56 | 12 | 92 | 13 | 56 | 11 | 92 | 14 | 58 |
| | 10 | 100 | 26 | 100 | 11 | 100 | 25 | 100 | 12 | 100 | 23 | 100 | 12 | 100 | 24 | 100 |
| | Chi-square = 1.58<br>df = 1; p = .21 | | | | Chi-square = 5.05<br>df = 1; p = .02 | | | | Chi-square = 3.47<br>df = 1; p = .06 | | | | Chi-square = 2.77<br>df = 1; p = .10 | | | |

| "Other" Tasks | Emotional Support | | | | "Eye on Things" | | | | Emergencies | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Yes | | No | | Yes | | No | | Yes | | No | |
| | n | % | n | % | n | % | n | % | n | % | n | % |
| Caregiver Role Strain | | | | | | | | | | | | |
| Absence | 6 | 23 | 5 | 50 | 5 | 24 | 6 | 40 | 4 | 20 | 7 | 44 |
| Presence | 20 | 77 | 5 | 50 | 16 | 76 | 9 | 60 | 16 | 80 | 9 | 56 |
| | 26 | 100 | 10 | 100 | 21 | 100 | 15 | 100 | 20 | 100 | 16 | 100 |
| | Chi-square = 1.36<br>df = 1; p = .24 | | | | Chi-square = .45<br>df = 1; p = .50 | | | | Chi-square = 1.38<br>df = 1; p = .24 | | | |

# CHAPTER 6

# DISCUSSION

Discussion of the research is presented in three sections. The first section provides a summary of empirical findings and relates these findings to the literature on caregiving and the caregiving model. Second, methodological and conceptual limitations of the research are described. Finally, the implications of this research for further study of family caregiving are presented.

## 6.0 SUMMARY AND DISCUSSION

This research attempted to address a gap in theoretical development identified in caregiving research (Zarit et al., 1986). A caregiving model, based on stress theory and social support theory, and consistent with empirical findings of caregiving research was tested with a group of elderly primary caregivers. The caregiving model is a social model of stress where the potential stressor is caregiving and the stress reaction is manifested in health status. Key components of the caregiving model include appraisal of caregiving as a possible stressor and the role of social support to potentially modify the relationship between stressor and stress reaction. An additional component of the model is the linking of caregiving characteristics with the appraisal of caregiving as difficult. From this caregiving model, several hypotheses were derived. A first set of hypotheses (#1 to #3) examined the relationship between caregiver role strain, social support and caregiver health status. A second set of hypotheses (#4 to #8) addressed caregiving characteristics and caregiver role strain.

The first set of hypotheses (#1, #2 and #3) tested the direct effects and buffering model of social support and health status with a sample of elderly primary caregivers who had reported varying levels of caregiver role strain. The direct effects model posits a direct relationship between social support and health status while the buffering model stipulates this relationship only when caregiver role strain is high. Two analytical approaches were taken, the grouping approach and the use of an interaction term. For the dependent variable, self-rated health, findings indicated functional disability as a significant correlate for the high caregiver role strain group (n=46) and for the combined group (n=197). Consistent with the literature that links self-rated health with functional ability (for example, Fillenbaum, 1979; Tissue, 1972), this finding lends further support to the notion that health ratings among elderly persons are anchored in the perceived ability to carrry out tasks of daily living. The optimism in health ratings indicated by this group of elderly caregivers likely reflects their overall good physical health status and ability to carry out everyday tasks.

Social support was not a significant correlate of self-rated health although perceived material support did explain 7% of the variance of self-rated health within the low caregiver role strain group. As discussed in chapter five, sample size and size of standard error may have influenced the lack of statistical significance between perceived material support and self-rated health for the low caregiver role strain group (n=42). Comparison of slopes indicated a statistically significant difference for perceived material support between the no caregiver role strain (n=109) and low caregiver role strain (n=42) groups. However, while the relationship between perceived material support and self-rated health was in the expected direction for the low caregiver role strain group, the relationship was inverse for the no caregiver role strain group.

The inverse relationship between high perceived material support and low self-rated health among those indicating no caregiver role strain is intuitively perplexing. It is possible that the difficulty may lie with the social support measure or the self-rated health measure. Both measures use three point scales and for those who have indicated no caregiver role strain, this limited range may be insufficient to detect differences. For those who have indicated the presence of caregiver role strain, the measures may be adequate. From this data on self-rated health, findings on the relationship between caregiver role strain, social support and health outcome were not consistent with either the direct effects or the buffering model. Instead, findings confirmed previous research that has linked self-rated health with perceptions of functional ability.

Hypotheses #1, #2 and #3 were also tested with self-reported depression symptoms as the measure of caregiver health status. Support for the buffering model of social support was evident when the grouping approach was taken. Perceived material support was a significant correlate of depression for the high caregiver role strain group but not for the no and low caregiver role strain groups. In comparing groups, the high caregiver role strain group had the highest mean score for depression and the lowest mean score for perceived material support. For the high caregiver role strain group, the relationship between depression and perceived material support was inverse as would be expected.

Support for the buffering model of caregiver depression was not confirmed using an interaction term in the regression equation with the total group of caregivers. Instead, level of strain became the sole significant correlate of depression. According to Ferraro (1989), the grouping approach and the use of an interaction term should produce similar results for significant correlates. The discrepancy between findings from the two approaches is likely attributable to the collapsing of data cells that preceded the creation of the interaction term. While findings from the two approaches are not directly comparable, the relationship between depression and caregiver role strain was evident for both analytic procedures. In the grouping approach, perceived material support was inversely related to depression for the high caregiver role strain group. When the entire group was tested with an interaction term (strain x support), caregiver role strain was the sole significant correlate explaining 11% of the variance in depression scores.

The relationship between caregiver depression and burden has been widely reported in the gerontological literature (for example, Fitting et al., 1986; Poulshock & Deimling, 1984). Following from this, findings that indicate a link between caregiver reported symptoms of depression and the appraisal of caregiving as difficult are not unexpected. As with previous caregiving research, the sequence of caregiver depression and perceived difficulty in caregiving is not clear. The cross sectional nature of research in both gerontological and social support literature has not provided a clear understanding of the direction of relationships involving depression. It may be that depressed individuals are more likely to feel oppressed and alone and thus report high levels of caregiver burden and low social support. On the other hand, the difficulties encountered in caregiving, including having few support persons to rely on, could lead to feelings of decreasing self-esteem and depression. The caregiving model suggested here conforms to the latter explanation but the cross sectional nature of data prohibits a causal explanation. Evidence for the sequential relationship inherent in the caregiving model will require longitudinal data.

It is noteworthy that for caregiver depression, perceived material support rather than perceived emotional support was the significant correlate. The literature on social support has indicated the primacy of emotional support over material support in reducing stressor-related symptoms (Cohen et al., 1985). On the other hand, separating these two types of support is difficult conceptually and in practice because material support tends to imply emotional support to some degree (Thoits, 1982). Much of the research on stressors, social support and health has not focused on the elderly as a distinct group. For a group of elderly primary caregivers, perceived material support may be relatively more important in buffering the relationship between caregiving and depression. It may be that material support is more salient among older groups due to an age-related heightened perception of vulnerability and associated need for material support. In other words, emotional support in itself may not be sufficient to buffer the relationship between stressor and stress reaction among elderly persons who already feel vulnerable. As George (1989) has suggested, some dimensions of social support may be more important during difficult times. In this case, it may be that perceived material support is more important as a buffer than perceived emotional support.

For this first set of hypotheses then, support for a buffering or direct effects model was evident to a limited extent when caregiver depression (but not self-rated health) was the measure of stress reaction. For caregiver depression as an indicator of health status, evidence for the buffering model of social support existed when the grouping approach was used. Multiple comparison procedure indicated differences across caregiver groups (no, low and high caregiver role strain) for mean scores of depression and perceived material support. Conversely, the mean score for self-rated health was not significantly different across caregiver groups. The three caregiver groups were similarly optimistic in rating their health, with the majority reporting good or excellent health. This optimism may be attributed to the health characteristics of this group of elderly primary caregivers. The vast majority reported no days in hopsital (85%) and no bedridden days at home (80%) during the past twelve months. In addition, more than two thirds reported no functional disability in performing their own activities of daily living.

It seems likely that the measure of self-rated health is less sensitive than the CES-

Depression scale for measuring health status as a stress reaction among these elderly primary caregivers. For the three caregiver groups, self-ratings of health were homogeneous. As discussed earlier, the self-rated health measure was treated as a scale. Although this reflects current research practice, and reliabilty and validity have been addressed, self-rated health is a three point scale, providing limited variability. The CES-Depression scale has a potential range of zero to sixty and for this group of elderly primary caregivers, the range was zero to forty-one. This measure of depression provides greater variation in response compared with the self-rated health measure. In addition, the literature on caregiver burden has indicated a relationship between caregiving and depression.

For the second set of hypotheses (#4 to #8), caregiving correlates were examined in relation to the presence or absence, and the level of caregiver role strain reported. Findings indicated that women (hypothesis # 4) and adult child caregivers (hypothesis #6) were more likely to report caregiver role strain. The literature on caregiver burden has shown that when men and women are compared and differences are found, it is women who report greater burden. As discussed earlier, there has been a great deal of speculation regarding the underlying reasons for this difference. Explanations have been based on gender-related management style, social support patterns, previous socialization, degree of involvement, perception of caregiving, and caregiving expectations (George & Gwyther, 1984; Miller, 1989; Morycz, 1985; Pruchno & Resch, 1989).

For this research, it was possible to pursue one explanation related to differences in caregiving task performance. The caregiver burden literature has empirically linked the reporting of burden with caregiving tasks that restrict or confine the caregiver in time and space or that are physically demanding (Hooyman et al., 1985; Montgomery et al., 1985; Robinson & Thurnher, 1979). An examination of the relationship between caregiving tasks and caregiver role strain indicated in general, that basic ADL, personal business tasks and "other" tasks including giving medications and telephoning were significantly associated with reporting caregiver role strain. However, a linkage between gender and the performance of these same tasks was not found when the relationship between task and caregiver role strain was examined while controlling for gender.

The other significant correlate of reported caregiver role strain was being an adult child caregiver rather than any other caregiver. Although comparative work is limited, the literature on caregiver burden has suggests that those "closest" to the care receiver, that is, spouse and adult child, are more likely to feel burdened compared to other caregivers. Findings from caregiver studies have indicated that spouse caregivers report greater burden compared to adult child caregivers (Cantor, 1983; Johnson & Catalano, 1983). One exception has been work done by Young and Kahana (1989), in which daughters reported greater burden compared to spouse caregivers. These daughters were significantly more likely to be helping parents with difficult and time-demanding tasks such as personal care, toileting and transportation.

Most research on adult child caregivers has focused on daughters rather than sons. Sample selection is often based on relationship to the caregiver, with the emphasis being on selection of daughter caregivers rather than son caregivers or a comparison of these sons and daughters. For this research, the majority of child caregivers were daughters. The caregiving literature suggests that caregiving difficulties reported by child caregivers are often based on competing time demands from jobs, younger family members and the care receiver (Brody, 1985; Scharlach, 1987). Living arrangement with the care receiver has also been suggested and studies have indicated that daughters who live with the care receiver experience greater burden (Danis & Silverstone, 1981). Young and Kahana's (1989) study suggested that performance of difficult caregiving tasks might be a factor.

Competing job demands were not a likely explanation given that most of these adult children were retired and no data were available on competing demands from other family members. The majority of adult child caregivers did not reside with the care receiver. However, when the relationship between caregiving tasks and caregiver role strain was examined, while controlling for relationship to the care receiver, findings indicated caregiving task as an important factor. In other words, it is likely the tasks that adult caregivers are performing, rather than their relationship to the care receiver, that contribute to the appraisal of caregiving as difficult. Clearly, this is not a complete explanation but underlines the importance of taking several factors into account in attempting to understand the sources of difficulty in caregiving.

No significant relationship between the presence of caregiver role strain and living with the care receiver (hypothesis #5), caregiver age (hypothesis #7) or caregiver functional disability (hypothesis #8) was indicated. It should be noted that this group of elderly primary caregivers differs from samples usually reported in the literature. As indicated earlier, caregiver samples are often drawn from formal health care agency records and self-help or support groups. These samples represent families who are already experiencing difficulty and require additional resources. In contrast, this research is based on a group of community dwelling elderly primary caregivers who have reported good or excellent health, very little functional disability, and are able to provide care to another person. So, although it is useful to compare these findings with the caregiver burden literature, there are some noteworthy differences in sample characteristics. In particular, this group of elderly primary caregivers is likely healthier and experiencing less difficulty in caregiving.

Finally, the second set of hypotheses (#4 to #8) also addressed the correlates of the level of caregiver role strain, that is, low versus high. None of the selected caregiving characteristics (age, gender, functional disability, living arrangement, spouse caregiver, adult child caregiver) were statistically significant correlates. While women and adult child caregivers were more likely to report caregiver role strain, these characteristics were not statistically significant in differentiating those who reported high versus low caregiver role strain. Reported high and low caregiver role strain were not significant distinctions among those who indicated role strain. In contrast, the distinction between those who indicated presence or absence of caregiver role strain was a significantly associated with gender and relationship to care receiver for the entire group of caregivers. This may be attributable to the measure itself or the way that those who indicated interference were dichotomized into high and low caregiver role strain groups. Respondents were asked to indicate level of interference as "some", "noticeable" or "considerable" and the last two groups were combined to form the high caregiver role strain group. .

## 6.1 LIMITATIONS

Limitations of this research include methodological and conceptual concerns. In terms of methodology, limitations are related to survey research in general and to surveying elderly persons in particular. Other limitations pertain to the selection of concepts including availability and suitability of measures. First, methodological limitations, including issues of demand characteristics, cross-sectional design, chance findings and small numbers are described.

Distortions in response related to "demand characteristics" are a hazard of survey research in general (Jackson, 1988). The question itself or the behavior of the interviewer may encourage a certain response. Although there is little research specifically on demand characteristics and elderly respondents, it has been suggested that older compared to younger respondents may be more reluctant to report possibly embarrassing information and more inclined to over report desirable information (Rodgers & Herzog, 1988). Survey respondents may feel that a specific answer is socially desirable or expected. For this research, some caregivers may have been reluctant to report caregiving as an interference. It seems plausible that spouses might have underreported the interference that caregiving entailed because this conflicts with social norms regarding family privacy or spousal obligation.

Demand characteristics based on question structure are best addressed through pretesting and the use of more than one measure of the same construct within the survey. For the caregiver interference question, there was only a single measure of caregiver role strain. However, the significant association between caregiver role strain and caregiver tasks that has been previously reported tends to support the validity of this measure, at least in terms of the dichotomy of presence versus absence of caregiver role strain. Demand characteristics based on the interviewer's behavior are preventable to a degree when interviewers are well trained. For the original living arrangements study, interviewers received group training and most had previous experience as interviewers.

A second limitation is cross-sectional design. Data were collected at one point with no intention of repeating the measures at a second point in time. Cross-sectional survey data cannot determine causal relationships and are appropriate for examining correlates at one point in time (Smith, 1981). Inasmuch as data are correlational, causality cannot be determined. For this research on primary elderly caregivers, no causal relationships were suggested and relationships among variables within the caregiving model were reported as significant correlates.

A third consideration is the potential for significant findings as the result of chance. For this research on elderly primary caregivers, the .05 level of significance was used in each procedure. On the basis of chance and the .05 level of significance, it is conceivable that one in twenty relationships will be statistically significant (Jackson, 1988). For this research, the possibility of significant findings based on chance is an issue. However, hypotheses for this research were theoretically and empirically based and the findings were not unexpected or highly incongruent with current literature. To some degree, this addresses the concern about chance findings.

A serious limitation of this research is that small numbers were used in analytic procedures for both the grouping and interaction term approaches. The grouping approach necessitated dividing caregivers according to their level of caregiver role strain (no, low or high). This resulted in relatively small groups for the purposes of regression analyses. For example, when self-rated health was the dependent variable, perceived material support was not a significant correlate but it did explain 7% of the variance. This inconsistency, in particular the size of the r-squared, might be due to small group size (n=42). Group size may have been insufficient to detect a significant relationship between self-rated health and perceived material support. For the interaction term approach, the small number of caregivers indicating no perceived support had to be combined with those who indicated one support person in order to have reasonable cell size numbers. This collapsing had to be carried out with both perceived emotional support and perceived material support. Findings from the two approaches (grouping and interaction term) differed and are not directly comparable because of this collapsing.

