

THE CONCEPT AND EXPERIENCE OF CAREGIVING
FOR ADULT DAUGHTERS AND SONS

by

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ABSTRACT

Although there exists a sizable literature addressing familial caregiving of the impaired elderly, the expanding empirical literature has not been matched by a corresponding increase in theoretical discussion and development in this area. Of related and particular concern is the absence of any clear and consistent concepts of "caregiving" and "caregivers." The literature has tended to focus on specific aspects of caregiving (e.g., caregiver burden) and on specific caregivers (e.g., adult daughters) as portraying typical caregiving experiences. Research has demonstrated, however, that caregiving involves a diversity of experiences and that a variety of individuals operate within the role of caregiver. The purpose of this study was to investigate the concept and subjective experience of caregiving from the perspective of caregivers, in addition to exploring the potentially different ways in which women and men experience caregiving. The approach taken in the study was based upon the researcher's interpretive framework, the Caregiving Corridor, which facilitated the exploration of the concept and experience of caregiving from the perspective of parameters (beginning, boundaries, development, end) and processes (motivation, expectations, activities, abilities, impact) involved in caregiving.

The sample consisted of 10 adult daughters and 6 adult sons who were acting as the primary caregiver (providing the majority of informal/unpaid assistance) for their parents. Participants were recruited through community support programs and an advertisement in a local newspaper. Participants took part in one recorded interview which took approximately 30 minutes and was subsequently transcribed and analyzed using a

primarily qualitative approach to data analysis involving thematic content analysis to identify the key themes and concepts that emerged from participants' responses.

Information about each of the dimensions of the Caregiving Corridor is reported, and serves to illuminate the concept and experience of caregiving. There were no substantial differences in the experiences of female and male participants in the study. Evidence was found to support a greater focus on the dynamic, developmental aspect of caregiving, as well as the emotional and positive dimensions of familial caregiving.

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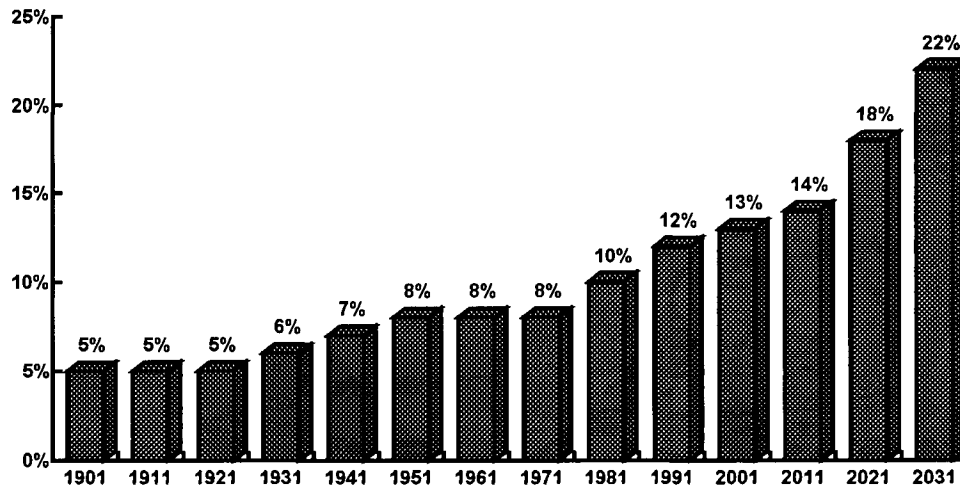
I would also like to thank my wife Susan, son Ryan and closest friend Justus Hayes for their unwavering support and affection.

INTRODUCTION

The past two decades have witnessed an expansion of interest, discussion and research on later life families. Governments, community organizations and academic researchers have all begun to invest significant resources in exploring a wide range of issues and experiences related to aged individuals and their families. In the academic community, a number of disciplines, including demography, sociology, psychology, social work and family studies, have sought to both individually and collaboratively investigate later life familial relationships and experiences.

The motivation behind this expanding examination of later life families stems from a number of interacting factors. The most influential factor concerns the identification by demographers that the sheer number of individuals entering old age is dramatically increasing. As Figure 1 indicates, the last century has seen a gradual but steady increase in the proportion of older individuals in Canada, a trend that is anticipated to sharply increase over the course of the next half-century.

Figure 1
Percentage of Population Aged 65 and Older in Canada
(Statistics Canada, 1990)



From the period 1901 to 1981, the proportion of individuals aged 65 and older doubled from roughly 5% to 10% of the overall population. However, this same proportion is anticipated to more than double to 22% in the fifty years leading to 2031 (Norland, 1994). In large part, this increasingly rapid growth in the proportion of aged in the Canadian population is due to the maturing of the “baby-boomers” generation, those born between 1946 and 1966. However, other factors also contribute to the expansion in the number of older Canadians, including sharply declining fertility rates.

In addition to the increase in the number of individuals entering old age, individuals are also living longer than ever before. Since 1961 the proportion of young-old (aged 65 to 74) has actually declined from 64% to 60% of the overall senior population, while the percentage of middle-old (aged 75 to 84) has remained relatively unchanged. However, the most noteworthy trend involves the rise of the old-old group (aged 85 and older),

which has increased from 6% to 9% of the seniors population during the same time period. This trend is anticipated to continue over the next two decades, with the result that by 2011, one in seven Canadian senior citizens will be age 85 or older (Norland, 1994). This increase in longevity can be attributed to a combination of changes in lifestyle, medical advances, and, in particular, the fact that individuals are surviving the onset of chronic disease and disability for longer than ever before (Brody, 1985). This change in the nature of illness in old age, from acute disease to chronic disability, has particular ramifications for the provision of care to the elder population.