Turning to conceptual limitations, concern relates to the availability and validity of measures from the primary research for the purposes of secondary analysis. Additional information would have been useful. For example, it was noted that measures of caregiver coping were desirable but not available in the primary research dataset. Except for the caregiving tasks performed, information on care receiver impairment was lacking. While links between care receiver impairment and burden have been inconsistent, suggesting the importance of other factors (Gwyther & George, 1986), it would have been useful to examine care receiver impairment as a correlate of caregiver health and role strain. For caregiver role strain, information was not available on caregiving expectations and the source of interference that caregiving had created. Subsequent research using the concept of caregiver role strain might address caregiver perception of expectations. Information on the source of caregiver role strain would be valuable in view of the limited attention this has received in the caregiving literature.

Information on caregiving tasks was available and caregiver reported performance of certain tasks was significantly associated with the presence or absence of caregiver role strain. However, the response set for questionnaire items on caregiving tasks was dichotomous (that is, tasks were or were not carried out) and no additional information was asked concerning difficulty or ease in providing care or on frequency of caregiving. Some of the tasks were broadly stated, such as providing the care receiver with emotional support. Further information was not elicited on the specific activities that providing emotional support entailed, making interpretation difficult.

While not all desirable information was available, those measures that were available were acceptable for secondary analysis. As indicated earlier, available measures of social support and health status (self-rated health and depression) reflected currently acceptable definitions and measurement in social research. The primary research study provided data on a group of community dwelling elderly primary caregivers who represented a range of caregiving experience not often studied. With the notable exception of the Informal Caregiver Survey (Stone et al., 1987, research on caregiving has tended to select samples using formal care agency resources that favor families who are experiencing difficulty and drawing upon formal care assistance. For this research, the group of primary elderly caregivers were likely relatively healthy and experiencing less difficulty in caregiving than those who are represented in much of the literature.

## 6.2 IMPLICATIONS

This research was based on a caregiving model derived from a social model of stress (Pearlin et al., 1981) and from empirical findings of caregiving research. Several hypotheses were generated from the model. Many of the hypotheses were not empirically supported. The caregiving model as currently formulated has contributed very little to advancing an understanding of caregiving difficulties. Caregiving research has not addressed needed theoretical development and testing (Zarit, 1986) and this is a continuing concern. The caregiving model represented an attempt to explore the relationship between caregiving, social support and caregiver health status. In addition, the relationship between caregiving characteristics and caregiver role strain was also examined. While the caregiving model has added little to an overall understanding of caregiving, this research does suggest future areas of study related to the importance of material support, women and adult children as caregivers, and depression among elderly primary caregivers.

Data on comparison of slopes for the grouping approach indicated a relationship between perceived material support and caregiver health status for measures of depression and self-rated health. For the high caregiver role strain group (n=46), perceived material support was a significant correlate of depression. The relative importance of material support compared with emotional support contrasts with much of the literature on social support that indicates the primacy of emotional support versus material support in reducing stressor-related health outcome (Cohen et al., 1985). It is possible that for some elderly persons, material support may be more important in moderating a relationship between stressor and stress reaction. Although cross-sectional design cannot address differences in age and cohort membership, either or both characteristics may be operating in the primacy of material support over emotional support. Perceived vulnerability and salience of material support may increase with advancing age or it may be that this cohort, because it is primarily female or because it has experienced economic deprivations is more sensitive to availability of material support. The relative importance of material support compared to emotional support for the elderly may be related to both age and cohort differences.

This research confirmed earlier findings on the greater difficulties reported by women caregivers compared to men caregivers but contrary to much of the burden literature, adult child caregivers were more likely to report the presence of caregiver role strain than other caregivers. Future work could delve into the underlying reasons for gender differences using multivariate models to examine together, factors such as social support (formal and informal) resources, coping strategies, caregiving expectations and task performance. Much less research has been carried out with male caregivers often because these caregivers have poorer response rates and are less likely to use the formal agencies that provide a source of respondents for caregiving research (Horowitz, 1989).

Another reason for the relatively limited research on male caregivers may be related to an overall expectation that caregiving of the elderly is an extension of the female role in families (Pruchno & Resch, 1989). This expectation is likely too narrow in view of the findings from this research and other community-based research (Stone et al., 1987) where at least among spousal caregivers, one-third are men. Indeed, it might prove useful to explore the caregiver role beyond the view of it as an extension of female caregiving using a formal role theory perspective. A role theory perspective on social and familial expectations of caregiving behavior would likely reveal that norms vary according to caregiver gender and relationship to the care receiver. Such variation is likely linked with caregiver with caregiver self-evaluation and feelings of difficulty and even satisfaction with the caregiving role.

The adult child caregivers in this research differed from most adult child caregivers reported in the literature by virtue of their age. The literature has tended to report on middle-aged adult caregivers commonly referred to as the "sandwich generation" (Miller, 1981). In contrast, for this research, adult child caregivers were elderly, that is, 60 years of age and older. Their elderly parent care receivers were of advanced age and likely relatively disabled compared to younger care receivers. This cannot be said with certainty because the original dataset did not provide information on care receiver disability. However, research on elderly child caregiver will likely gain importance in the future. Demographic projections indicate that the most rapid growth within the elderly population will occcur among those aged 85 and older (Manton & Soldo, 1985; Stone & Fletcher, 1980). Elderly children as caregivers to their very old parents may have an increasing role in the future.

The third area for future work suggested by this research relates to caregiver depression. This group of communty dwelling caregivers differs from samples usually studied and reported in the literature. These elderly primary caregivers are optimistic in their self-health assessment and more objective measures of hospital and bedridden days also indicate a relatively healthy group. However, multiple comparison procedures indicated a direct relationship between caregiver role strain and depression scores. Those indicating high caregiver role strain also reported the highest depression scores. While the depression score (mean=11.85; s.d=10.53) for the high caregiver role strain group was less than the cutoff score of sixteen which indicates a high level of depression symptoms and has been correlated with clinical indicators of depression, it is possible that these caregivers are still relatively depressed compared with non-caregiving peers. Future work within the original dataset could include a comparative study of caregivers and non-caregivers on a number of variables including depression scores. As indicated by George and Gwyther (1986), the advantage of well-being measures as opposed to burden measures is that the former allow a comparison of caregivers and non-caregivers. The original dataset could provide an oportunity to make this comparison.

Much work remains to be done in the area of elder caregiving. Limited research has been carried out on non-kin informal caregiving, and within family caregiving, research is needed beyond the dyad of caregiver and care receiver to include the larger family network. Very little is known about the interaction of caregiver and care receiver and how this relates to difficulties on the part of the caregiver and the care receiver. Much of the caregiving research has emphasized burden and the negative aspects of caregiving and there needs to be continuing research on the dimensions of burden. However, little attention has been given to potential positive aspects of caregiving including caregiver coping and satisfaction. Finally, further theoretical work aimed at explaining and understanding the process and outcome of caregiving is needed. The caregiving model has not added significantly to theory development. However, future work might look to stress, social support and role theory for guidance to develop and test alternative models.

# REFERENCES

Achen, C.H. (1982). Interpreting and Using Regression. Beverly Hills: Sage Publications.

Aneshensel, C.S. & Stone, J.D. (1982). Stress and depression: A test of the buffering model of social support. Archives of General Psychiatry 39:1392-1396.

Antonucci, T.C. (1985). Social support: Theoretical advances, recent findings and pressing issues. in I.G. Sarason & B.R. Sarason (Eds.), Social Support: Theory, Research and Application. DOrdrecht: Martinus Nijhoff Publishers.

Archbold, P.G., Stewart, B.J. & Greenlick, M.R. (1988). Predictors of Caregiver Role Strain. Paper presented at the 37th annual meeting of the Gerontological Society of America, _

Archbold, P.G., Stewart, B.J., Lucas, S. & Greenlick, M. (1987). Analysis of refusers in a study of the effects of organized family caregiver relief. Paper presented at the 40th annual meeting of the Gerontological Society of America, Washington, D.C.

Aronson, J. (1985). Family care of the elderly: Underlying assumptions and their consequences. Canadian Journal on Aging 4(3):115-125.

Bailey, E.J. & Young, R.F. (1986). The effects of caregiving on the family. Paper presented at the 39th annual meeting of the Gerontological Society of America, Chicago, Illinois.

Barer, B.M. & Johnson, C.L. (1990). A critque of the caregiving literature. The Gerontologist 30(1):26-29.

Barrera, M. (1986). Distinctions between social support concepts, measures and models. American Journal of Community Psychology 14:413-445.

Barusch, A.S. (1988). Problems and coping strategies of elderly spouse caregivers. The Gerontologist 28(5):677-685.

Barusch, A.S. & Spaid, W.M. (1989). Gender differences in caregiving: Why do wives report greater burden. The Gerontologist 29(5): 667-676.

Bass, D.M. & Noelker, L.S. (1987). The influence of family caregivers on elder's use of in-home services: An expanded conceptual framework. Journal of Health and Social Behavior 28(6):184-196.

Bass, D.M., Tausig, M.B. & Noelker, L.S. (1988-89). Elder impairment, social support and caregiver strain: A framework for understanding support's effects. Journal of Applied Social Sciences 13(1):81-115.

Bell, W.G. (1973). Community care for the elderly: An alternative to institutionalization. The Gerontologist 13(3): 349-354.

Berkman, L.F. (1984). Assessing the physical health effects of social networks and social support. Annual Review of Public Health, 1984 5:413-432.

Berkman, L.F. (1985). The relationship of social networks and social support to morbidity and mortality. In S. Cohen and S.L.Syme (Eds.), Social Support and Health. New York: Academic Press.

Berkman, L.F. & Syme, S.L. (1979). Social networks, host resistance, and mortality: A nine year follow-up of Alameda County residents. American Journal of Epidemiology 109(2):186-204.

Blalock, H.M. (1982). Social Statistics. New York: McGraw-Hill Book Company.

Blazer, D.G. (1982). Social support and mortality in an elderly community population. American Journal of Epidemiology 115:684-694.

Blazer, D. & Williams, C.D. (1980). Epidemiology of dysphoria and depression in an elderly population. American Journal of Psychiatry 137(4):439-444.

Boruch, R.F. (Ed.) (1978). Secondary analysis. San Francisco: Jossey-Bass Inc., Publishers.

Boruch, R.F. & Reis, J. (1980). The student, evaluative data, and secondary analysis. In L. Sechrest (Ed.), Training Program Evaluators. San Francisco: Jossey-Bass, Inc., Publishers.

Bowers, B. (1988). Family perceptions of care in a nursing home. The Gerontologist 28(3):361-368.

Boyd, J.H., Weissman, M.M., Thompson, W.D., & Myers, J.K. (1982). Screening for depression in a community sample. Archives of General Psychiatry 39:1195-1200.

Branch, L.G. & Jette, A.M. (1981). The Framingham Disability Study: Social disability among the aging. American Journal of Public Health 71(11): 1202-1210.

Brody, E.M. (1981). Women in the middle and family help to older people. The Gerontologist 25, 19-29.

Brody, E.M. (1985). Parent care as normative family stress. The Gerontologist 25(1):19-29.

Brody, E.M., Johnsen, P.T., & Fulcomer, M.C. (1984). What should adult children do for elderly parents? Opinions and preferences of three generations of women. The Journal of Gerontology 39(6):736-746.

Brownell, A. & Schumaker, S.A. (1984). Social support: An introduction to a complex phenomenon. Journal of Social Issues 40(4):1-9.

Bryant, F.B. & Wortman, P.M. (1978). Seondary analysis: The case for data archives. American Psychologist (April), 381-387.

Cantor, M.H. (1979). Neighbours and friends. Research on Aging 1(4): 434-463.

Cantor, M.H. (1980). The informal support system, its relevance in the lives of the elderly. In E. Borgatta and N. McCloskey (Eds.), Aging and Society. Beverly Hills: Sage Publications.

Cantor, M.H. (1983). Strain among caregivers: A study of experience in the United States. The Gerontologist 23(6):597-604.

Caplan, G. (1974). Support Systems and Community Mental Health. New York: Behavioral Publications.

Cassel, J. (1979). An epidemiological perspective of psychosocial factors in disease etiology. American Journal of Public Health 64: 1040-1043.

Chaisson-Stewart, G.M. (1985). Depression in the Elderly. New York: John Wiley & Sons.

Chappell, N.L. (1981). Measuring functional ability and chronic health conditions among the elderly: A research note on the adequacy of three instruments. Journal of Health and Social Behavior 22(3):90-102.

Chappell, N.L. (1985). Social support and receipt of home care services. The Gerontologist 25(1):47-54.

Chappell, N.L., Strain, L.A. & Blandford, A.A. (1986). Aging and Health Care: A Social Perspective. Toronto: Holt, Rinehart and Winston of Canada, Limited.

Chenoweth, B. & Spencer, B. (1986). Dementia: The experience of family caregivers. The Gerontologist 26(3):267-272.

Chiriboga, D.A. (1989). The measurement of stress exposure in later life. In K.S. Markides and C.L. Cooper (Eds.). Aging, Stress and Health. New York: John Wiley & Sons Limited.

Cleary, P.D. & Angel, R. (1984). The analysis of relationships involving dichotomous dependent variables. Journal of Health and Social Behavior 25(9):334-348.

Cleary, P., Mechanic, D. & Greenley, J. (1982). Sex differences in medical care utilization. Journal of Health and Social Behavior 23:106-118.

Cobb, S. (1976). Social support as a moderator of life stress. Psychosomatic Medicine 38:300-314.

Cohen J. & Cohen, P. (1983). Applied Multiple Regression/Correlation Analysis for the Behavioral Sciences. Hillsdale, N.J.: Lawrence Erlbaum Associates, Publishers.

Cohen, D. & Eisdorfer, C. (1988). Depression in family members caring for a relative with Alzheimer's Disease. Journal of the American Geriatrics Society 36(10):885-889.

Cohen, S. & McKay, G. (1986). Social support, stress and the buffering hypothesis: A theoretical analysis. In A. Baum, J.E. Singer & S.E. Taylor (Eds.), Handbook of Psychology and Health (Volume 4). Hillsdale, N.J.:Lawrence Erlbaum Associates, Publishers.

Cohen, S. & Willis, T.A. (1985). Stress, social support and the buffering hypothesis. Psychological Bulletin 98(2):310-357.

Cohen, S., Mermelstein, R., Kamarack, T. & Hoberman, H.M. (1985). Measuring the functional components of social support. In I.G. Sarason & B.R. Sarason (Eds.), Social Support: Theory, Research and Application. Dordrecht: Martinus Nijhoff Publishers.

Colerick, E.J. & George, L.K. (1986). Predictors of institutionalization among caregivers of patients with Alzheimer's disease. Journal of the American Geriatrics Society 34:493-498.

Coyne, J.C. & Lazarus, R.S. (1980). Cognitve style, stress perception, and coping. In I.L. Kutash, L.B. Schlesinger & Associates, Handbook on Stress and Anxiety: Contemporary Knowledge, Theory and Treatment. San Francisco: Jossey-Bass Publishers.

Crossman, L., London, C. & Barry, C. (1975). Older women caring for disabled spouses: A model for supportive services. The Gerontologist 21(5):464-470.

Crossman, L., London, C., & Barry, C. (1981). Older women caring for disabled spouses: A model for supportive services. The Gerontologist 21(5):464-470.

Danis, B.G., & Silverstone, B. (1981). The impact of caregiving: A difference between wives and daughters. Paper presented at the 34th annual meeting of the Gerontological Society of America, Toronto, Canada.

Dean, A. & Lin, N. (1977). The stress-buffering role of social support. Journal of Nervous and Mental Disease 165(6):403-417.

Deimling, G.T. & Bass, D.M. (1986). Symptoms of mental impairment among elderly adults and their effects on family caregivers. Journal of Gerontology 41: 778-784.

Deimling, G.T. & Poulshock, S.W. (1985). The transition from family in-home care to insitutional care. Research on Aging 7(4):563-576.

Depner, C.E., Wethington, E., & Ingersoll-Dayton, B. (1984). Social support: Methodological issues in design and measurment. Journal of Social Issues 40(4):37-54.

Depue, R.A. & Monroe, S.M. (1986). Life stress and human disorder: Conceptualization and measurement of the disordered group. In I.G. Sarason & B.R. Sarason (Eds.) Social Support: Theory, Research and Applications. Dordrecht: Martinus Nijhoff Publishers.

Doll, W., Thompson, E.H., & Lefton, M. (1976). Beneath acceptance: Dimensions of family affect towards former patients. Social Science and Medicine 10: 307-313.

Dura, J.R. & Kiecolt-Glaser, J.K. (1990). Sample bias in caregiving research. Journal of Gerontology 45(5):200-203.

Dwyer, J.W. & Secombe, K. (1989). Elder care as family labor: Gender differences in primary caregiver task performance, hours of care and burden. Paper presented at the Interrnational Congress of Gerontology, Acapulco, Mexico.

Elliot, G.R. & Eisdorfer, C. (1982). Stress and Human Health: Analysis and Implications of Research. New York: Springer Publishing Company.

Ernst, M. & Ernst, N.S. (1984). Functional capacity. In D.J. Mangen & W.A. Peterson (Eds.), Research instruments in social gerontology (volume III) (pp. 9-17). Minneapolis: University of Minnesota Press.

Fengler, A.P., & Goodrich, N. (1979). Wivers of elderly disabled men. The Gerontologist 19(2):175-183.

Ferraro, K.F. (1980). Self-ratings of health among the old and the old-old. Journal of Health and Social Behavior 21:377-383.

Ferraro, K.F. (1987). Double jeopardy to health for Black older adults? Journal of Gerontology 42(5):528-533.

Fillenbaum, G.G. (1979). Social content of self-assessments of health among the elderly. Journal of Health and Social Behavior 20:45-51.

Fisher, J.D., Nadler, A. & Whitcher-Alagna, S. (1983). Four conceptualizations of reactions to aid. In J.D. Fisher, A. Nadler & B.M. DePaulo (Eds.), New Directions in Helping. New York: Academic Press.

Fitting, M., Rabins, P., Lucas, M.J. & Eastham, J. (1986). Caregivers for dementia patients: A comparison of husbands and wives. The Gerontologist 26(3):248-252.

Ford, A.B., Folmar, S.J., Salmon, R.B., Medalie, J.H., Roy, A.W. & Galazka, S.S. (1988). Health and function in the old and very old. Journal of the American Geriatrics Society 36:187-197.

Fortune, J.C. & McBee, J.K. (1984). Considerations and methodology for the preparation of data files. In D.J. Bowering (Ed.), Secondary analysis of available data bases (pp.27-49). San Francisco: Jossey-Bass Inc., Publishers.

Frankfather, D., Smith, M.J. & Caro, F.G. (1981). Family Care of the Elderly: Public Initiatives and Private Obligations. Lexington, MA: Lexington Publishers.

Garrity, T.F., Somes, G.W. & Marx, M.B. (1978). Factors influencing self-assessment of health. Social Science and Medicine 12:77-81.

George, L.K. (1989). Stress, social support, and depression over the life-course. In K.S. Markides and C.L. Cooper (Eds.). Aging, Stress and Health. New York: John Wiley & Sons Limited.

George, L.K. & Gwyther, L.P. (1984). The dynamics of cargiver burden: Changes in caregiver well-being over time. Paper presented at the 37th annual meeting of the Gerontological Society of America, San Antonio, Texas.

George, L.K., & Gwyther, L.P. (1986). Caregiver well-being: A multidimensional examination of family caregivers of demented adults. The Gerontologist 26(3):253-259.

Goldberg, E.L., Van Natta, P., & Comstock, G.W. (1985). Depressive symptoms, social networks and social support of older women. American Journal of Epidemiology 121(3):448-456.

Gonyea, J.G., & Montgomery, R.J.V. Family caregiving: Who's burdened? Paper presented at the 37th annual meeting of the Gerontological Society of American, San Antonio, Texas.

Goode, W.J. (1960). A theory of role strain. American Sociological Review 25(4):483-496.

Gore, S. (1978). The effect of social support in moderating the health consequences of unemployment. Journal of Health and Social Behavior 19:157-165.

Gove, W.R., Hughes, M. & Style, C.B. (1983). Does marriage have positive effects on psychological well-being of the individual? Journal of Health and Social Behavior 24(2):122-131.

Grad, J., & Sainsbury, P. (1963). Mental illness and the family. The Lancet 1:544-547.

Graney, M.J. & Zimmerman, R.M. (1980). Health self-report correlates among older people in a national random sample. Mid-American Review of Sociology 5(2):47-59.

Graney, M.J. & Zimmerman, R.M. (1981). Causes and consequences of health self report variations among older people. International Journal of Aging amd Human Development 12(4): 291-300.

Gwyther, L.P., & George, L.K. (1986). Caregivers for dementia patients: Complex determinants of well-being and burden. The Gerontologist 26(3):245-247.

Haber, L.D. (1970). Age and capacity devaluation. Journal of Health and Social Behavior 11:167-188.

Hakim, C. (1982). Secondary Analysis in Social Research. London: George Allen and Unwin.

Hamburg, D.A., Elliot, G.R. & Parron, D.L. (1982). Health and Behavior: Frontiers of Reserach in the Biobehavioral Sciences. Washington, DC: National Academy Press.

Harrell, F.E. (n.d.). The LOGIST procedure. SAS Users Group Supplemental Library Users Guide.

Heller, K. & Mansbach, W.E. (1984). The mulitfaceted nature of social support in a community sample of elderly women. Journal of Social Issues 40(4):99-112.

Hoenig, J., & Hamilton, M.W. (1966). The schizophrenic patient in the community and his effect on the household. International Journal of Social Psychiatry 12:165-176.

Hooyman, N., Gonyea, J., & Montgomery, R. (1985). The impact of in-home services termination on family caregivers. The Gerontologist 25(2):141-145.

Horowitz, A. (1985). Sons and daughters as caregivers to older parents: Differences in role performance and consequences. The Gerontologist 25(6):612-617.

Horowitz, A. (1989). Methodological issues in the study of gender-specific caregiving. Paper presented at the 38th annual meeting of the Gerontological Society of America, Minneapolis, Minnesota.

Horowitz, A. & Shindelman, L. (1983). Reciprocity and affection: Past influences on current caregiving. Journal of Gerontological Social Work 5:5-20.

House, J.S. (1981). Work, Stress and Social Support. Reading, MA: Addison-Wesley.

House, J.S. & Kahn, R.L. (1985). Measures and concepts of social support. In S. Cohen and L.S. Syme (Eds.), Social Support and Health. New York: Academic Press.

Huck, S.W., Cormier, W.H. & Bounds, W.G. (1974). Reading Statistics and Research. New York: Harper and Row, Publishers.

Ingersoll, B. & Antonucci, T. (1983). Non-reciprocal social support: Another side of intimate relationships. Paper presented at the 32nd annual meeting of the Gerontological Society of America, San Francisco, California.

Israel, B. (1982). Social networks and health status: Linking theory research and practice. Patient Counselling and Health Education 4(2):65-79.

Jackson, W. (1988). Research Methods: Rules for Survey Design and Analysis. Scarborough: Prentice-Hall Canada Inc.

Jette, A.M. & Branch, L.G. (1981). The Framingham Disability Study: Physical disability among the aging. American Journal of Public Health 71(11):1211-1216.

Johnson, C.L. (1983). Dyadic family relations and social support. The Gerontologist 23(4):377-383.

Johnson, C.L., & Catalano, D.J. (1983). A longitudinal study of family supports to impaired elderly. The Gerontologist 23(6): 612-618.

Kane, R.A. & Kane, R.L. (1981). Assessing the Elderly. Lexington: Lexington Books.

Kaplan, G., Barell, V., & Lusky, A. (1988). Subjective state of health and survival in elderly adults. Journal of Gerontology 43 (4):114-120.

Kasl, S.V. (1984). Chronic life stress and health. In A. Steptoe and A. Mathews (Eds.), Health Care and Human Behavior. London: Academic Press.

Katz, S., Ford, A.M., Moskowitz, R.W., Jackson, B.A., & Jaffe, M.W. (1963). Studies of illness in the aged: The index of ADL. Journal of the American Medical Association 185(12):914-919.

Kessler, R.C. & McLeod, J.D. (1985). Social support and mental health in community samples. In S. Cohen & L.S. Syme (Eds.), Social Suport and Health. New York: Academic Press.

Kiecolt, K.J., & Nathan, L.E. (1985). Secondary Analysis of Survey Data. Beverly Hills: Sage Publications.

Kinney, J.M. & Stephens, M.A.P. (1989). Caregiving Hassles Scale: Assessing the daily hassles of caring for a family member with dementia. The Gerontologist 29(3):328-332.

Kinney, J.M., Stephens, M.A.P. & Norris, V.K. (1986). Evaluation of scales to assess stresses of caregiving: A theoretical analysis. Paper presented at the Annual Meeting of the Gerontological Society of America, Chicago, Illinois.

Kinney, J.M., Stephens, M.A.P., Ogocki, P.A. & Bridges, A. (1989). Daily hassles and well-being among caregivers to older adults with dementia: The in-home versus nursing home experience. Paper presented at the Annual Meeting of the Gerontological Society of America, Minneapolis, Minnesota.

Kosberg, J.I., Cairl, R.E. & Keller, D.M. (1989). Components of burden: Interventive implications. Paper presented at the 38th annual meeting of the Gerontological Society of America, Minneapolis, Minnesota.

Kraus, A.S. (1984). The burden of care for families of elderly persons with dementia. Canadian Journal on Aging 3(1):45-51.

Krause, N. (1987). Satisfaction with social support and self-rated health in older adults. The Gerontologist 27(3):301-308.

Krause, N. (1987). Understanding the stress process: Linking social support with locus of control beliefs. Journal of Gerontology 42(6):589-593.

Krause, N. (1989) Issues of measurment and analysis in studies of social support, aging and health. In K.S. Markides and C.L. Cooper (Eds.). Aging, Stress and Health. New York: John Wiley & Sons Limited.

LaRue, A., Bank, L., Jarvik, L., & Hetland, M. (1979). Health in old age: How do physicians'ratings and self-ratings compare? Journal of Gerontology 34:687-691.

Lazarus, R.S. (1976). Cognitive and coping processes in emotion. In A. Monat & R.S. Lazarus (Eds.), Stress and Coping. New York: Columbia University Press.

Lazarus, R.S. & Folkman, S. (1984). Stress, Appraisal and Coping. New York: Springer Publishing Company.

Lewis-Beck, M.S. (1980). Applied Regression: An Introduction. Beverly Hills: Sage Publications.

Liang, J., Tran, T.V., Krause, N. & Markides, K.S. (1989). Generational differences in the structure of the CES-D Scale in Mexican Americans. Journal of Gerontology 44(3):S110-S120.

Liberman, M.A. (1982). The effects of social support on responses to stress. In L. Goldberger & S. Breznitz (Eds.), Handbook of Stress: Theoretical and Clinical Aspects. New York: The Free Press.

Lin, N., Ensel, W.M. Simeone, R.S. & Kuo, W. (1979). Social support, stressful life events and illness: A model and empirical test. Journal of Health and Social Behavior 20(6):108-119.

Linn, B.S. & Linn, M.W. (1980). Objective and self-assessed health in the old and very old. Social Science and Medicine 14A:311-315.

Maddox, G. (1962). Some correlates of differences in self-assessment of health status among the elderly. Journal of Gerontology 17:180-185.

Maddox, G. & Douglass, E. (1973). Self-assessment of health: A longitudinal study of elderly subjects. Journal of Health and Social Behavior 14:87-93.

Manton, K.G., & Soldo, B.J. (1985). Dynamics of health changes in the oldest old: New perspectives and evidence. Milbank Memorial Fund Quarterly, 63:206-285.

Marcus, L., & Jaeger, V. (1984). The elderly as family caregivers. Canadian Journal on Aging 3(1):33-43.

Matthews, S.H. (1985). The burdens of parent care: A critical assessment of the recent literature. Paper presented at the 38th annual meeting of the Gerontological Society of America,

Matthews, S.H. (1987). Methods for studying older families. Paper presented at the Annual Meeting of the Gerontological Socity of America, Washington, D.C.

Meichenbaum, D. & Turk, D.C. (1982). Stress, coping and disease: A cognitive-behavioral perspective. In R. Neufeld (Ed.) Psychological Stress and Psychopathology. New York: McGraw-Hill.

Miller, B. (1987). Gender and control among spouse of the cognitively impaired: A research note. The Gerontologist 27(4):447-453.

Miller, B. (1989). Gender differences in spouse caregiver strain: Socialization and role expectations. Paper presented at the 38th annual meeting of the Gerontological Society of America, Minneapolis, Minnesota.

Miller, B. & Montgomery, A. (1990). Family caregivers and limitations in social activities. Research on Aging 12(1):72-93.

Miller, D.A. (1981). The "sandwich" generation: Adult children of the aging. Social Work (September): 419-423.

Minkler, M. (1981). Applications of social support theory to health education: Implications for work with the elderly. Health Education Quarterly 8(2):147-165.

Montgomery, R.J.V. (1989). Investigating caregiver burden. In K.S. Markides and C.L. Cooper (Eds.), Aging, Stress and Health. New York: John Wiley & Sons Limited.

Montgomery, R.J.V., Gonyea, J.G., & Hooyman, N.R. (1985). Caregiving and the experience of subjective and objective burden. Family Relations 34(1):19-25.

Montgomery, R.J.V., Stull, D.E., & Borgatta, E.F. (1985). Measurement and the analysis of burden. Research on Aging 7(1):137-152.

Moritz, D.J., Kasl, S.V. & Berkman, L.F. (1989). The health impact of living with a cognitively impaired elderly spouse: Depressive symptoms and social functioning. Journal of Gerontology 44(1): 517-527.

Morycz, R.K. (1985). Caregiving strain and the desire to institutionalize family members with Alzheimer's disease. Research on Aging 7(3):329-361.

Mossey, J.M., & Shapiro, E. (1982). Self-rated health: A predictor of mortality among the elderly. American Journal of Public Health 72:800-808.

Motenko, A.K. (1989). The frustrations, gratifications and well-being dementia caregivers. The Gerontologist 29(2):166-172.

Neufeld, R.W.J. (1982). Psychological Stress and Psychopathology. New York: McGraw-Hill.

Noelker, L.S. & Wallace, R.W. (1985). The organization of family care for impaired elderly. Journal of Family Issues 6(1):23-44.

Norusis, M.J. (1986). The SPSS Guide to Data Anlaysis. SPSS Incorporated.

Novak, M., & Guest, C. (1987). Application of a Multi-dimensional Caregiver Burden Inventory. Paper presented at the Third Congress of International Psychogeriatric Association, Chicago.

Novak, M. & Guest, C. (1989). Application of a multidimensional caregiver burden inventory. The Gerontologist 29(6):798-803.

Ory, M.G., Williams, T.F., Emr, M., Lebowitz, B., Rabins, P., Salloway, J., Sluss-Radbaugh, T., Wolff, E. & Zarit, S. (1985). Families, informal supports and Alzheimer's Disease. Research on Aging 7: 623-644.

Parmalee, P.A. (1983). Spouse versus other family caregivers: Psychological impact of impaired aged. American Journal of Community Psychology 11(4):337-349.

Pearlin, L.I. (1982). The social contexts of stress. In L. Goldberger & S.Breznitz (Eds.), Handbook of Stress: Theoretical and Clinical Aspects. New York: The Free Press.

Pearlin, L.I. (1983) Role strains and personal stress. In H.B. Kaplan (Ed.), Psychosocial Stress: Trends in Theory and Research. New York: Academic Press.

Pearlin, L.I. (1985). Social structure and processes of social support. In S. Cohen & L.S. Syme (Eds.), Social Support and Health. New York: Academic Press.

Pearlin, L.I. & Schooler, C. (1978). The structure of coping. Journal of Health and Social Behavior 19:2-21.

Pearlin, L.I., Lieberman, M.A., Menaghan, E.G. & Mullan, J.T. (1981). The stress process. Journal of Health and Social Behavior 22:337-356.

Pearlin, L.I., Mullan, J.T., Semple, S.J. & Skaff, M.M. (1990). Caregiving and the stress process: An overview of concepts and their measures. The Gerontologist 30(5):583-594.

Pearson, J., Verma, S. & Nellet, C. (1988). Elderly psychiatric patient status and caregiver perceptions as predictors of caregiver burden. The Gerontologist 28(1):79-83.

Pilisuk, M. & Froland, C. (1978). Kinship, social networks and health. Social Science and Medicine 12B:273-280.

Poulshock, S.W., & Deimling, G.T. (1984). Families caring for elders in residence: Issues in the measurement of burden. Journal of Gerontology 39(2):230-239.

Powers, E.A. & Bultena, G.L. (1976). Sex differences in intimate friendships in old age. Journal of Marriage and the Family 38:739-747.

Pratt, C.C., Schmall, V.L., Wright, S., & Cleland, M. (1985). Burden and coping strategies of caregivers to Alzheimer's patients. Family Relations 34(1): 27-33.

Procidano, M.E. & Heller, K. (1983). Measures of perceived social support from friends and from family: Three validation studies. American Journal of Community Psychology 11(1):1-24.

Pruchno, R.A., Kleban, M.H., Michaels, J.E. & Dempsey, N.P. (1990). Mental and physical health of caregiving spouses: Development of a causal model. Journal of Gerontology 45(5):192-199.