Another related factor that motivates the study of aging families stems from increasing health care costs coupled with diminishing health care budgets. In response to these pressures, governments can be expected to redefine their role as care providers; this is currently evident in Canada with the continuing shift from an institutionally-based long-term care system to one that is community-based (Rosenthal, 1994). An important role lies herein for researchers in the area of aging. As policy-makers strive to identify and address important issues related to the aging population, they will rely upon the collective investigations and assessments of researchers in this area. To this end, it is important that reliable, empirically and conceptually well-grounded research pertaining to aging individuals and their families be pursued.

While a substantial amount of research has been accomplished to date on the increasing aging population, especially with regards to informal caregiving of the elderly, much of the caregiving research has been based on weak methodological and conceptual foundations. In particular, the operational treatment and conceptual descriptions of

'caregiver' have been poorly elaborated and inconsistently employed across different investigations. With the rapid expansion of research about familial caregiving, the research and discourse in this area is well overdue for a re-examination of the central issues involved in assuring a high level of clarity and unity of purpose.

The purpose of this study is to investigate the concept and subjective experience of caregiving from the perspective of caregivers, in addition to exploring the potentially different ways in which women and men experience caregiving. This study is based upon the position that the consideration of informal elder caregiving in primarily instrumental (e.g., hours spent providing care, tasks performed) and negative (e.g., focusing on strain and burden) terms fails to achieve a more holistic and integrated perspective of the caregiving experience. The study also addresses the importance of subjective interpretation in caregiving experiences. In addition, this study is designed to explore the potentially different ways in which particular caregivers (e.g., daughters and sons) experience and interpret their role as caregivers. Too often, previous research on caregiving has omitted male caregivers and chosen not to explore potential differences that may exist within different familial caregiving relationships. Instead, research has tended to focus on specific groups of caregivers (primarily adult daughters), or has amalgamated a diverse range of caregivers into a single, presumably homogeneous, group. This study is based on the fundamental assumption that individuals in differing family relationships will have different conceptions of their role as caregivers, and that these varying interpretations will in turn have implications for the ways in which these individuals adopt, perform and experience their role as caregiver.

CHAPTER ONE

THE TOPIC OF CAREGIVING

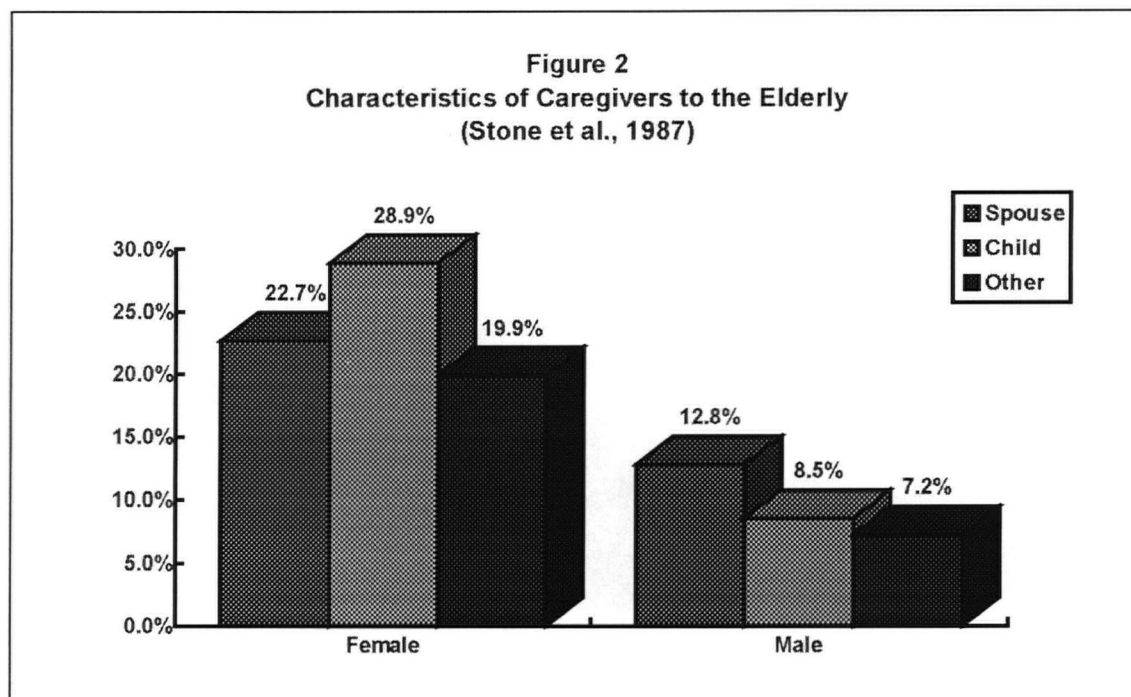
Informal, familial caregiving of the elderly is a major issue in the literature on aging. As is evident in a review of almost any aging publication (e.g., *The Gerontologist*, *Canadian Journal on Aging*, *Research on Aging*) or conference agenda, caregiving continues to be an issue of central interest and concern to both researchers and practitioners. Much like the overall focus on aging, there are several, interacting reasons behind this preoccupation with caregiving. The scope of caregiving research has also been multi-dimensional, with the common thread of caregiver burden and stress permeating much of the existing research.