Pruchno, R.A. & Resch, N.L. (1989). Husbands and wives as caregivers: Antecedents of depression and burden. The Gerontologist 29:159-165.

Rabkin, J.G. & Struening, G.L. (1976). Life events, stress and illness. Science 194:1013-1020.

Radloff, L.S. (1977). The CES-S Scale: A self-report depression scale for research in the general population. Applied Psychological Measurement 1(3):385-401.

Rathbone-McCuan, E. & Coward, R.T. (1985). Male helpers: Unrecognized informal supports. Paper presented at the th annual meeting of the Gerontological Society of America, New Orleans, Louisiana.

Robinson, B.C. (1983). Validation of a caregiver strain index. Journal of Gerontology 38(3):344-348.

Robinson, B., & Thurnher, M. (1979). Taking care of aged parents: A family cycle transition. The Gerontologist 19(6):586-593.

Rodgers, W.L. & Herzog, A.R. (1988). Interviewing the Elderly: The Accuracy of Factual Information. Paper presented at the 37th annual meeting of the Gerontological Society of America,

Schaefer, C., Coyne, J.C. & Lazarus, R.S. (1981). The health-related functions of social support. Journal of Behavioral Medicine 4(4): 381-406.

Scharlach, A.E., & Boyd, S.L. (1989). Caregiving and employment: Results of an employee survey. The Gerontologist 29(3):382-387.

Schoenbach, V.J., Kaplan, B.H., Fredman, L. & Kleinbaum, D.G. (1986). Social ties and mortality in Evans County, Georgia. American Journal of Epidemiology 123(4):577-591.

Schulz, R. (1990). Theoretical perspectives on caregiving: Concepts, variables and methods. In D.E. Biegel and A. Blum (Eds.), Aging and Caregiving: Theory, Research and Policy. Newbury Park: Sage Publications.

Selye, H. (1956). The Stress of Life. New York: McGraw-Hill Book Company.

Shanas, E. (1979a). The family as a support system in old age. The Gerontologist 19:169-174.

Shanas, E. (1979b). Social myth as hypothesis: The case of family relations of old people. The Gerontologist 19:3-9.

Shanas, E. & Maddox, G.L. (1976). Aging, health and organization of health resources. In R.H. Binstock & E. Shanas (Eds.), Handbook of Aging and the Social Sciencs. New York: Van Nostrand Reinhold Co.

Shaw, B.F. (1982). Stress and depression: A cognitive perspective. In R.W.J. Neufeld (Ed.), Psychological Stress and Psychopathology (pp. 125-146). New York: McGraw-Hill Book Company.

Silliman, R.A. & Sternberg, J. (1988). Family caregiving: Impact of patient functioning and underlying causes of dependency. The Gerontologist 28(3):377-382.

Sjoquist, D.L., Schroeder, L.D. & Stephan, P.E. (1974). Interpreting Linear Regression Analysis: A Heuristic Approach. Morristown, N.J.: General Learning Press.

Smith, H.W. (1981). Strategies of Social Research. Englewood Cliffs, NJ: Prentice-Hall, Inc.

Snow, D.L. & Gordon, J.B. (1980). Social network analysis and intervention with the elderly. The Gerontologist 20(4):463-467.

Snow, D.L., Davidson, J.K., Puterski, D., Sussman, R. & Tworkowski, S. (1987). Perceptions of burden, informal support and contexts of impairment among family caregivers of frail elderly. Paper presented at the 40th annual meeting of the Gerontological Society of America, Washington, D.C.

Soldo, B.J. & Manton, K. (1985). Health status and service needs of the oldest old: Current patterns and future trends. Milband Memorial Fund Quarterly 63:286-376.

Soldo, B.J. & Myllyloma, J. (1983). Caregivers who live with dependent elderly. The Gerontologist 23(6):605-611.

Springer, D. & Brubaker, T.H. (1984). Family Caregivers and Dependent Elderly. Beverly Hills: Sage Publications.

Stahl, S.M. (1983). Health. In D.J. Mangen & W.A. Peterson (Eds.), Research Instruments in Gerontology (volume III) (pp. 85-95). Minneapolis, University of Minnesota.

Stewart, A., Ware, J.E. & Brook, R.H. (1977). The meaning of health: Understanding functional limitations. Medical Care 15(11):939-952.

Stone, L.O. & Fletcher, S. (1980). A Profile of Canada's Older Population. Montreal: The Institute for Research on Public Policy.

Stone, R., Cafferata, G. & Sangl, R. (1987). Caregivers of the frail elderly: A national profile. The Gerontologist 27(5): 616-626.

Stone, R.I. & Murtaugh, C.M. (1990). The elderly population with chronic functional disability. The Gerontologist 30(4):491-496.

Stull, D.E., Montgomery, R.J.V. & Scarisbrick-Hauser, A. (1988). Caregiver well-being: The importance of two caregivers. Paper presented at the 37th annual meeting of the Gerontological Society of America, San Francisco, California.

Tennstedt, S. L., McKinlay, J.B. & Sullivan, L.M. (1989). Informal care for frail elders: The role of secondary caregivers. The Gerontologist 29(5):677-683.

Thoits, P. (1982). Conceptual, methodological and theoretical problems in studying social support as a buffer against life stress. Journal of Health and Social Behavior 23:145-159.

Thompson, E.H., & Doll, W. (1982). The burden of families coping with the mentally ill: An invisible crisis. Family Relations 31:379-388.

Tissue, T. (1972). Another look at self-rated health among the elderly. Journal of Gerontology 27:91-94.

Treas, J. (1977). Family support systems for the aged: Some social demographic considerations. The Gerontologist 17(6):486-491.

Treat, N.J. (1986). Elders in multigeneration families: Congruence of elder-caregiver attitudes. Paper presented at the 39th annual meeting of the Gerontological Society of America, Chicago, Illinois.

Walizer, M.H. & Wienir, P.L. (1978). Research Methods and Analysis. New York: Harper & Rowe, Publishers.

Wan, T.T.H. Stressful Life Events, Social Support Networks and Gerontological Health. Lexington, Massachusetts: Lexington Books.

Wan, T.T.H., Odell, B.G. & Lewis, D.T. (1982). Promoting the Well-Being of the Elderly-. New York: The Haworth Press.

Wethington, E. & Kessler, R.C. (1986). Perceived support, received support and adjustment to stressful life events. Journal of Health and Social Behavior 27(3):78-89.

Wright, S. (1985). Subjecitve evaluation of health: A theoretical view. Social Indicators Research 16:169-179.

Young, R.F. & Kahana, E. (1989). Specifying Caregiver Outcomes: Gender and relationship aspects of caregiving strain. The Gerontologist 29(5):660-666.

Zarit, S.H. (1989). Do we need another "stress and caregiving study? The Gerontologist 29(2): 147-148.

Zarit, S.H. & Toseland, R. W. (1990). Current and future direction in family caregiving research. The Gerontologist 29(4):481-483.

Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired eldelry: Correlates of feelings of burden. The Gerontologist 20(6):649-655.

Zarit, S.H., Todd, P.A., & Zarit, J.M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. The Gerontologist 26(3):260-266.

Zweibel, N.R. (1986). Sampling biases created by self-selection of respondents into studies on caregiving. Paper presented at the 39th annual meeting of the Gerontological Society of America, Chicago, Illinois.

# APPENDIX A

# LIVING ARRANGEMENTS AND PRIMARY CARE:
# THEIR RELEVANCE FOR FORMAL HEALTH CARE

## INTERVIEW SCHEDULE

Summer, 1985

# FACE SHEET

IDENTIFICATION NO. Line _ 0 1

INTERVIEWER __________________________ _ _

DATE OF INTERVIEW (Day/month/year) ____________________ _ _ _ _ _ _

TIME STARTED ____________ _ _ _ _ _ _ _ _

TIME FINISHED ____________ Time (minutes) _ _ _

NO. OF CALLS TO OBTAIN INTERVIEW (talk to someone)
1 2 3 4 _

NO. OF CALLS TO COMPLETE INTERVIEW
1 2 3 4 _

HOUSING ARRANGEMENTS

1 - Detached
2 - Semi-detached
3 - Apartment (no more than 4 stories)
4 - Highrise
5 - Boarding home
6 - Hostel
7 - Other (specify) ____________________
9 - Missing _

SEX

1 - Male
2 - Female _

LANGUAGE USED FOR INTERVIEW (specify) ______________________ _

CENSUS TRACT ____________ _ _ _ _ _

INTERVIEWER: Introduce yourself to the respondent. Select the proper form of address from the respondent list.

HELLO (MR./MRS./MS.) ________________________________. MY NAME IS ________________________. I AM FROM THE UNIVERSITY OF MANITOBA. WE ARE INTERESTED IN TALKING TO PEOPLE OF YOUR AGE ABOUT THEIR FAMILY AND FRIENDS AND THEIR HEALTH. YOU ARE ONE OF ABOUT 1,200 PEOPLE WHOM WE ARE INTERVIEWING IN THE WINNIPEG AREA. YOUR NAME WAS SELECTED BY CHANCE FROM A LIST OF PEOPLE AGED 60 AND OVER LIVING IN THE CITY. I WANT TO ASSURE YOU THAT EVERYTHING YOU SAY IS CONFIDENTIAL AND YOUR NAME WILL NOT BE USED ANYWHERE. WE ARE INTERESTED IN GENERAL PATTERNS AND NOT IN THE WAY AN INDIVIDUAL BEHAVES.

I AM GOING TO WANT TO TALK TO YOU ABOUT YOU, YOUR FAMILY AND FRIENDS, THE THINGS YOU DO TOGETHER, YOUR HEALTH AND HOW YOU MANAGE. SOME OF THE QUESTIONS MAY NOT SEEM TO APPLY TO YOU. HOWEVER, WE WANT INFORMATION FROM PEOPLE LIVING IN ALL KINDS OF CIRCUMSTANCES. IF THERE ARE ANY QUESTIONS YOU WOULD RATHER NOT ANSWER, PLEASE DO NOT FEEL OBLIGATED TO DO SO. WE REALLY APPRECIATE YOUR HELP.

## DEMOGRAPHIC SECTION

First, I'd like to know a little about you.

1. In what year were you born? What month? What day?

(CODE DAY, MONTH, YEAR) ____________________ _ _
(CODE AGE IN YEARS) _ _

_ _
_ _ _

2. Were you born in Canada? (IF YES, ASK FOR PROVINCE)
(IF NO, ASK FOR COUNTRY)

01 Ontario
02 B.C.
03 Alberta
04 Saskatchewan
05 Manitoba
06 Quebec
07 Atlantic Provinces
08 Other English speaking country
(SPECIFY) ________________________________________
09 Other country ____________________________________
99 Missing _ _

3. Do you consider yourself a member of a particular ethnic group?

1 No
2 Yes
9 Missing _

(IF YES) Which ethnic group?

01 Canadian
02 British (ISLES) English
03 U.S.A. or Western Hemisphere
04 French
05 German
06 Norwegian/Danish/Swedish/Icelandic
07 Dutch/Belgian
08 Polish
09 Russian/Ukrainian
10 Other European-Middle East
(Italian, Spanish, Portuguese, Greek, Slavic, etc.)
11 Asia Oceanic (Chinese, Japanese, Polynesian, East
Indian, etc.)
12 Native Indian or Eskimo
13 Other (SPECIFY ______________________)
14 Jewish (ASK FOR COUNTRY OF ORIGIN ______________________)
99 Missing _ _

## DEMOGRAPHIC SECTION (cont'd)

4. What languages do you speak? (LIST LANGUAGES SPOKEN)

____________________________________________ _ _

____________________________________________ _ _

____________________________________________ _ _

5. What language do you prefer?

01 English
02 French
03 German
04 Scandinavian languages
05 Dutch/Belgian
06 Polish
07 Russian/Ukrainian
08 Europe, Mid-East
09 Asia Oceanic
10 Native
11 Other (SPECIFY ____________________)
99 Missing _ _

6. What is your religious preference, if any?

01 No preference
02 Anglican
03 Baptist
04 Greek Orthodox
05 Jehovah's Witness
06 Jewish
07 Lutheran
08 Mennonite
09 Pentecostal
10 Presbyterian
11 Roman Catholic
12 United Church
13 Other (SPECIFY) ________________________
99 Missing _ _

7. How many years of schooling do you have? (IF EDUCATION WAS OBTAINED OUTSIDE CANADA, HAVE RESPONDENT SPECIFY CANADIAN EQUIVALENT IF POSSIBLE.) _ _

**DEMOGRAPHIC SECTION (cont'd)**

8. What is your marital status?

1 Single
2 Married
3 Divorced/separated
4 Widowed
5 Other (SPECIFY) ______________________________
9 Missing _

(IF WIDOWED) How long have you been widowed? ________________ _ _ _
(CODE IN MONTHS)

9. What was your major occupation in life? (SPECIFY) ______________

1 Professional (self-employed or employed)
2 High level management, semi-professional
3 Low level management, skill crafts, trades, technical
4 Semi-skilled or unskilled
5 Farm labourer
6 Housewife
7 Other (SPECIFY _______________________)
9 Missing _

10. Are you currently employed?

1 No
2 Yes, full-time
3 Yes, part-time
4 Yes, occasional
9 Missing _

(IF YES) What occupation are you working in now? (CODE SAME AS ABOVE)

(SPECIFY) __________________________________________ _

(IF NO) When did you quit working? (CODE DATE DIRECTLY, MONTH/YEAR)

______________________________ _ _

## DEMOGRAPHIC SECTION (cont'd)

11. Now I would like to ask about your income and expenses. What you tell me is confidential information.

(EXPLAIN THAT THE QUESTIONNAIRE IS NOT MENTIONING HIS/HER NAME AND THAT THE INFORMATION WILL BE USED STATISTICALLY AS WE WANT TO KNOW WHAT INCOMES OLDER PEOPLE MAKE IN GENERAL AND NOT THE INCOME OF ANY ONE INDIVIDUAL.) (HAND RESPONDENT CARD #1)

a) What is your average monthly income including the old age security payment?

____________________

| | |
|---|---|
| 01 | No income |
| 02 | Less than $250 |
| 03 | $250 - 499 |
| 04 | $500 - 749 |
| 05 | $750 - 999 |
| 06 | $1000 - 1249 |
| 07 | $1250 - 1499 |
| 08 | $1500 - 1749 |
| 09 | $1750 - 1999 |
| 10 | $2000 - 2249 |
| 11 | $2250 - 2499 |
| 12 | $2500 - 2749 |
| 13 | $2750 - 2999 |
| 14 | $3000 or more |
| 97 | Don't know |
| 99 | MV |

_ _

(HAND RESPONDENT CARD #2)

b) Now, looking at monthly expenses, what are your average monthly expenses?

____________________

| | |
|---|---|
| 01 | No expenses |
| 02 | Less than $250 |
| 03 | $250 - 499 |
| 04 | $500 - 749 |
| 05 | $750 - 999 |
| 06 | $1000 - 1249 |
| 07 | $1250 - 1499 |
| 08 | $1500 - 1749 |
| 09 | $1750 - 1999 |
| 10 | $2000 - 2249 |
| 11 | $2250 - 2499 |
| 12 | $2500 - 2749 |
| 13 | $2750 - 2999 |
| 14 | $3000 or more |
| 97 | Don't know |
| 99 | MV |

_ _

## DEMOGRAPHIC SECTION (cont'd)

12. What is your primary (largest) source of income?

1 Old Age Security (O.A.S.)
2 Old Age Security and government supplement
3 Private pension
4 Interest earnings/dividends
5 Family or spouse
6 Other (SPECIFY) ______________________________
7 DK
9 MV _

13. How do you think your income and assets currently satisfy your needs? (READ CATEGORIES, IF NECESSARY)

1 Very well
2 Adequately
3 With some difficulty
4 Not very well
5 Totally inadequate
9 Missing _

14. Do you own or rent this dwelling?

1 Own
2 Rent
3 Other (SPECIFY ______________________________)
9 Missing _

15. Is this seniors only housing?

1 No
2 Yes
9 Missing _

16. How long have you lived in this dwelling (accommodation, apartment, etc.)? (CODE NUMBER OF YEARS DIRECTLY) _ _

17. Where did you live before coming here? (BE SPECIFIC, GET NAME OF TOWN AND NEAREST CITY)

______________________________________________

IF NO MOVES IN THE PAST 10 YEARS, GO TO LIFE SATISFACTION QUESTIONS ON PAGE 13.

## MIGRATION SECTION

THIS SECTION OF QUESTIONS PERTAINS ONLY TO THOSE PEOPLE WHO HAVE MOVED IN THE PAST 10 YEARS.

18. I would like to ask you more questions about the move(s) you made in the past 10 years. (IF MANY MOVES, RECORD INFORMATION FOR 3 MOST RECENT MOVES.) What I would like to know is where you moved from, when you moved, the type of accommodation you lived in, and the reason or reasons for your move. (IF MORE THAN ONE MOVE, START WITH THE MOST RECENT.)

IN FINDING OUT THE REASON FOR THE MOVE, PROBE TO SEE IF ANY OF THE FOLLOWING REASONS APPLY: better shopping facilities, better leisure activities, better health care facilities, better residential facilities, closer to family and friends, moved for employment reasons (self or spouse), moved because of less expensive housing, lower cost of living, etc. IF MORE THAN ONE REASON, TRY TO ESTABLISH WHICH ONE WAS THE MAIN REASON FOR MOVING.

USE THE FOLLOWING CATEGORIES FOR CODING TYPE OF DWELLING:

1 Detached
2 Semi-detached
3 Apartment (no more than 4 stories)
4 Highrise
5 Boarding home
6 Hostel
7 Other (SPECIFY ______________________)
9 Missing

| | Community Size | | | Type of Dwelling | | |
|---|---|---|---|---|---|---|
| | Moved To | Moved From | When | Moved To | Moved From | Reason for Move |
| Most Recent | | | | | | |
| Second Most Recent | | | | | | |
| Third Most Recent | | | | | | |

## MIGRATION SECTION (cont'd)

NOW I WOULD LIKE TO ASK YOU SOME QUESTIONS ABOUT YOUR MOST RECENT MOVE, THAT IS, YOUR MOVE FROM ____________________ TO ____________________.

19. How long had you been thinking of moving before your last move?

1 Less than a year
2 1 - 2 years
3 Up to 5 years
4 For many years
9 Missing ___

20. Did you feel you had to move or not?

1 Very much felt I had to move
2 Felt I had to move
3 Did not feel one way or the other that I had to move
4 Felt I did not have to move
5 Very much felt I did not have to move
9 Missing ___

21. Did you want to move or not?

1 Very much wanted to move
2 Wanted to move
3 Did not want to one way or the other
4 Did not want to move
5 Very much did not want to move
9 Missing ___

22. Did you consider any other locations before moving to this one?

1 Yes
2 Neither yes or no
3 No
9 Missing ___

23. If yes, where was this location(s)?

1 Elsewhere in Winnipeg
2 Within the community where you were living
3 Another city (________________________________)
4 Other (SPECIFY ________________________________)
9 Missing ___

MIGRATION SECTION (cont'd)

24. Why did you reject this(these) alternative location(s) before choosing your present dwelling?

1 Too expensive
2 Too isolated from family and friends
3 Too inconvenient for shopping and services
4 Unsuitable (SPECIFY ______________________________)
9 Missing
_

NOW I WOULD LIKE TO GO INTO MORE DETAIL ABOUT YOUR FEELINGS CONCERNING YOUR CURRENT LOCATION AND THE WAY YOU ARE PRESENTLY LIVING.

25. Were you reasonably familiar with this area before you came here or not?

1 Very familiar
2 Somewhat familiar
3 Neither familiar or unfamiliar
4 Somewhat unfamiliar
5 Very unfamiliar
9 Missing
_

26. Have you family and friends here?

1 Yes
2 No
9 Missing
_

27. (IF YES) Does being close to a relative or friend make you like this neighbourhood better or not?

1 Very much influences liking
2 Somewhat influences liking
3 Neither yes or no
4 Does not influence liking
5 Very much does not influence liking
9 Missing
_

## MIGRATION SECTION (cont'd)

NOW I WOULD LIKE YOU TO THINK ABOUT THE LIVING CONDITIONS IN YOUR PREVIOUS LOCATION. I AM GOING TO ASK YOU TO COMPARE THE QUALITY OF LIFE THAT YOU EXPERIENCED IN THAT COMMUNITY WITH THE QUALITY OF LIFE YOU ARE EXPERIENCING NOW IN YOUR PRESENT LOCATION.

28. Did you find friendships easier or more difficult to make here than in the previous location?

1 Very much easier
2 Somewhat easier
3 No difference in making friendships
4 Somewhat more difficult
5 Very much more difficult
9 Missing _

29. Do you feel more or less lonely here than in the previous location?

1 Very much more lonely
2 Somewhat more lonely
3 No difference in loneliness
4 Somewhat less lonely
5 Very much less lonely
9 Missing _

30. On the whole, do you prefer living here in your present location rather than there?

1 Very much prefer here
2 Somewhat prefer here
3 No difference in preference
4 Somewhat prefer there
5 Very much prefer there
9 Missing _

31. Are you more or less satisfied with the shopping facilities here?

1 Very much more satisfied
2 Somewhat more satisfied
3 No difference in satisfaction
4 Somewhat less satisfied
5 Very much less satisfied
9 Missing _

## MIGRATION SECTION (cont'd)

32. Are you more or less satisfied with the health care facilities here?

    1 Very much more satisfied
    2 Somewhat more satisfied
    3 No difference in satisfaction
    4 Somewhat less satisfied
    5 Very much less satisfied
    9 Missing
    _

33. Are you more or less satisfied with the recreation and social activities here?

    1 Very much more satisfied
    2 Somewhat more satisfied
    3 No difference in satisfaction
    4 Somewhat less satisfied
    5 Very much less satisfied
    9 Missing
    _

## LIFE SATISFACTION SECTION

Now I would like you to consider your life as it is right now. Here are a number of key words or phrases which people use to identify various areas of their lives. (HAND RESPONDENT CARD #3) After you have read each key word or phrase, please consider how you would rate your own life, as it is right now, in terms of that descriptive word or phrase.

To assist you in giving your rating, we have designed a labeled scale which runs from "TERRIBLE" to "DELIGHTFUL" in seven equal steps. Each of these steps has a corresponding number.

When you have picked the level from the scale that comes closest to describing how you feel about the particular area of your life you have just read, please tell me which label and number you have picked. For example, is your HEALTH "dissatisfying", "satisfying", "very satisfying", etc.?

USE THE FOLLOWING SCALE FOR EACH CATEGORY:

1 - Terrible
2 - Very Dissatisfying
3 - Dissatisfying
4 - Mixed
5 - Satisfying
6 - Very Satisfying
7 - Delightful
8 - No Opinion - this covers not applicable, can't remember, no comment, etc.
9 - Missing

| | | |
|---|---|---|
| 34. HEALTH | The present state of your general, overall health (relatively free of common and chronic illnesses). | _ |
| 35. FINANCES | Your income and assets (including investments, property, etc.) | _ |
| 36. FAMILY RELATIONS | Kind of contact and frequency of contact you have with your family members. This includes personal contact, phone calls, and letters. | _ |
| 37. PAID EMPLOYMENT | Any work for wages, salaries or fees. | _ |
| 38. FRIENDSHIPS | Kind of contact and frequency of contact you have with your friends. This includes personal contact, phone calls, and letters. | _ |

## LIFE SATISFACTION SECTION (cont'd)

| | | | |
|---|---|---|---|
| 39. | HOUSING | The present type, atmosphere and state of your home (e.g., apartment, house, farm, room, etc.). | _ |
| 40. | LIVING PARTNER | Includes a marriage partner; partner sharing intimate relations. | _ |
| 41. | RECREATION ACTIVITY | Personal recreation activities you engage in for pure pleasure when you are not doing normal daily living chores or some type of work. This includes relaxing, reading, TV, regular get togethers, church activities, arts & crafts, exercises, trips, etc. | _ |
| 42. | RELIGION | Your spiritual fulfillment. | _ |
| 43. | SELF-ESTEEM | How you feel about yourself; your sense of self-respect. | _ |
| 44. | TRANSPORTATION | Public and private transportation (e.g., including convenience, expense). | _ |

45. Now, using the same scale, how do you feel about your life as a whole right now? Is life generally dissatisfying, satisfying, etc.?

1 - Terrible
2 - Very dissatisfying
3 - Dissatisfying
4 - Mixed
5 - Satisfying
6 - Very satisfying
7 - Delightful
8 - No opinion
9 - Missing _

## LIFE SATISFACTION SECTION (cont'd)

### LONELINESS SCALE

I have some more statements I would like you to read. Please tell me how often each of the statements is descriptive of you.

HAND RESPONDENT CARD #4

| | Never | Rarely | Sometimes | Often | Missing |
|---|---|---|---|---|---|
| 46. I lack companionship. | 1 | 2 | 3 | 4 | 9 |
| 47. There is no one I can turn to. | 1 | 2 | 3 | 4 | 9 |
| 48. I am an outgoing person. | 1 | 2 | 3 | 4 | 9 |
| 49. There are people I feel close to. | 1 | 2 | 3 | 4 | 9 |
| 50. I feel left out. | 1 | 2 | 3 | 4 | 9 |
| 51. I feel isolated from others. | 1 | 2 | 3 | 4 | 9 |
| 52. I can find companionship when I want it. | 1 | 2 | 3 | 4 | 9 |
| 53. I am unhappy being so withdrawn. | 1 | 2 | 3 | 4 | 9 |
| 54. People are around me but not with me. | 1 | 2 | 3 | 4 | 9 |

### DEPRESSION SCALE

55. How do you see the future? (IF SUBJECT DIFFERENTIATES "<u>MY</u> FUTURE" FROM "<u>THE</u> FUTURE" ACCEPT EITHER. IF THE SUBJECT GIVES A <u>DIFFERENT</u> ANSWER FOR EACH, RECORD THE ANSWER FOR "<u>MY</u> FUTURE").

1 Bright
2 Not so bright
3 Neither bright nor gloomy
4 Somewhat gloomy
5 Gloomy
6 Can't say
9 Missing

NOTE ANY NON-VERBAL NEGATIVE RESPONSE, SUCH AS SHAKING HEAD 'NO', TURNING AWAY, WAVES INTERVIEWER AWAY, SIGHS, ETC.

## LIFE SATISFACTION SECTION (cont'd)

56. There's a difference between saying "I'm ready to die", and "I want to die". Which would you say?

1 Ready to die
2 Wants to die
3 Both
4 Neither
5 No opinion
9 Missing —

57. When you go to bed at night, do you ever feel it doesn't matter whether you wake up? (WRITE DOWN RESPONDENT'S ANSWER)

____________________________________________

____________________________________________

1 Rarely or none of the time
2 Some or a little of the time
3 Occasionally or a moderate amount of time
4 Most or all of the time
9 Missing —

## CES-D SCALE

Now I'm going to read you a list of ways you might have felt or behaved. Please tell me how often you have felt this way during the past week.

USE THE FOLLOWING SCALE FOR RESPONDENTS' ANSWERS.

0 Rarely or none of the time (less than 1 day)
1 Some or a little of the time (1-2 days)
2 Occasionally or a moderate amount of time (3-4 days)
3 Most or all of the time (5-6 days)
9 Missing

HAND RESPONDENT CARD #5

During the past week:

58. I was bothered by things that usually don't bother me. —

59. I did not feel like eating; my appetite was poor. —

60. I felt that I could not shake off the blues even with help from my family or friends. —

## LIFE SATISFACTION SECTION (cont'd)

61. I felt that I was just as good as other people. ___
62. I had trouble keeping my mind on what I was doing. ___
63. I felt depressed ___
64. I felt that everything I did was an effort. ___
65. I felt hopeful about the future. ___
66. I thought my life had been a failure. ___
67. I felt fearful. ___
68. My sleep was restless. ___
69. I was happy. ___
70. I talked less than usual. ___
71. I felt lonely. ___
72. People were unfriendly. ___
73. I enjoyed life. ___
74. I had crying spells. ___
75. I felt sad. ___
76. I felt that people dislike me. ___
77. I could not get "going". ___

<u>Scale</u>

0 Rarely or none of the time (less than 1 day)
1 Some or a little of the time (1-2 days)
2 Occasionally or a moderate amount of time (3-4 days)
3 Most or all of the time (5-6 days)
9 Missing

## RECREATION SECTION

78. I would like to ask you about some of your present activities. Do you ever participate in the following:

(READ RESPONSE CATEGORIES)

| | | OFTEN | SOMETIMES | NEVER | MV |
|---|---|---|---|---|---|
| a) | Television | 3 | 2 | 1 | 9 |
| b) | Reading/listening to music | 3 | 2 | 1 | 9 |
| c) | Visiting/talking/telephone | 3 | 2 | 1 | 9 |
| d) | Playing cards (or bingo) | 3 | 2 | 1 | 9 |
| e) | Walking | 3 | 2 | 1 | 9 |
| f) | Outdoor yard work | 3 | 2 | 1 | 9 |
| g) | Shopping/browsing/window shopping | 3 | 2 | 1 | 9 |
| h) | Theatre/movies/spectator sports/ courses/church services | 3 | 2 | 1 | 9 |
| i) | Dining out | 3 | 2 | 1 | 9 |
| j) | Sports (curling, bowling, etc.) | 3 | 2 | 1 | 9 |
| k) | Travel | 3 | 2 | 1 | 9 |
| l) | Other (SPECIFY) | | | | |
| | ______________________ | 3 | 2 | 1 | 9 |
| | ______________________ | 3 | 2 | 1 | 9 |
| | ______________________ | 3 | 2 | 1 | 9 |

## FAMILY AND FRIENDS SECTION

NOW I HAVE A SERIES OF QUESTIONS ON THE NUMBER OF FAMILY AND FRIENDS CLOSE TO YOU AND THE PART YOU FEEL THEY PLAY IN YOUR LIFE.

79. How many people, if any, live here with you? ____________
(CODE DIRECTLY, 99 MISSING VALUE)

Could you tell me something about them? What is their relationship to you? For example, husband, son, daughter, son-in-law, etc.
What is their sex?
How old are they?
What is their marital status?

| Relationship to Respondent | Sex | Age | Marital Status |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |
| | | | |

CODE: Relationship

01 Spouse
02 Child
03 Sibling
04 Grandchild
05 Parent
06 Niece/Nephew
07 Friend-peer
08 Friend-not peer
09 Other
(SPECIFY ________________)
99 Missing

Sex

1 Male
2 Female
9 Missing

Marital Status

1 Single
2 Married
3 Divorced/separated
4 Widowed
5 Other
(SPECIFY __________)
9 Missing

Age

Code Directly
99 Missing

80. Do you have any children? If yes, how many?
(Code only those who are living and outside household)
(Code number directly, missing values - 99, no children - 00)

FAMILY AND FRIENDS SECTION (cont'd)

81. How close or far away is the nearest one? _

1 - within walking distance
2 - not within walking distance but same city
3 - less than a day's journey away
4 - a day's journey away
5 - more than a day's journey away
9 - MV

82. Do you have any sisters or brothers? If yes, how many? _ _
(Code only those who are living and outside the household)
(Code number directly, missing values - 99, no siblings - 00)

83. How close or far away is the nearest one? _

1 - within walking distance
2 - not within walking distance but in same city
3 - less than a day's journey away
4 - a day's journey away
5 - more than a day's journey away
9 - MV

84. Are either of your parents still living? If yes, which one(s)? _

0 - neither
1 - mother
2 - father
3 - both
9 - MV

85. If yes, how close or far away is the nearest one? _

1 - within walking distance
2 - not within walking distance but in same city
3 - less than a day's journey away
4 - a day's journey away
5 - more than a day's journey away
9 - MV

86. Roughly speaking, about how many other living relatives in total do you have contact with or feel close to, if any? Include aunts, uncles, cousins, nieces, nephews, grandchildren, great-grandchildren, second cousins, in-laws, who live outside the household. (RECORD NUMBER DIRECTLY)

______________________ _ _

## FAMILY AND FRIENDS SECTION (cont'd)

87. How close or far away is the nearest one? _

    1 - within walking distance
    2 - not within walking distance but in same city
    3 - less than a day's journey away
    4 - a day's journey away
    5 - more than a day's journey away
    9 - MV

88. Other than relatives, how many people if any do you consider close friends? That is, how many of your friends do you feel close to, confide in, etc.? (CODE DIRECTLY) _ _

89. NEIGHBOURS: Other than relatives or friends, how many people do you have as neighbours? (CODE DIRECTLY) _ _

90. Thinking about people you see for a specific purpose (SUCH AS STORE KEEPERS, BUS DRIVERS, WAITERS, SALES PEOPLE, LETTER CARRIER, BANKER, MEALS-ON-WHEELS, VOLUNTEERS, HOMEMAKER, ETC.) about how many would you see fairly regularly in a week, would you say? (TRY TO PIN THE RESPONDENT DOWN TO A NUMBER EVEN IF ONLY APPROXIMATE.) _ _

## PRIMARY CAREGIVER SECTION

91. People sometimes have one or more individuals they can count on for help in time of need. Can you think of someone like this in your life? If yes, how many such persons? _

0 - none (IF 0, GO TO QUESTION 111 ON PAGE 26)
1 - one
2 - two
3 - three
4 - > three
9 - missing