Factors Influencing the Focus on Caregiving

A contemporary belief about the aged is that they are neglected or abandoned by their families, especially their children (Connidis, 1989; Horowitz, 1985). This notion of abandonment and subsequent institutionalization is, however, empirically unfounded. In 1990 only 7.5% of Canadians aged 65 and older were living in institutional care with the remainder living in a private residence (Statistics Canada, 1990). Research has demonstrated clearly that families provide the vast majority of care to aging individuals (Stone, Cafferata, & Sangl, 1987), and that adult children in particular provide the major, the most immediate, and the most continuous support of the elderly experiencing a health care crises (Thomas, 1987). Thus, familial caregiving for the elderly is currently the

primary means of care for those elderly individuals no longer capable of complete independence.

A related impetus for studying caregiving stems from a more detailed understanding of who specifically cares for the elderly. There has been much discussion about the move away from formal care towards a new emphasis on community care, and this notion has been particularly directed towards care of the elderly. However, community care does not involve all members of the community equally. Instead, community care is primarily performed by the family, and family care is most often provided by women family members (Finch & Groves, 1980). Thus, as the move towards community care continues, it becomes increasingly important to understand the implications of such a shift in policy for families as a whole as well as individual family members and women in particular. One recent study by Stone et al. (1987) identified those individuals within a family who typically provide care to aging members. As Figure 2 reveals, both gender and, to a lesser extent, relationship to the care recipient emerged as significant variables regarding familial caregivers of the elderly. However, with the exception of a select number of investigations, few studies have specifically examined these primary caregiver variables (i.e., gender, relationship to care recipient). It seems likely that this is in large part due to the use of selective samples (Mui, 1995).



Caregiver burden, defined as the negative stress and strain of caring for the elderly, has been a dominant theme in the majority of caregiving research and discussion (Barer & Johnson, 1990). Elevated levels of burden and stress have been associated with caregiving for a majority of caregivers (Kosberg & Cairl, 1992; Zarit, 1989); this has provided considerable incentive for researchers to identify both individual differences and circumstances which act to moderate caregiver burden. Absent from the literature, however, are the reasons why particular individuals commence and continue to provide care, as well as any potentially positive aspects of caregiving. If a more comprehensive understanding of caregiving experiences is to be achieved, an expanded, multi-dimensional investigative approach must to be employed.

While the definition of “caregiving” may at first appear to be self-evident, research indicates that the concept is actually quite complex. It involves a wide range of individuals (i.e., spouses and adult children, women and men) who act as care providers to a similarly

diverse group of individuals with varying needs. The care itself may vary considerably in amount (i.e., from infrequent to almost constant assistance), and in type of care provided (i.e., instrumental, emotional and/or financial). Much of this variability has been missed through the use of the global term, "caregiver." Thus, if researchers are to begin to better synthesize and integrate their findings, it is especially important that there be careful evaluation of the ways in which key concepts and issues are defined and operationalized as well as the ways in which data are analyzed.

Topics in Caregiving Research

The research on caregiving has accumulated into a large literature. The following review is necessarily selective and attempts to note the major topics and approaches that have been incorporated to date. The topics reviewed include caregiver burden, the impact of caregiving, demographic variations, caregiving tasks, formal and informal care, balancing multiple roles and the motivation to provide care.

Caregiver Burden

The single most studied issue in the caregiving literature is likely that of caregiver burden experienced by informal (and mostly familial) caregivers (George, 1994; Kosberg & Cairl, 1992). So many resources have been directed towards investigating caregiver burden in such a relatively short period of time that some researchers have begun to question whether there is anything more to learn about caregiver burden, especially using existing methods and approaches (George, 1990). A broad range of topics have been addressed under this rubric, including (1) the nature and extent of burden experienced by

caregivers, (2) variations in burden as a function of the caregiver-care recipient relationship or the involvement of formal supports, and (3) the potential consequences of burden (Cantor, 1983; Gwyther & George, 1986; Zarit, Reever, & Peterson, 1980; Zarit, Todd, & Zarit, 1986).

There has also been much discussion addressing the measurement of caregiver burden. A number of different measurement tools have been developed to gauge caregiver burden, most notably Zarit's (1980) Burden Inventory. Yet all of this discussion has not yielded an unequivocal preference for only one measurement technique and there remains considerable debate over the meaning and comparability of the different burden measures that have been employed (Stull, Koloski, & Kercher, 1994).

Many caregiver burden studies have examined a limited number of variables and their correlational relationship to measures derived from caregiver burden scales. For example, Zarit, Reever, and Bach-Peterson (1980) investigated the correlation between the amount of time spent with the care recipient and the care recipient's level of impairment as related to measures of caregiver burden. Results indicated that the severity of symptoms was not strongly associated with caregiver's feelings of burden. Instead, the extent of burden experienced by caregivers depended largely on how they responded to the patient's disabilities (e.g., how they contended with providing care and what supportive resources they had available). Choi (1993) investigated the relationship between caregiver burden and daily caregiving hours, caregiver's health and economic factors and found that increased hours spent providing care, greater care recipient

disability and lower family financial income were all significantly associated with greater caregiver burden.