92. Thinking now of the main such person, what is this person's relation to you? _ _

1 - spouse
2 - child
3 - sibling
4 - parent
5 - friend
6 - neighbour
7 - formal service provider (SPECIFY ____________________)
8 - other (SPECIFY ________________________________________)
9 - missing

93. Is this person male or female? _

1 - male
2 - female

94. How old is this person? _ _

95. How close or far does this person live? _

1 - same household
2 - within walking distance
3 - not within walking distance
4 - less than a day's journey away
5 - a day's journey away
6 - more than a day's journey away
9 - missing

96. How long have you known this person? (IN YEARS) _ _

PRIMARY CAREGIVER SECTION (cont'd)

97. Of all the people in your life, how close would you say you are to this person? _

1 - Closer to this person than any other
2 - Only 1 or 2 other people I am closer to
3 - Only 3 or 4 other people I am closer to
4 - 5 or 6 other people I am closer to
5 - Quite a few other people I am closer to
9 - Missing

PRIMARY CAREGIVER SECTION (cont'd)

(IF APPLICABLE, REPEAT FOR SECOND CAREGIVER)

98. Thinking now of the second main such person, what is this person's relation to you? _ _

1 - spouse
2 - child
3 - sibling
4 - parent
5 - friend
6 - neighbour
7 - formal service provider (SPECIFY ________________)
8 - other (SPECIFY ____________________________)
9 - missing

99. Is this person male or female? _

1 - male
2 - female

100. How old is this person? _ _

101. How close or far does this person live? _

1 - same household
2 - within walking distance
3 - not within walking distance
4 - less than a day's journey away
5 - a day's journey away
6 - more than a day's journey away
9 - missing

102. How long have you known this person? (IN YEARS) _ _

103. Of all the people in your life, how close would you say you are to this person? _

1 - Closer to this person than any other
2 - Only 1 or 2 other people I am closer to
3 - Only 3 or 4 other people I am closer to
4 - 5 or 6 other people I am closer to
5 - Quite a few other people I am closer to
9 - Missing

PRIMARY CAREGIVER SECTION (cont'd)

(IF APPLICABLE, REPEAT FOR THIRD CAREGIVER)

104. Thinking now of the third main such person, what is this person's relation to you? _ _

1 - spouse
2 - child
3 - sibling
4 - parent
5 - friend
6 - neighbour
7 - formal service provider (SPECIFY ____________________)
8 - other (SPECIFY ________________________________________)
9 - missing

105. Is this person male or female? _

1 - male
2 - female

106. How old is this person? (IN YEARS) _ _

107. How close or far does this person live? _

1 - same household
2 - within walking distance
3 - not within walking distance
4 - less than a day's journey away
5 - a day's journey away
6 - more than a day's journey away
9 - missing

108. How long have you known this person? (IN YEARS) _ _

109. Of all the people in your life, how close would you say you are to this person? _

1 - Closer to this person than any other
2 - Only 1 or 2 other people I am closer to
3 - Only 3 or 4 other people I am closer to
4 - 5 or 6 other people I am closer to
5 - Quite a few other people I am closer to
9 - Missing

110. I have a list of some types of care and assistance. I am interested in whether or not this person is currently providing any of them, and also your own ability to perform the tasks.

| | Can the person perform the task?<br>0 - yes<br>1 - no | Irrespective of ability, does the person receive help? (CODE hrs/wk) | Is help regular or sporadic?<br>R<br>S | Does anyone else provide these services (formal or informal agencies)? | | Can you use any or more assistance than receiving now?<br>0 - yes<br>1 - no |
|---|---|---|---|---|---|---|
| | PRIMARY CAREGIVER | | | Who? | hrs/wk | |
| BASIC ADL | | | | | | |
| walking, transfers | | | | | | |
| dressing | | | | | | |
| feeding, eating | | | | | | |
| washing, bathing, grooming | | | | | | |
| using toilet | | | | | | |
| INSTRUMENTAL ADL | | | | | | |
| housekeeping | | | | | | |
| household maintenance | | | | | | |
| transportation | | | | | | |
| food preparation | | | | | | |
| grocery shopping | | | | | | |
| personal business affairs | | | | | | |
| OTHER | | | | | | |
| using the telephone | | | | | | |
| cutting toenails | | | | | | |
| taking medication, treatment | | | | | | |
| reading, writing | | | | | | |
| emotional support | N/A | | | | | |
| keeping an eye on things for you | N/A | | | | | |
| emergencies/crises | N/A | | | | | |
| other (SPECIFY) | | | | | | |

PRIMARY CAREGIVER SECTION (cont'd)

111. If you were injured and alone and could not leave your home, who, if anyone, would you call for help: How long would it be before help arrived? (PROBE FOR WHO THEY WOULD CONTACT, IF ANYONE. NOTE IF THIS HAS EVER HAPPENED TO THEM.)

______________________________

______________________________

______________________________

______________________________

If you were unhappy and depressed, more than usual, for a considerable length of time, would you talk to anyone about it? If yes, whom would it be?

______________________________

______________________________

______________________________

112. If you were not feeling well, for whatever reason, among your family, friends, and neighbours: (NOTE ALL PERSONS NAMED)

a) Who, if any, would call you regularly? (NOT INCLUDING SPOUSE OR HOUSEHOLD MEMBER)

______________________________

______________________________

b) Who, if any, would get groceries, essentials, etc. for you? (CAN INCLUDE SPOUSE OR HOUSEHOLD MEMBER)

______________________________

______________________________

## PRIMARY CAREGIVER SECTION (cont'd)

c) That you would ask to help clean the house, prepare meals, go to the doctor/hospital, etc. with you? (CAN INCLUDE SPOUSE OR HOUSEHOLD MEMBER)

______________________________

______________________________

113. Are you the main person providing help for someone else at the present time? If yes, for whom? (NOTE RELATION) Where does this person live? (NOTE PROXIMITY)

______________________________

______________________________

114. If yes, in which of the following activities?

| | | |
|---|---|---|
| BASIC ADL | walking, transfers | ________ |
| | dressing | ________ |
| | feeding, eating | ________ |
| | washing, bathing, grooming | ________ |
| | using toilet | ________ |
| INSTRUMENTAL ADL | housekeeping | ________ |
| | household maintenance | ________ |
| | transportation | ________ |
| | food preparation | ________ |
| | grocery shopping | ________ |
| | personal business | ________ |
| OTHER | using the telephone | ________ |
| | cutting toenails | ________ |
| | taking medication, treatment | ________ |
| | nursing care | ________ |
| | financial information/ guidance | ________ |
| | reading, writing | ________ |
| | emotional support | ________ |
| | keeping an eye on things | ________ |
| | emergencies/crises | ________ |
| | other (specify ________ ________________) | ________ |

PRIMARY CAREGIVER SECTION (cont'd)

115. Considering the help you gave in the last 6 months, how much of an interference would you say it placed on you? ___

1 - no interference at all
2 - not much of an interference
3 - a noticeable interference
4 - a considerable interference
9 - missing

116. Because of the care you are providing or anticipate providing in the future, have you (in the last 5 years):

| | Yes/No | If No, Are There Any Likely Circumstances That Would Warrant It |
|---|---|---|
| Left the labour force totally | ______ | ______ |
| Left the labour force partially | ______ | ______ |
| Not entered the labour force | ______ | ______ |
| Moved yourself geographically | ______ | ______ |
| Helped or moved others | ______ | ______ |
| Altered your education plans | ______ | ______ |
| Provided housing or modified your housing so you could offer help | ______ | ______ |
| Other (SPECIFY ________________) | ______ | ______ |

## HEALTH STATUS SECTION

I'D LIKE TO SPEND A BIT OF TIME TALKING ABOUT YOUR HEALTH.

117. For your age, would you say, in general your health is:

1 - Excellent (never prevents activities)
2 - Good for your age (rarely prevents activities)
3 - Fair for your age (occasionally prevents some activities)
4 - Poor for your age (very often prevents activities)
5 - Bad for your age (health troubles of infirmity all the time - prevents most activities, or requires confinement to bed)
9 - Missing _

118. Now I have a list of health problems that people often have. I'll read them and you tell me if you have had any of them within the last year or otherwise still have after effects from having had them earlier.
(CODE: 0 - NO, 1 - YES, 9 - MISSING)

a) Heart and circulation problems (HARDENING OF THE ARTERIES, HIGH BLOOD PRESSURE, HEART TROUBLES, ANAEMIA, OR OTHER BLOOD DISEASES) _

b) Have had stroke _

c) Arthritis or rheumatism (JOINTS, BACK, ORTHOPAEDIC) _

d) Palsy (PARKINSON'S DISEASE) _

e) Eye trouble not relieved by glasses (CATARACTS, GLAUCOMA) _

f) Ear trouble (HEARING LOSS) _

g) Dental problems (TEETH NEED CARE, DENTURES DON'T FIT) _

h) Chest problems (ASTHMA, EMPHYSEMA, T.B., BREATHING PROBLEMS) _

i) Stomach trouble (INCLUDING LOWER GASTRO-INTESTINAL PROBLEMS) _

j) Kidney trouble (INCLUDING BLADDER TROUBLES) _

k) Diabetes _

l) Foot trouble _

m) Nerve trouble (INCLUDING ALL MENTAL ILLNESS OR EMOTIONAL PROBLEMS) _

n) Skin problems _

o) Other (SPECIFY) (INCLUDING AMPUTATIONS) _

HEALTH STATUS SECTION (cont'd)

119. About how many days have you spent in a hospital during the last twelve months? (CODE NUMBER OF DAYS DIRECTLY) _ _ _

120. About how many days during the past twelve months have you been sick in bed at home all or most of the day? (CODE NUMBER OF DAYS DIRECTLY) _ _ _

121. Do you have a regular person(s) or place for health care or not? If yes, is there one person you usually see or not? If yes, type of person (medical doctor, pharmacist, dentist, etc.) (This need not be a medical person) _

1 - No
2 - Yes
9 - Missing

a) If yes, type of person ____________________

b) Location ____________________ _

c) On average, about how often do you see this person?

____________________

122. Has or would your family doctor ever visit you at home? _

1 - Yes
2 - No
9 - Missing

123. Under what circumstances, if any, would you prefer he/she made home visits?

____________________

____________________

____________________

## HEALTH STATUS SECTION (cont'd)

124. The Manitoba Government provides a service known as Home Care to individuals who need assistance in caring for themselves in their own homes when family and/or friends cannot provide the type or amount of care required. Examples of these services include nursing, therapy, social work, homemaking and arrangements of volunteer services. Are you currently using this service? _

1 - no (IF NO, GO TO NEXT PAGE)
2 - yes, in the past
3 - yes, currently

If yes, currently (up to and including the past 6 months), what services such as homemakers, bath help, and so on do you receive from Home Care?

Do you receive: (circle correct response)

| | | | |
|---|---|---|---|
| 1 - visit from nurse (including VON) | no | yes | _ |
| 2 - visit from social worker | no | yes | _ |
| 3 - homemaker - household tasks | no | yes | _ |
| 4 - exercises/physiotherapy/equipment | no | yes | _ |
| 5 - sitter attendant | no | yes | _ |
| 6 - meals-on-wheels | no | yes | _ |
| 7 - regular "drop in" visitors/daily hello | no | yes | _ |
| 8 - bath help/shampoo | no | yes | _ |
| 9 - medication supervised by Health Care Professional | no | yes | _ |
| 10 - foot care | no | yes | _ |
| 11 - meal preparation | no | yes | _ |
| 12 - social relief | no | yes | _ |
| 13 - orderly | no | yes | _ |
| 14 - other (specify) | no | yes | _ |

______________________________________________

______________________________________________

______________________________________________

b) About how many hours per week do you receive these services? (SPECIFY)

______________________________________________

______________________________________________

______________________________________________

## MSQ AND SET TEST SECTION

Now I have some questions which relate to memory. There are not many of them. We are interested in asking you these questions because doctors and other clinicians frequently use them for assessing their patients. Yet we do not know how normal older persons respond to these questions. Without such information from people such as yourself, clinicians have difficulty identifying those with problems.

125. Memory and Orientation

a) What is your full name? (Correct forename and surname) ________

b) Where is your address? (Correct street address & municipality) ________

c) What year is this? (Correct year) ________

d) What month is this? (Correct month) ________

e) What day of the week is this? (Correct day of week, not date) ________

f) How old are you? (Correct age, verified from date of birth) ________

g) What is the name of the Prime Minister of Canada? ________

h) When did the first World War start? (1914) ________

i) Remember these three items. I will ask you to recall them in a few minutes ... bed, chair, window (have subject repeat items correctly before proceeding) ________

j) Count backwards from 20 to 1. (If necessary, like this, 20, 19 and so on.) ________

k) Repeat the three items I asked you to remember. ________

## MSQ AND SET TEST SECTION (cont'd)

(REPEAT OR REPHRASE INTRODUCTORY PARAGRAPH)

126. The Set Test (Colours, Animals, Fruits, Towns)

I want you to tell me all the __________________ you can think of.

a) Colours ______

b) Animals ______

c) Fruits ______

d) Towns ______

REPEAT THE INSTRUCTIONS AS OFTEN AS REQUIRED, BUT GIVE NO OTHER HELP. NO TIME LIMIT, BUT STOP WHEN 10 DIFFERENT COLOURS, ANIMALS, ETC., ARE OFFERED.

THE END POINT IS USUALLY CLEAR, THE SUBJECT COMING TO AN ABRUPT STOP WITH AN ADMISSION OF FAILURE, SUCH AS "THAT'S ALL I CAN THINK OF", OR A DEFENSIVE RATIONALIZATION (E.G., "THERE ARE LOTS MORE).

SCORE A maximum of 10 points is given for each set, i.e., 40 for the 4 sets.

## UTILIZATION SECTION

127. Have you used any of the following in the past 6 months? If yes, how often and why?

| | Frequency | Reason | Who suggested you contact them (referring to Last Visit*) |
|---|---|---|---|
| General Practitioner | | | |
| Specialist MD | | | |
| Emergency Department | | | |
| Other Hospital departments | | | |
| Day Hospital | | | |
| Emergency Walk-in Clinic | | | |
| ENVOY/other doctor home visiting services | | | |
| Medical Lab (outside hospital) | | | |
| Visiting Lab Service | | | |
| Dentist | | | |
| Chiropractor | | | |
| OT/PT | | | |
| Podiatrist (foot care) | | | |
| Pharmacist | | | |
| Optometrist/Optician | | | |
| Nutritionist/Dietician | | | |
| Audiologist (hearing) | | | |
| Public/Community Health Nurse | | | |

## UTILIZATION SECTION (cont'd)

| | Frequency | Reason | Who suggested you contact them (referring to Last Visit*) |
|---|---|---|---|
| Social Worker | | | |
| Minister | | | |
| Senior Centre | | | |
| Home Care | | | |
| Fitness Program | | | |
| Community Health Clinic | | | |
| Lawyer | | | |
| Other | | | |

* Try to categorize as: self, primary caregiver, other informal, doctor, other professional.

The interview is just about over and I would like to ask you one more question.