Coping with the range of difficulties often associated with providing elder care has also received considerable attention in the literature. A study by Williamson and Schulz (1993) examined key stressors identified by spousal and adult children caregivers (including memory loss and the loss of the ability to communicate on the part of the care-recipient) and the ways in which these groups attempted to contend with caregiving difficulties. Results indicated that active strategies (e.g., direct problem solving) resulted in less caregiver depression than did passive strategies (e.g., avoidance and passivity towards identified problem areas). Knight, Lutzky, and Macofsky-Urban (1993) conducted a meta-analytic review of interventions for caregiver distress, and concluded that both psychosocial interventions and respite programs were moderately effective at reducing burden, with respite programs being slightly more effective.

The Impacts of Caregiving

Other dimensions of the impact of caregiving have also been investigated. Skaff and Pearlin (1992) examined the effect of loss of self (a loss of identity that comes about as a result of engulfment in the caregiver role) on caregivers for the elderly. The authors found that loss of self was more common among spouses, females, and younger caregivers. Also related to a greater loss of self was limited social contacts, lack of social roles outside that of caregiver, lower self-esteem and mastery, and greater depressive symptomology. A negative relationship between caregiving stressors and subsequent well-being following the death of the care recipient has also been identified (Mullan, 1992).

Bass and Bowman (1990) found that caregivers who appraised caregiving as more difficult and those who reported more negative caregiving consequences for the family assessed bereavement as more difficult and reported more bereavement strain.

Demographic Variations

A number of studies have explored the ways in which caregiving experiences differ as a function of select demographic characteristics, most notably, gender and, to a lesser extent, race. One study investigating the role of men and women as caregivers found that men generally tend to provide intermittent assistance with occasional tasks, and that there may be a preference for or move towards female caregivers as the functional capacity of the care recipient decreases (Stoller, 1990). Miller and Cafasso (1992) used a meta-analysis technique in an effort to determine the size and significance of gender differences in caregiver stressors and caregiver burden. Although several aspects of caregiving did not vary significantly as a function of gender (e.g., total caregiver involvement, money management tasks), other aspects did vary significantly (including women's greater likelihood to carry-out personal care and household tasks, and women's greater tendency to report more burden). A study by Hinrichsen and Ramirez (1992) compared black and white caregivers in their adaptation, adjustment and service utilization as they cared for demented elderly relatives. Results revealed few significant differences regarding caregivers' adaptation to caregiving responsibilities. However, black caregivers had less burden, less desire to institutionalize their care recipients, and were more likely to report unfulfilled service needs than were white caregivers included in the study.

Caregiving Tasks

Research on familial caregiving for the elderly has revealed the existence of a wide range of caregiving tasks and levels of assistance. Horowitz (1985) categorizes caregiving tasks as largely falling within four types of assistance: (1) direct service provision, (2) linkage with formal services, (3) emotional support, and (4) financial aid. Caregivers tend to focus more or less on any of these areas as a function of the care recipient's current needs (Cantor, 1980). Additionally, female family members have been identified as providing the majority of care, in addition to providing more hands-on type of tasks, such as attending to personal hygiene, household tasks and meal preparation (Stoller 1983; Stone et al., 1987).

Formal and Informal Care

The relationship between formal and informal care for the elderly is, as mentioned above, an issue of growing concern in this area. The move from institutional-based care to community care in the face of health care restructuring is the central motivation behind recent efforts to investigate how best to coordinate these two primary sources of care for aging individuals (Rosenthal, 1994). A study by Mittelman (1993) found that counseling for caregivers of elderly individuals with Alzheimer's disease significantly reduced the rate at which the Alzheimer's patients were subsequently institutionalized. Duncan and Morgan (1994) explored the issues caregivers identified as the most salient regarding the provision of care to their elderly family members residing in formal care institutions. Results highlighted caregivers' desire for emotionally sensitive care and not just the technically competent performance of tasks. A study by Rosenthal, Sulman and Marshall (1993)

found that caregivers of impaired elderly in an institution had the highest levels of reported burden if they were having conflicts with the facility's staff. This study also undermined the notion that once a care recipient is placed in an institutional setting, caregiver burden and stress are significantly reduced. In fact, one study by Stephens, Kinney and Ogrocki (1991) found that, after controlling for caregiver problems, nursing home caregivers reported more stressors (due to Activities of Daily Living assistance, their relative's behaviour and cognitive functioning, and a lack of caregiving support from family and friends) than those caregivers who cared for a relative with dementia at home. It has also been suggested that women may be less likely to utilize community services because they may feel obligated to provide exclusive care based on social expectations surrounding the appropriate role of women (Stephens, et al., 1991).

Balancing Multiple Roles

Several researchers have explored the ways in which caregiving interacts with other roles. For example, a study by Scharlach (1994) found that individuals who were working full-time while also providing substantial caregiving assistance reported that overall they felt that the positive aspects of balancing these two roles (e.g., sense of accomplishment, role diversity) outweighed the negative costs. Another study by Scharlach, Sobel and Roberts (1991), however, found that employment was highly related to caregiver strain and the perceived likelihood of job termination. A study by Brody et al. (1992) looked at the differential effects of adult daughters' marital status on their parental care experiences. Findings indicated that married women had more support and less reported strain related to their role as caregiver than did unmarried women.

Motivation to Provide Care

A few articles have explored the motivation behind caregivers' decision to provide care. Guberman, Maheu and Maille (1992) used in-depth interviews in an effort to account for why individuals (all female in their sample) become primary caregivers. The authors identify a number of such factors, including love, guilt, a strong sense of duty, women's social identity being built around caring, the absence of appropriate public or private alternatives, and women's socioeconomic dependence. A study by Wolfson et al. (1993) measured adult children caregivers' ratings of the amount of financial, emotional, and physical support they "should" and "could" offer to dependent elderly care recipients. Only minor gender differences emerged and overall scores were high, with "should" being higher than "could" for each of the three types of support. Cicirelli (1993) found that daughter's feelings of obligation and levels of attachment were positively related to the amount of assistance they provided. Furthermore, perceived obligation and amount of help provided were found to be positively related to greater feelings of burden.

The number and diversity of topics that have been incorporated into research on caregiving highlights both the perceived importance and complexity of caregiving. In reviewing the many issues and aspects of caregiving that have been studied to date, it is important to note that issues and measures related to caregiver burden and the functional aspects of care provision have dominated much of the existing research.

CHAPTER TWO

CONCEPTS & METHODOLOGY IN CAREGIVING RESEARCH

A number of conceptual and methodological concerns guide the focus of the following topics in the caregiving research. For example, caregiving research has focused primarily on female caregivers and on younger caregivers, adult daughters in particular (Baruch & Barnett, 1983; Nissel, 1984). Methodological advancements in the form of measurement tools have been primarily related to instrumental aspects of care (for example, the development of the Activities of Daily Living and Instrumental Activities of Daily Living scales) and burden scales (George, 1990). Despite these advancements, some researchers have been critical of the extent to which burden in particular has become a dominant issue in caregiving, while the positive aspects of caregiving have been largely overlooked (see Cohen, Gold, Shulman, & Zuccherro, 1994). A presentation of these and related issues form the basis of this section.

Barer and Johnson's 1990 Critique of Caregiving Research

A recent five-year review of caregiving research by Barer and Johnson (1990) identified five methodological problems evident in the existing caregiving literature. The first problem was that the definition of caregiver varies widely from study to study. The authors state that "how the caregiver is defined determines how that individual is identified and studied" (p.26). These widely varying definitions of caregiver have led to a broad range of individuals and circumstances being included under the single label of

‘caregiver.’ The authors describe a number of different ways in which caregivers are commonly defined, including family relationships (e.g., spouse, adult child of care recipient), style of care (e.g., amount of time spent caring, or tasks performed), proportion of caregiving responsibilities assumed (e.g., primary caregiver), and a variety of other vague, single label descriptions (e.g., unpaid helpers, households).

The second issue pertains to the status and needs of care recipients. The authors note that, “logically the level of the caregiver’s involvement is better understood if studied in relation to the needs of the recipient” (Barer & Johnson, 1990, p.27). The authors found that roughly half of the articles they reviewed did not sufficiently delineate the conditions and associated needs of the care recipients. However, there have been some attempts to develop categories that capture a wide range of supportive services. One such attempt involved describing primary versus secondary types of assistance (Cicerelli, 1983). Primary types of assistance included homemaking, housing, income, maintenance, personal care, and home health care. Secondary types of care were described as transportation, psychological support, social and recreational activities, spiritual support, protection and beaurocratic mediation.

A third problem identified in this review was that most samples of caregivers are non-representative, frequently drawn from self-help support groups and other formal organizations. Since many elderly rely solely on their families for support without any contact with formal support agencies or groups (Barer & Johnson, 1990), it is questionable how representative the findings from these studies might be in relation to the total population of informal caregivers.

A fourth concern is that information regarding the perspective of the care recipient is seldom included and/or analyzed in caregiving studies. For example, Horowitz (1985) declares that it is important to include demographic information such as the gender, age, and marital status of both the care recipient and the caregiver. Such information is seen as crucial in delineating the individuals and processes under investigation. Furthermore, Barer and Johnson (1990) note that important information is needed regarding the care recipient's interpretation of how well the care meets their needs, whether there is conflict with the caregiver, and whether care is provided on a regular basis.

The final issue raised in this review was that the majority of caregiving studies fail to include characteristics of the total support network. Barer and Johnson (1990) state, "When a single caregiver's role is measured through checklists of numerous tasks, the dynamics of the relationships among all the people involved or the subjective or objective rewards they exchange cannot be understood" (p.28). This narrow focus of attention on a single caregiver and care recipient leaves open the question of the validity of much of the instrumental as well as the psychological/emotional understanding of caregiving as experienced by both parties. For example, the role of a third party in providing care may be crucial to understanding the true nature of the caregiving relationship between a care recipient and his or her primary caregiver.

Of particular salience to this investigation, recent editorials (see, for example, Stone, 1991), and a critical review of the caregiving literature highlight the prevalence of problems surrounding the definition and concept of caregivers and caregiving. There is no consensus as to what constitutes caregivers or caregiving by researchers in this area. As

surprising as it may seem given the sheer number of studies exploring caregiving, the conceptual and operational definitions of caregiving are often so vague and variable as to seriously compromise comparability with other closely related investigations. For example, two studies may both be investigating the experiences of female caregivers, yet differences in the ways in which participants were selected, operationalized and examined may prevent integrating the findings from both studies. The conceptual and operational definitions of the phenomena under investigation represent the most basic foundation upon which any subsequent research or theory must be judged. That caregiving as a conceptual and operational variable is so variably and often superficially treated within the existing caregiving literature is a cause for major concern.