128. Considering your life as a whole, would you describe it as happy, unhappy, or somewhere in between?

1 - Very unhappy
2 - Unhappy
3 - Mixed
4 - Happy
5 - Very happy
6 - No opinion
9 - Missing

# APPENDIX B

### TABLE B.1
### CAREGIVING CHARACTERISTICS
### No Caregiver Role Strain Group (n=109)

| | n | % |
|---|---|---|
| Relationship of care receiver to caregiver | | |
| Spouse | 35 | 32 |
| Parent | 11 | 10 |
| Sister | 17 | 16 |
| Friend | 17 | 16 |
| Neighbour | 12 | 11 |
| Other Family | 11 | 10 |
| Brother | 5 | 5 |
| In-Law | 1 | 1 |
| | 109 | 101 |
| Caregiver living arrangement with care receiver | | |
| Same household | 68 | 69 |
| Walking distance | 19 | 20 |
| Same city | 11 | 11 |
| | 98 | 100 |
| Changes in lifestyle attributable to caregiving (more than one response) | | |
| Provided housing | 3 | 3 |
| Moved yourself | 4 | 4 |
| Quit work totally | 3 | 3 |
| Moved others | 2 | 2 |
| Quit work partially | 2 | 2 |
| Altered education plan | 0 | 0 |
| Not started working | 1 | 1 |
| Tasks performed by caregivers (more than one response) | | |
| Emotional support | 68 | 62 |
| Grocery shopping | 62 | 57 |
| Eye on things | 54 | 50 |
| Emergencies | 52 | 48 |
| Housekeeping | 60 | 55 |
| Personal business | 45 | 41 |
| Food preparation | 52 | 48 |
| Transportation | 42 | 39 |
| House maintenance | 48 | 44 |
| Taking medications | 10 | 9 |
| Walking | 11 | 10 |
| Dressing | 7 | 6 |
| Cut toenails | 8 | 7 |
| Reading/Writing | 9 | 8 |
| Washing | 7 | 6 |
| Telephoning | 4 | 4 |
| Feeding | 1 | 1 |
| Toileting | 1 | 1 |

Note: Totals may not equal 109 because of missing values
Due to rounding, percentage exceeds 100%

## SELECTED SOCIODEMOGRAPHIC CHARACTERISTICS
### No Caregiver Role Strain Group (n=109)

| | n | % |
|---|---|---|
| Employment status | | |
| Not employed | 88 | 81 |
| Employed full-time | 15 | 14 |
| Employed part-time | 5 | 5 |
| Employed occasionally | 1 | 1 |
| | 109 | 101 |
| Age | | |
| 60 to 64 | 35 | 32 |
| 65 to 69 | 26 | 24 |
| 70 to 74 | 22 | 20 |
| 75 to 79 | 14 | 13 |
| 80 to 84 | 7 | 6 |
| 85 and older | 5 | 5 |
| | 109 | 100 |
| Gender | | |
| Male | 47 | 43 |
| Female | 62 | 57 |
| | 109 | 100 |
| Marital status | | |
| Married | 47 | 43 |
| Widowed | 26 | 24 |
| Single | 24 | 22 |
| Divorced/Separated | 6 | 6 |
| Common law | 6 | 6 |
| | 109 | 101 |
| Average monthly income | | |
| No income | 3 | 3 |
| <$250 | 1 | 1 |
| $250-499 | 12 | 12 |
| $500-749 | 25 | 25 |
| $750-999 | 10 | 10 |
| $1000-1249 | 16 | 16 |
| $1250-1499 | 7 | 7 |
| $1500-1749 | 8 | 8 |
| $1750-1999 | 5 | 5 |
| $2000-2249 | 5 | 5 |
| $2250+ | 10 | 10 |
| | 102 | 102 |

| | n | % |
|---|---|---|
| Income satisfying needs | | |
| Very well | 36 | 33 |
| Adequately | 56 | 52 |
| With some difficulty | 11 | 10 |
| Not very well | 3 | 3 |
| Totally inadequate | 2 | 2 |
| | 108 | 100 |
| Previous occupation | | |
| Semi-skilled | 40 | 40 |
| Skill crafts/trades | 31 | 28 |
| Housewife | 14 | 13 |
| Professional | 10 | 9 |
| High level management | 8 | 7 |
| Farmer | 5 | 5 |
| | 108 | 102 |
| Years of schooling | | |
| None to six years | 5 | 5 |
| Seven to twelve years | 82 | 75 |
| More than thirteen years | 22 | 20 |
| | 109 | 100 |
| Ethnic group membership | | |
| No ethnic group | 43 | 39 |
| Canadian | 22 | 20 |
| British | 14 | 13 |
| German/Austrian | 7 | 6 |
| Ukrainian | 2 | 2 |
| French | 8 | 7 |
| Other | 13 | 13 |
| | 109 | 100 |
| Religious preference | | |
| Protestant | 68 | 62 |
| Catholic | 23 | 21 |
| No preference | 13 | 12 |
| Jewish | 3 | 3 |
| Eastern Orthodox | 2 | 2 |
| | 109 | 100 |

Note: Due to rounding, percentage exceeds 100%
Totals may not equal 109 because of missing values

## TABLE B.3
## SELECTED HEALTH CHARACTERISTICS
### No Caregiver Role Strain Group (n=109)

| | n | % |
|---|---|---|
| Self-rated health | | |
| Excellent | 30 | 28 |
| Good | 57 | 53 |
| Fair | 19 | 18 |
| Poor/Bad | 2 | 3 |
| | 108 | 101 |
| Days in hospital | | |
| None | 93 | 85 |
| 2 to 7 days | 8 | 8 |
| 10 to 21 days | 6 | 6 |
| 35 to 90 days | 2 | 2 |
| | 109 | 101 |
| Bedridden days | | |
| None | 90 | 83 |
| 1 to 7 days | 15 | 13 |
| 10 to 20 days | 4 | 4 |
| | 109 | 100 |
| Functional disability | | |
| No disability | 76 | 70 |
| Some disability | 33 | 30 |
| | 109 | 100 |
| Chronic conditions (more than one response) | | |
| Arthritis and Rheumatism | 53 | 49 |
| Heart and circulation | 39 | 36 |
| Stomach troubles | 24 | 22 |
| Ear problems | 22 | 20 |
| Foot trouble | 18 | 17 |
| Nerves/emotional | 12 | 11 |
| Skin problems | 12 | 11 |
| Chest problems | 19 | 17 |
| Dental problems | 13 | 12 |
| Eye problems | 12 | 11 |
| Kidney problems | 10 | 9 |
| Diabetes | 3 | 3 |
| Cancer | 9 | 5 |
| Stroke | 3 | 3 |
| Palsy | 2 | 2 |

Note: Due to rounding, percentage exceeds 100%
Totals may not equal 109 because of missing values

## TABLE B.4
## CAREGIVING CHARACTERISTICS
### Combined Low and High Caregiver Role Strain Group (n=88)

| | n | % |
|---|---|---|
| Relationship of care receiver to caregiver | | |
| Spouse | 20 | 23 |
| Parent | 25 | 29 |
| Sister | 14 | 16 |
| Friend | 10 | 11 |
| Neighbour | 8 | 9 |
| Other family | 8 | 9 |
| Brother | 2 | 2 |
| In-Law | 1 | 1 |
| | 88 | 100 |
| Caregiver living arrangement with care receiver | | |
| Same household | 48 | 60 |
| Walking distance | 14 | 17 |
| Same city | 18 | 22 |
| Outside city | 1 | 1 |
| | 81 | 100 |
| Tasks performed by caregivers (more than one response) | | |
| Emotional support | 71 | 81 |
| Grocery shopping | 57 | 65 |
| Eye on things | 60 | 68 |
| Emergencies | 57 | 65 |
| Housekeeping | 49 | 56 |
| Personal business | 63 | 72 |
| Food preparation | 50 | 57 |
| Transportation | 41 | 47 |
| House maintenance | 32 | 36 |
| Taking Medications | 25 | 28 |
| Walking | 22 | 25 |
| Dressing | 26 | 30 |
| Cut toenails | 24 | 27 |
| Reading/Writing | 23 | 26 |
| Changes in lifestyle attributable to caregiving (more than one response) | | |
| Provided housing | 13 | 15 |
| Moved yourself | 9 | 11 |
| Quit work totally | 9 | 11 |
| Moved others | 6 | 7 |
| Quit work partially | 4 | 5 |
| Altered education plan | 3 | 3 |
| Not started working | 2 | 2 |

Note: Totals may not equal 88 because of missing values
Due to rounding, percentages do not equal 100%

### TABLE B.5
### SELECTED SOCIODEMOGRAPHIC CHARACTERISTICS
### Combined Low and High Caregiver Role Strain Group (n=88)

| | n | % |
|---|---|---|
| Employment status | | |
| Not employed | 70 | 80 |
| Employed full-time | 12 | 14 |
| Employed part-time | 5 | 6 |
| Employed occasionally | 1 | 1 |
| | 88 | 101 |
| Age | | |
| 60 to 64 | 24 | 27 |
| 65 to 69 | 27 | 31 |
| 70 to 74 | 17 | 19 |
| 75 to 79 | 13 | 15 |
| 80 to 84 | 6 | 7 |
| 85 and older | 1 | 1 |
| | 88 | 100 |
| Gender | | |
| Male | 22 | 25 |
| Female | 66 | 75 |
| | 88 | 100 |
| Marital status | | |
| Married | 30 | 34 |
| Widowed | 26 | 30 |
| Single | 18 | 21 |
| Divorced/Separated | 11 | 13 |
| Common law | 3 | 3 |
| | 88 | 101 |
| Average monthly income | | |
| <$250 | 2 | 2 |
| $250-499 | 11 | 13 |
| $500-749 | 19 | 23 |
| $750-999 | 14 | 17 |
| $1000-1249 | 16 | 20 |
| $1250-1499 | 4 | 5 |
| $1500-1749 | 5 | 6 |
| $1750-1999 | 4 | 5 |
| $2000-2249 | 4 | 5 |
| $2250+ | 3 | 4 |
| | 82 | 100 |

| | n | % |
|---|---|---|
| Income satisfying needs | | |
| Very well | 24 | 27 |
| Adequately | 49 | 56 |
| With some difficulty | 10 | 11 |
| Not very well | 3 | 4 |
| Totally inadequate | 2 | 2 |
| | 88 | 100 |
| Years of schooling | | |
| None to six years | 8 | 9 |
| Seven to twelve years | 60 | 68 |
| More than thirteen years | 20 | 23 |
| | 88 | 100 |
| Previous occupation | | |
| Semi-skilled | 34 | 39 |
| Skill crafts/trades | 23 | 26 |
| Housewife | 13 | 15 |
| Professional | 9 | 10 |
| High level management | 8 | 9 |
| Farmer | 1 | 1 |
| | 88 | 100 |
| Ethnic group membership | | |
| No ethnic group | 33 | 38 |
| Canadian | 21 | 24 |
| British | 7 | 8 |
| German/Austrian | 5 | 6 |
| Ukrainian | 7 | 8 |
| Other | 15 | 18 |
| | 88 | 102 |
| Religious preference | | |
| Protestant | 50 | 57 |
| Catholic | 22 | 25 |
| No preference | 9 | 10 |
| Jewish | 4 | 5 |
| Eastern Orthodox | 3 | 3 |
| | 88 | 100 |

Note: Due to rounding, percentage exceeds 100%
Totals may not equal 88 because of missing values

## TABLE B.6
## SELECTED CAREGIVER HEALTH CHARACTERISTICS
### Combined Low and High Caregiver Role Strain Group (n=88)

| | n | % |
|---|---|---|
| Self-rated health | | |
| Excellent | 18 | 21 |
| Good | 36 | 41 |
| Fair | 27 | 31 |
| Poor/Bad | 6 | 8 |
| | 87 | 101 |
| Days in hospital | | |
| None | 73 | 83 |
| 2 to 7 days | 8 | 9 |
| 10 to 21 days | 5 | 6 |
| 35 to 90 days | 2 | 2 |
| | 88 | 100 |
| Bedridden days | | |
| None | 66 | 77 |
| 1 to 7 days | 15 | 17 |
| 10 to 20 days | 7 | 8 |
| | 88 | 102 |
| Functional disability | | |
| No disability | 58 | 66 |
| Some disability | 30 | 34 |
| | 88 | 100 |
| Chronic conditions (more than one response) | | |
| Arthritis and Rheumatism | 49 | 56 |
| Heart and circulation | 43 | 49 |
| Stomach troubles | 25 | 28 |
| Ear problems | 21 | 24 |
| Foot trouble | 6 | 7 |
| Nerves/emotional | 23 | 26 |
| Skin problems | 23 | 26 |
| Chest problems | 14 | 16 |
| Dental problems | 19 | 22 |
| Eye problems | 17 | 19 |
| Kidney problems | 10 | 11 |
| Diabetes | 6 | 7 |
| Cancer | 5 | 6 |
| Stroke | 1 | 1 |
| Palsy | 0 | 0 |

Note: Due to rounding, percentage exceeds 100%
Totals may not equal 88 because of missing values

## TABLE B.7
## CAREGIVING CHARACTERISTICS
### Low Caregiver Role Strain Group (n=42)

| | n | % |
|---|---|---|
| Relationship of care receiver to caregiver | | |
| Spouse | 9 | 21 |
| Parent | 13 | 31 |
| Sister | 1 | 2 |
| Friend | 7 | 17 |
| Neighbour | 5 | 12 |
| Other Family | 5 | 12 |
| Brother | 2 | 5 |
| | 42 | 100 |
| Caregiver living arrangement with care receiver | | |
| Same household | 20 | 51 |
| Walking distance | 8 | 21 |
| Same city | 10 | 26 |
| Outside city | 1 | 3 |
| | 39 | 101 |
| Tasks performed by caregivers (more than one response) | | |
| Emotional support | 33 | 79 |
| Grocery shopping | 26 | 62 |
| Eye on things | 27 | 64 |
| Emergencies | 23 | 55 |
| Housekeeping | 20 | 48 |
| Personal business | 26 | 62 |
| Food preparation | 18 | 43 |
| Transportation | 18 | 43 |
| House maintenance | 14 | 33 |
| Taking medications | 10 | 9 |
| Walking | 2 | 12 |
| Dressing | 8 | 19 |
| Cut toenails | 9 | 21 |
| Reading/Writing | 9 | 21 |
| Washing | 7 | 17 |
| Telephoning | 5 | 12 |
| Feeding | 2 | 5 |
| Toileting | 0 | 0 |
| Changes in lifestyle attributable to caregiving (more than one response) | | |
| Provided housing | 3 | 7 |
| Moved yourself | 3 | 8 |
| Quit work totally | 1 | 2 |
| Moved others | 3 | 8 |
| Quit work partially | 0 | 0 |
| Altered education plan | 1 | 3 |
| Not started working | 0 | 0 |

Note: Due to rounding, percentage exceeds 100%
Totals may not equal 42 because of missing values

## TABLE B.8
## SELECTED SOCIODEMOGRAPHIC CHARACTERISTICS
### Low Caregiver Role Strain Group (n=42)

| | n | % |
|---|---|---|
| Employment status | | |
| Not employed | 33 | 79 |
| Employed full-time | 7 | 17 |
| Employed part-time | 2 | 5 |
| | 42 | 101 |
| Age | | |
| 60 to 64 | 12 | 29 |
| 65 to 69 | 15 | 38 |
| 70 to 74 | 8 | 19 |
| 75 to 79 | 5 | 12 |
| 80 to 84 | 2 | 5 |
| | 42 | 103 |
| Gender | | |
| Male | 11 | 26 |
| Female | 31 | 74 |
| | 42 | 100 |
| Marital status | | |
| Married | 15 | 38 |
| Widowed | 14 | 33 |
| Single | 7 | 17 |
| Divorced/Separated | 5 | 12 |
| Common law | 1 | 2 |
| | 42 | 101 |
| Average monthly income | | |
| <$250 | 3 | 8 |
| $500-749 | 8 | 21 |
| $750-999 | 8 | 21 |
| $1000-1249 | 9 | 23 |
| $1250-1499 | 2 | 5 |
| $1500-1749 | 2 | 5 |
| $1750-1999 | 2 | 5 |
| $2000-2249 | 4 | 10 |
| $2250+ | 1 | 3 |
| | 39 | 101 |

| | n | % |
|---|---|---|
| Income satisfying needs | | |
| Very well | 13 | 31 |
| Adequately | 22 | 52 |
| With some difficulty | 5 | 12 |
| Not very well | 2 | 5 |
| | 42 | 100 |
| Previous occupation | | |
| Semi-skilled | 17 | 41 |
| Skill crafts/trades | 9 | 21 |
| Housewife | 7 | 17 |
| Professional | 7 | 17 |
| High level management | 1 | 2 |
| Farmer | 1 | 2 |
| | 42 | 100 |
| Years of schooling | | |
| None to six years | 3 | 7 |
| Seven to twelve years | 28 | 67 |
| More than thirteen years | 11 | 26 |
| | 42 | 100 |
| Ethnic group membership | | |
| No ethnic group | 17 | 41 |
| Canadian | 11 | 26 |
| British | 1 | 2 |
| German/Austrian | 2 | 5 |
| Ukrainian | 4 | 10 |
| Other | 7 | 17 |
| | 42 | 101 |
| Religious preference | | |
| Protestant | 27 | 64 |
| Catholic | 10 | 24 |
| No preference | 2 | 5 |
| Jewish | 3 | 7 |
| | 42 | 100 |

Note: Due to rounding, percentage exceeds 100%
Totals may not equal 42 because of missing values