Caregiving Research in the 1990's: A Focus on Concept

In an effort to evaluate the nature and magnitude of conceptual limitations in the concept of caregiving, the author conducted a five-year literature review of articles published in *The Gerontologist* over the years 1990 to 1994, inclusive. *The Gerontologist* was selected based upon the eminence of this journal in the field of gerontology and caregiving in particular. The five-year span selected for review fulfilled two important requirements: (1) there were sufficient articles to make valid observations and suggest trends, and (2) the time period added to Barer and Johnson's 1990 review.

Articles for this review were selected based upon the criteria that the word "caregiver" appeared in either the article's title and/or abstract. Additionally, articles were included which contained the word "care" or "caring" in their title and/or abstract, and

which also clearly pertained to elderly caregiving issues. Finally, editorials containing the word “caregiver” were also included in this review (although omitted from the quantitative portion of the analysis because they did not involve either the recruitment or analysis of participants). These criteria produced a total of 66 articles and 7 editorials.

Individual articles were reviewed according to three key aspects: (1) the treatment of the term and/or label ‘caregiver,’ (2) the treatment of gender, and (3) the treatment of caregiver-care recipient relations. The ‘treatment of caregiver’ section investigated the ways in which caregivers were operationally defined. The ‘treatment of gender’ section addressed whether or not researchers had included both females and males in their study, if and how gender was analyzed, and whether or not significant gender variations emerged. The last component, ‘treatment of caregiver-care recipient relations,’ examined whether or not both spousal and adult child caregivers were included in the study, if and how these two primary types of caregivers were analyzed, and whether or not significant variations were reported.

The Definition and Treatment of Caregiver

This review concludes that the manner in which “caregiver” is operationally defined in the literature is both vague and variable. The following discussion deals with a number of trends and approaches that were revealed through analyzing the ways in which researchers have attempted to define caregivers in their studies and discussions.

Caregivers are often operationally defined using the label “primary caregiver.” More than a third (36.4%) of the articles reviewed included this label as either a portion or the entire description of the caregiver subjects in the studies. It is also evident from this

review that this label has become increasingly common over the last several years. While it is encouraging to observe researchers adopting some measure of standardization, it is unfortunate that a further detailed description of what constitutes a primary caregiver is rarely offered. For example, an article by Seltzer and Buswell (1994) simply describes the caregivers in the study as "the primary caregivers" of a subset of dementia patients drawn from a dementia study program. Similarly, Williamson and Schulz (1993), in describing the subjects in their study, state that, "participants were primary caregivers of non-institutionalized family members diagnosed with mild to moderate Alzheimer's disease" (p. 748). Horowitz, Silverstone and Reinhardt (1991) describe their study's participants as "twenty-eight older individuals who were over age sixty-five and a primary family caregiver were included in the study" (p. 25). These are only some of the many instances in which the term "primary caregiver" was utilized as the central (or lone) description of caregiver participants. Seldom was an operational definition provided which clarified the meaning nor were measurements employed that identified individuals as primary caregivers. This lack of detail and discussion of the meaning of the term "primary caregiver" raises potentially serious doubts about whether or not researchers utilizing this term are in fact measuring the same population.

The problem of inadequate information describing the primary caregiver label is often compounded by the frequent absence of other information about how caregivers were selected. This is not always the case, however, and some researchers have included varying degrees of qualifying descriptions about caregiver subjects. For example, in an article by Mui (1992), the author presents the sample as:

“...individuals who were identified by the elders as the primary caregiver - the family member or friend who provided the greatest amount of unpaid assistance to the elderly person in terms of taking care of him or her, attending to his or her affairs, or performing chores around the house” (Mui, 1992, p. 205).

While this level of description may not represent an ideal operational definition, in contrast to many caregiving articles it offers substantially more elaboration. A clearer operational definition is utilized in an article by Rankin, Haut, and Keefover (1992). In describing the subject acquisition procedure, these authors state:

“Identification of the patient’s primary caregiver was based on Cantor’s (1983) concept of caregiver centrality (e.g., spouse, adult daughter, etc.). When it was unclear who provided primary care, all prospective caregivers were asked to complete a 10-item caregiving checklist (Pfeiffer, 1976) and the individual scoring the highest on the four direct care items was selected” (Rankin, Haut, and Keefover, 1992, p. 814).

The question arises that, if such measurement techniques are available and have been previously published (e.g., Cantor’s measure and Pfeiffer’s measure), why then are they not utilized and/or identified by more researchers?

A second and related definitional issue involves the use of the label “caregiver” or “caring for...” as the sole descriptive characteristic of participants in a study. More than a quarter (27.3%) of articles reviewed used this approach to define their sample. For example, an article by Sankar (1991) describes the sample by stating, “The research reported here is based on an in-depth ethnographic study of 16 caregivers” (p. 44). An article by Farran, Keane-Hagerty, Salloway, Kupferer and Wilken (1991) describe their sample as: “Care receivers were diagnosed as having Alzheimer’s disease, multi-infarct dementia, or some other form of irreversible, progressive dementia. Their family caregivers were recruited through the following sites...” (p. 484). In light of the many

different ways in which care can be provided and the number of caregivers that can be involved in providing care, this simplified descriptive approach is inadequate. Even the non-elaborated label “primary caregiver” is relatively more informative and marginally better than nothing.