### TABLE B.9
### SELECTED HEALTH CHARACTERISTICS
### Low Caregiver Role Strain Group (n=42)

| | n | % |
|---|---|---|
| Self-rated health | | |
| Excellent | 9 | 21 |
| Good | 19 | 45 |
| Fair | 12 | 29 |
| Poor/Bad | 2 | 5 |
| | 42 | 100 |
| Days in hospital | | |
| None | 36 | 86 |
| 2 to 7 days | 2 | 5 |
| 10 to 21 days | 2 | 5 |
| 35 to 90 days | 2 | 5 |
| | 42 | 101 |
| Bedridden days | | |
| None | 32 | 78 |
| 1 to 7 days | 6 | 14 |
| 10 to 20 days | 2 | 5 |
| 30 to 50 days | 2 | 5 |
| | 41 | 100 |
| Functional disability | | |
| No disability | 30 | 71 |
| Some disability | 12 | 29 |
| | 42 | 100 |
| Chronic conditions (more than one response) | | |
| Arthritis and Rheumatism | 23 | 56 |
| Heart and circulation | 16 | 38 |
| Stomach troubles | 8 | 19 |
| Ear problems | 4 | 10 |
| Foot trouble | 18 | 43 |
| Nerves/emotional | 8 | 19 |
| Skin problems | 12 | 29 |
| Chest problems | 6 | 14 |
| Dental problems | 7 | 17 |
| Eye problems | 8 | 19 |
| Kidney problems | 7 | 17 |
| Diabetes | 2 | 5 |
| Cancer | 1 | 2 |
| Stroke | 0 | 0 |
| Palsy | 0 | 0 |

Note: Due to rounding, percentage exceeds 100%
Totals may not equal 42 because of missing values

## TABLE B.10
## CAREGIVING CHARACTERISTICS
### High Caregiver Role Strain Group (n=46)

| | n | % |
|---|---|---|
| Relationship of care receiver to caregiver | | |
| Spouse | 11 | 24 |
| Parent | 12 | 26 |
| Sister | 13 | 28 |
| Friend | 3 | 7 |
| Neighbour | 3 | 7 |
| Other Family | 3 | 7 |
| In-Law | 1 | 2 |
| | 46 | 101 |
| Caregiver living arrangement with care receiver | | |
| Same household | 28 | 67 |
| Walking distance | 6 | 14 |
| Same city | 8 | 19 |
| | 42 | 100 |
| Tasks performed by caregivers<br>(more than one response) | | |
| Emotional support | 38 | 83 |
| Grocery shopping | 31 | 64 |
| Eye on things | 33 | 72 |
| Emergencies | 34 | 74 |
| Housekeeping | 29 | 63 |
| Personal business | 37 | 80 |
| Food preparation | 32 | 70 |
| Transportation | 23 | 50 |
| House maintenance | 18 | 39 |
| Taking medications | 20 | 44 |
| Walking | 17 | 37 |
| Dressing | 18 | 39 |
| Cut toenails | 15 | 33 |
| Reading/Writing | 14 | 30 |
| Washing | 14 | 30 |
| Telephoning | 15 | 33 |
| Feeding | 13 | 28 |
| Toileting | 10 | 22 |
| Changes in lifestyle attributable to caregiving<br>(more than one response) | | |
| Provided housing | 10 | 22 |
| Moved yourself | 6 | 13 |
| Quit work totally | 8 | 18 |
| Moved others | 3 | 7 |
| Quit work partially | 4 | 9 |
| Altered education plan | 2 | 4 |
| Not started working | 2 | 4 |

Note: Due to rounding, percentage exceeds 100%
Totals may not equal 46 because of missing values

TABLE B.11

## SELECTED SOCIODEMOGRAPHIC CHARACTERISTICS
### High Caregiver Role Strain Group (n=46)

| | n | % |
|---|---|---|
| **Employment status** | | |
| Not employed | 37 | 80 |
| Employed full-time | 5 | 11 |
| Employed part-time | 3 | 7 |
| Employed occasionally | 1 | 2 |
| | 46 | 100 |
| **Age** | | |
| 60 to 64 | 12 | 26 |
| 65 to 69 | 12 | 26 |
| 70 to 74 | 9 | 20 |
| 75 to 79 | 8 | 17 |
| 80 to 84 | 4 | 9 |
| 85 and older | 1 | 2 |
| | 46 | 100 |
| **Gender** | | |
| Male | 11 | 24 |
| Female | 35 | 76 |
| | 46 | 100 |
| **Marital status** | | |
| Married | 15 | 33 |
| Widowed | 12 | 26 |
| Single | 11 | 24 |
| Divorced/Separated | 6 | 13 |
| Common law | 2 | 4 |
| | 46 | 100 |
| **Average monthly income** | | |
| <$250 | 2 | 5 |
| $250-499 | 8 | 19 |
| $500-749 | 11 | 26 |
| $750-999 | 6 | 14 |
| $1000-1249 | 7 | 16 |
| $1250-1499 | 2 | 5 |
| $1500-1749 | 3 | 7 |
| $1750-1999 | 2 | 5 |
| $2250+ | 2 | 5 |
| | 43 | 102 |

| | n | % |
|---|---|---|
| **Income satisfying needs** | | |
| Very well | 11 | 24 |
| Adequately | 27 | 59 |
| With some difficulty | 5 | 11 |
| Not very well | 1 | 2 |
| Totally inadequate | 2 | 4 |
| | 46 | 101 |
| **Previous occupation** | | |
| Semi-skilled | 17 | 37 |
| Skill crafts/trades | 14 | 30 |
| Housewife | 6 | 13 |
| Professional | 2 | 5 |
| High level management | 7 | 15 |
| | 46 | 100 |
| **Years of schooling** | | |
| None to six years | 5 | 10 |
| Seven to twelve years | 32 | 70 |
| More than thirteen years | 9 | 20 |
| | 46 | 100 |
| **Ethnic group membership** | | |
| No ethnic group | 16 | 34 |
| Canadian | 10 | 22 |
| British | 6 | 13 |
| German/Austrian | 3 | 7 |
| Ukrainian | 3 | 7 |
| Other | 8 | 17 |
| | 42 | 100 |
| **Religious preference** | | |
| Protestant | 23 | 50 |
| Catholic | 12 | 26 |
| No preference | 7 | 15 |
| Jewish | 3 | 7 |
| Eastern Orthodox | 1 | 2 |
| | 46 | 100 |

Note: Due to rounding, percentage exceeds 100%
Totals may not equal 46 because of missing values

# TABLE B.12
## SELECTED HEALTH CHARACTERISTICS
### High Caregiver Role Strain Group (n=46)

| | n | % |
|---|---|---|
| Self-rated health | | |
| Excellent | 9 | 20 |
| Good | 17 | 38 |
| Fair | 15 | 33 |
| Poor/Bad | 4 | 9 |
| | 45 | 100 |
| Days in hospital | | |
| None | 37 | 80 |
| 2 to 7 days | 6 | 13 |
| 10 to 21 days | 3 | 7 |
| | 46 | 100 |
| Bedridden days | | |
| None | 34 | 76 |
| 1 to 7 days | 9 | 20 |
| 10 to 20 days | 1 | 2 |
| More than 21 days | 1 | 2 |
| | 45 | 100 |
| Functional disability | | |
| No disability | 28 | 61 |
| Some disability | 18 | 39 |
| | 46 | 100 |
| Chronic conditions (more than one response) | | |
| Arthritis and Rheumatism | 26 | 57 |
| Heart and circulation | 27 | 59 |
| Stomach troubles | 17 | 37 |
| Ear problems | 12 | 26 |
| Foot trouble | 16 | 35 |
| Nerves/emotional | 15 | 33 |
| Skin problems | 11 | 24 |
| Chest problems | 8 | 17 |
| Dental problems | 12 | 26 |
| Eye problems | 9 | 20 |
| Kidney problems | 3 | 7 |
| Diabetes | 4 | 9 |
| Cancer | 4 | 9 |
| Stroke | 1 | 2 |
| Palsy | 0 | 0 |

Note: Totals may not equal 46 because of missing values

# APPENDIX C

Table C.1

## Correlates of Self-rated Health
## Low Caregiver Role Strain Group (n=109)

| | Age | | | | Gender | | | | Functional Disability | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 60-74 | | 75-91 | | Male | | Female | | Yes | | No | |
| | n | % | n | % | n | % | n | % | n | % | n | % |
| Self-rated Health: | | | | | | | | | | | | |
| Fair | 17 | 20 | 4 | 16 | 8 | 17 | 13 | 21 | 10 | 31 | 11 | 14 |
| Good | 43 | 52 | 14 | 56 | 30 | 64 | 27 | 44 | 13 | 41 | 44 | 58 |
| Excellent | 23 | 28 | 7 | 28 | 9 | 19 | 21 | 34 | 9 | 28 | 21 | 28 |
| | 83 | 100 | 25 | 100 | 47 | 100 | 61 | 100 | 32 | 100 | 76 | 100 |

| Age | Gender | Functional Disability |
|---|---|---|
| Chi-square = 0.26<br>df=2; p=.88 | Chi-square = 4.41<br>df=2; p=.11 | Chi-square = 4.53<br>df=2; p=.10 |

| | Emotional Support | | | Material Support | |
|---|---|---|---|---|---|
| | n | mean | s.d. | mean | s.d. |
| Self-rated Health: | | | | | |
| Fair | 21 | 1.43 | .75 | 1.33 | .66 |
| Good | 57 | 1.25 | .61 | 1.21 | .56 |
| Excellent | 30 | 1.60 | .56 | 1.10 | .55 |
| | 108 | | | | |

| Emotional Support | Material Support |
|---|---|
| F = 3.25<br>df = 2 and 105<br>p = .04 | F = 1.02<br>df = 2 and 105<br>p = .36 |

Note: Tables do not equal 109 because of missing values

Table C.2

**Correlates of Self-rated Health**
**No Caregiver Role Strain Group (n=42)**

| | Age | | | | Gender | | | | Functional Disability | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 60-74 | | 75-91 | | Male | | Female | | Yes | | No | |
| | n | % | n | % | n | % | n | % | n | % | n | % |
| Self-rated Health: | | | | | | | | | | | | |
| Fair | 11 | 31 | 3 | 43 | 4 | 36 | 10 | 32 | 5 | 42 | 9 | 30 |
| Good | 16 | 46 | 3 | 43 | 5 | 46 | 14 | 45 | 4 | 33 | 15 | 50 |
| Excellent | 8 | 23 | 1 | 14 | 2 | 18 | 7 | 23 | 3 | 25 | 6 | 20 |
| | 35 | 100 | 7 | 100 | 11 | 100 | 31 | 100 | 12 | 100 | 30 | 100 |

Chi-square = .44
df=2; p=.80

Chi-square = .11
df=2; p=.94

Chi-square = .98
df=2; p=.61

| | Emotional Support | | | Material Support | |
|---|---|---|---|---|---|
| | n | mean | s.d. | mean | s.d. |
| Self-rated Health: | | | | | |
| Fair | 14 | 1.50 | .76 | 1.36 | .50 |
| Good | 19 | 1.37 | .60 | 1.37 | .60 |
| Excellent | 9 | 1.67 | .50 | 1.78 | .44 |
| | 42 | | | | |

F = .68
df = 2 and 39
p = .51

F = 2.12
df = 2 and 39
p = .13

Table C.3

## Correlates of Self-rated Health
## No Caregiver Role Strain Group (n=46)

| | Age | | | | Gender | | | | Functional Disability | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | 60-74 | | 75-91 | | Male | | Female | | Yes | | No | |
| | n | % | n | % | n | % | n | % | n | % | n | % |
| Self-rated Health: | | | | | | | | | | | | |
| Fair | 16 | 49 | 3 | 25 | 6 | 55 | 13 | 38 | 10 | 59 | 9 | 32 |
| Good | 11 | 33 | 6 | 50 | 2 | 18 | 15 | 44 | 6 | 35 | 11 | 39 |
| Excellent | 6 | 18 | 3 | 25 | 3 | 27 | 6 | 18 | 1 | 6 | 8 | 29 |
| | 33 | 100 | 12 | 100 | 11 | 100 | 34 | 100 | 17 | 100 | 28 | 100 |

Chi-square = 2.00
df=2; p=.37

Chi-square = 2.39
df=2; p=.30

Chi-square = 4.55
df=2; p=.10

| | Emotional Support | | | Material Support | |
|---|---|---|---|---|---|
| | n | mean | s.d. | mean | s.d. |
| Self-rated Health: | | | | | |
| Fair | 19 | 1.42 | .70 | 1.05 | .62 |
| Good | 17 | 1.24 | .75 | .94 | .75 |
| Excellent | 9 | 1.22 | .67 | 1.33 | .71 |
| | 45 | | | | |

F = .40
df = 2 and 42
p = .68

F = .96
df = 2 and 42
p = .39

Note: Totals do not equal 46 beause of missing values

## TABLE C.4

### PERCEIVED EMOTIONAL SUPPORT

| | None/One Person | Two Persons |
|---|---|---|
| Caregiver Role Strain | | |
| None/Low | 77 | 74 |
| High | 26 | 20 |

### PERCEIVED MATERIAL SUPPORT

| | None/One Person | Two Persons |
|---|---|---|
| Caregiver Role Strain | | |
| None/Low | 100 | 51 |
| High | 34 | 12 |

## TABLE C.5

## MEAN DEPRESSION SCORE BY AGE, GENDER, FUNCTIONAL DISABILITY, PERCEIVED EMOTIONAL AND MATERIAL SUPPORT

No Caregiver Role Strain Group (n = 109)

| | Mean | s.d. | n |
|---|---|---|---|
| Age | | | |
| 60 to 74 | 5.09 | 5.64 | 83 |
| 75 to 91 | 5.76 | 5.04 | 26 |
| | F = .30; df = 1 and 107; p = .59 | | |
| Gender | | | |
| Male | 5.83 | 5.81 | 47 |
| Female | 4.82 | 5.23 | 62 |
| | F = .90; df = 1 and 107; p = .35 | | |
| Functional Disability | | | |
| None | 5.63 | 5.87 | 76 |
| Some | 4.40 | 4.46 | 33 |
| | F = 1.17; df = 1 and 107; p = .28 | | |
| Perceived Emotional Support | | | |
| None | 6.78 | 6.12 | 9 |
| One | 4.65 | 5.65 | 49 |
| Two | 5.57 | 5.25 | 51 |
| | F = .72; df = 2 and 106; p = .49 | | |
| Perceived Material Support | | | |
| None | 4.67 | 3.50 | 9 |
| One | 5.70 | 6.03 | 69 |
| Two | 4.45 | 4.65 | 31 |
| | F = .60; df = 2 and 106; p = .55 | | |

## TABLE C.6

## MEAN DEPRESSION SCORE BY AGE, GENDER, FUNCTIONAL DISABILITY, PERCEIVED EMOTIONAL AND MATERIAL SUPPORT

Low Caregiver Role Strain Group (n = 42)

| | Mean | s.d. | n |
|---|---|---|---|
| Age | | | |
| 60 to 74 | 7.20 | 6.76 | 35 |
| 75 to 91 | 6.86 | 4.49 | 7 |
| | F = .02; df = 1 and 40; p = .90 | | |
| Gender | | | |
| Male | 7.18 | 4.21 | 11 |
| Female | 7.13 | 7.06 | 31 |
| | F = .01; df = 1 and 40; p = .98 | | |
| Functional Disability | | | |
| None | 6.57 | 6.16 | 30 |
| Some | 8.58 | 6.99 | 12 |
| | F = .85; df = 1 and 40; p = .36 | | |
| Perceived Emotional Support | | | |
| None | 11.33 | 10.26 | 3 |
| One | 5.31 | 3.81 | 16 |
| Two | 7.87 | 7.16 | 23 |
| | F = 1.49; df = 2 and 39; p = .24 | | |
| Perceived Material Support | | | |
| None | 0.00 | .00 | 1 |
| One | 8.95 | 7.06 | 21 |
| Two | 5.60 | 5.17 | 20 |
| | F = 2.17; df = 2 and 39; p = .13 | | |

# TABLE C.7

## MEAN DEPRESSION SCORE BY AGE, GENDER, FUNCTIONAL DISABILITY, PERCEIVED EMOTIONAL AND MATERIAL SUPPORT

### High Caregiver Role Strain Group (n = 46)

| | Mean | s.d. | n |
|---|---|---|---|
| Age | | | |
| 60-74 | 10.30 | 10.48 | 33 |
| 75-91 | 15.77 | 9.98 | 13 |
| | F = 2.60; df = 1 and 44; p = .11 | | |
| Gender | | | |
| Male | 8.64 | 8.48 | 11 |
| Female | 12.86 | 11.00 | 35 |
| | F = 1.36; df = 1 and 44; p = .25 | | |
| Functional Disability | | | |
| None | 9.86 | 10.31 | 28 |
| Some | 14.94 | 10.40 | 18 |
| | F = 2.65; df = 1 and 44; p = .11 | | |
| Perceived Emotional Support | | | |
| None | 11.00 | 9.34 | 6 |
| One | 9.05 | 10.71 | 20 |
| Two | 14.90 | 10.32 | 20 |
| | F = 1.61; df = 2 and 43; p = .21 | | |
| Perceived Material Support | | | |
| None | 20.56 | 10.74 | 9 |
| One | 10.48 | 10.99 | 25 |
| Two | 8.17 | 4.99 | 12 |
| | F = 4.68; df = 2 and 43; p = .02 | | |