Another less prevalent, yet consistent trend for defining caregivers involves relying on group membership (e.g., participants in support groups) as denoting caregiver status. Approximately 17% of the studies reviewed used this approach in detailing the caregivers who took part in these studies. For example, a study by Forinsky and Hathaway (1990) reported that subjects were contacted via questionnaires mailed out to “[Alzheimer’s disease] support group leaders” who were affiliated with an Alzheimer’s project (p. 605). In an article by Kingson and O’Grady-LeShane (1993), women were designated as later life caregivers if they reported to the Social Security Administration’s 1982 New Beneficiary Survey (NBS) that “the major reason for leaving their last job was to give care to others” (p. 232). And in an article by Gallagher-Thompson and DeVries (1994) no mention is made regarding the classification of participants as caregivers beyond the means by which participants were recruited (e.g., via media advertisement, flyers, community agencies, etc.). The hypothesis that group membership or recruitment procedures alone are particularly useful or meaningful ways in which to operationalize caregivers is debatable. Even if one was to contact a very specialized group (e.g., a local Alzheimer’s disease support group) with a relatively homogenous membership (e.g., spouse’s of Alzheimer’s patients), there may still be a great deal of variability within that group.

Further effort to ascertain the nature of care being provided should be employed to better detail the nature of the caregiving circumstances being investigated.

Also cause for concern was a trend of describing care recipients in disproportionately greater depth as compared with caregivers. It is important to note that this bias is in reference to sample descriptions, not analyses. As noted earlier, Barer and Johnson (1990) comment that too infrequently are care recipients' needs incorporated into analyses. However, it appears that sample descriptions often include considerable detail regarding the care recipient. In an effort to gauge the prevalence of this bias, each article was assessed as to how many individual descriptive points were listed regarding the care recipient and the caregiver. Rarely was more information provided about the caregiver than the care recipient, and for 12.1% of the articles reviewed the descriptive information concerning the care recipient was at least *twice* that of the information provided regarding the caregiver. This is surprising given that these articles went on to focus almost exclusively on the experiences of the care providers and not the care recipients. As an example, an article by Collins, Strommel, King and Given (1991) noted that caregiver/patient dyads had to meet the following criterion to be included in their study: (1) patient at least 55 years old, (2) patient dependent in at least one Instrumental Activities of Daily Living (IADL) and one Activities of Daily Living (ADL), (3) patient had received a diagnosis of Alzheimer's, (4) caregiver was self-identified as providing the most care, and (5) patient was residing in the community. This example highlights the obvious absence of descriptive information provided about caregivers in these articles. Again the question arises as to why caregivers have repeatedly been described with

relatively low levels of detail. At this time there appears to be no evidence to support the hypothesis that caregivers are significantly more homogenous than the recipients of their care.

The Treatment of Gender

The caregiving literature has largely focused on the experiences of women; this has been based in large part on the recognition that an estimated 72% of caregivers of the elderly are female (Stone et al., 1987). A similar trend is evident in this review. There were seven times as many studies which focused exclusively on female caregivers as compared to exclusively male caregivers, and while there were six studies looking solely at daughters, only one study focused exclusively on caregiving sons. Curiously, the bias towards studying female caregivers was not evident in those studies that looked exclusively at spousal caregivers. While this represented a small number of articles, there was no trend towards focusing more so on wives than husbands.

This tendency to focus on female caregivers seems reasonable at a common sense level. Despite this, a number of factors exist suggesting that male caregivers should be given more empirical attention in the literature. First, the fact that over 25% of caregivers are male (Stone, Cafferata & Sangl, 1987) indicates a real need to explore further the experiences of these caregivers as individuals and (perhaps most importantly) in relation to what is already known based upon a predominantly female perspective. Second, two demographic trends offer support to the value of including more male caregivers in research studies and analyses. The "baby-boomer" generation is poised to enter old age and along with them are their relatively smaller number of children upon which they will

depend for care. The decreased fertility rate which began following the end of the baby-boom and which has continued to the present means that there is an increased probability of having only one and/or only male children. Without the presence of an adult daughter, it will be interesting to note the role adult men play in the future as they provide care for their aging parents.

Although there is a predominant focus on female caregivers, a sizable proportion of articles did include both female and male caregivers (74.2%). While at first this appears to be a constructive and positive advance, this opportunity was not taken advantage of in a large number of instances as little or no effort was made to distinguish the experiences of men and women in these studies. Prior to this review it was determined by the author that a cell size of at least 10 could be considered sufficient to label a study as having had the potential to include gender in analyses. This figure was determined by the fact that several studies have conducted analyses with groups smaller than 10, and by the recognition that both ANOVA and MANOVA are able to operate under these circumstances. Results indicated that approximately 29% of the studies reviewed could have included gender in their analyses but did not. (In a small number of studies the gender composition of the sample was listed briefly in text or as a table of percentages and then subsequently omitted from the analyses.) It is unclear as to why such data were not included in the analyses, or if they were included, why the results were omitted. Regardless, the fact remains that although some studies may have included both genders, this dimension was seldom included in any analyses and hence little was gained in terms of knowledge about potential differences or similarities as a function of gender.

Of those studies that included both male and female caregivers, 38.8% did employ analyses designed to explore potential gender differences. What makes this particularly interesting is the fact that more than two-thirds of this sub-set of articles went on to report one or more statistically significant gender differences. It is, of course, difficult to know how many authors may have omitted reporting gender analyses because of non-significant findings. Still, given the present probability (roughly two-in-three) of finding significant gender differences, gender would still be an important variable to consider in understanding caregivers and their varied experiences.

The Treatment of Caregiver-Care Recipient Relationship

Included in this review were analyses involving the relationship between caregiver and care recipient. It is possible that spousal and adult child caregivers may differ on a number of potentially influential variables. For example, the role relationships between the caregiver and care recipient are quite different for spousal and adult child caregivers, as may be the case with daughters and sons acting as the primary caregiver. Issues of relationship history, responsibility, reciprocity, and obligation may differentially characterize these two relationship types. A number of objective differences may also distinguish these two groups in significant ways. Often spousal caregivers themselves are in old age, potentially dealing with their own health-related limitations. In addition, a greater number of spousal caregivers are likely to reside with their care recipient. For adult children, the demands involved in caring for an aging parent will likely coincide with other significant responsibilities, such as their career, young children, and their own marital relationships. Since the existing research literature has not demonstrated that spousal and

adult child caregivers are overwhelmingly alike, there is good reason for researchers on caregiving to compare and contrast the ways in which these two groups differ and are similar.

Slightly more than half of the articles reviewed (56.1%) included both spousal and adult child caregivers. Articles dealing exclusively with spousal caregivers (approximately 7.6% of articles surveyed) were just as common as articles dealing exclusively adult child caregivers (roughly 9.1%). However, although generation information was collected for more than half of the articles, this did not directly translate into spousal versus adult child caregivers being included in statistical analyses. From the articles that did gather information on both spousal and adult child caregivers, 27.3% did not report on these groups separately in their analyses. While 1.5% (n=1) of the articles chose to use generational relation solely as a control variable, the majority of articles simply indicated the two groups in the descriptive presentation of the study's participants, and subsequently treated both as representing a single, homogeneous group.

As with those studies that did analyze for gender differences, the most striking feature of this particular analysis was that of the 18.2% (n=12) of studies that did report an analysis of generational relationship to care recipient, 83.5% (n=10) of these articles subsequently reported statistically significant findings. With such an apparently high rate for finding differences between these two types of caregiving relationships, it seems pertinent to consider including generational relationship as a key variable in caregiving research and subsequent discussions.

Additional Issues Related to Subject Selection

There appear to be a number of mutually exclusive approaches at work with regards to subject selection in the caregiver articles covered in this review. The first approach pertains to the selection of a single caregiver category (e.g., adult daughter caregivers) versus a mixed and/or representative collection of caregiver participants. For example, a study by Smith, Smith and Toseland (1991) included the statement that “given that both the caregiver’s gender and relationship to the care recipient are thought to have an impact on the caregiving experience (Horowitz, 1985), participation was limited to adult women who were primary caregivers to a frail elderly parent or parent-in-law” (p. 16). In contrast, Duncan and Morgan (1994) state “recruitment was designed to include both spouses and adult children, as well as those providing care at home and in foster care or nursing homes” (p. 237). And, Pearlin, Mullan, Semple and Skaff (1990) did not analyze for differences within their sample after they state that “the proportions who are husbands, wives, daughters and sons are almost the same as in a national study (Stone, Cafferata, & Sangl, 1987)” (p. 584). It is worth noting that the majority of studies include mixed, but not always representative, samples of caregivers. What is troublesome throughout much of this review is that all of these articles’ titles include the label “family caregivers” or “caregivers.” At issue is the broad, inconsistent manner in which the terms caregiver and caregiving are used in the literature.

A second, somewhat related issue involves the selection processes by which care recipients were chosen. In a large number of articles, authors went to some lengths to describe the clinical diagnosis of the care recipient. As an example, Teri and Truax (1994)

note that in their study “the patients had all met the DSM-II-R criteria for primary degenerative dementias (American Psychological Association, 1987)” (p. 232). However, while this was the predominant approach to identifying care recipients, it was not the only one. In an article by Bass, Bowman and Noelker (1991), the authors state: “Another advantage of this study’s sample is that it included respondents representing diverse caregiving situations. The elderly family relatives who received family care had a wide range of physical and mental impairments, rather than a single disease condition such as dementia” (p. 33). While the merits of both approaches can be argued, the difficulty arises with the fact that in both instances the reader is informed that the investigation examined “caregivers.” Whether or not individuals caring for elderly care-recipients with varied health issues can be appropriately combined under the all-inclusive heading of “caregivers” is an issue. Similarly, how generalizable to other types of caregiving situations and experiences are caregiver studies based on very specialized samples of care recipients?

It would appear that many of the problems identified by Barer and Johnson’s (1990) critique of the caregiving literature have not yet been addressed. The present study was formulated with many of these issues in mind. In the interests of clarity, a summary of these deficiencies is presented below.

1. Descriptions of the caregiving role and it’s subjective meaning for those who adopt the role have not been developed adequately. Attention in the literature has focused much more frequently on the caregiver rather than on the care recipient.
2. The treatment of ‘caregiver’ and ‘caregiving’ remains imprecise and overly-varied in both operationalization and conceptualization. Often, caregivers were simply defined by virtue of their group membership (e.g., participants in support groups).

3. The frequent absence of information about how caregivers were selected has often compounded the problem of vague or variable caregiver definitions.
4. Although there was a recognition of the diversity of individuals who act as caregivers, most notably in terms of gender and relationship variations, the majority of studies reviewed neglected to incorporate these dimensions in their statistical analyses.

CHAPTER THREE

THEORY IN CAREGIVING RESEARCH

Overall, the research and literature on caregiving has been primarily atheoretical. No dominant theory has emerged with which to integrate existing findings and to direct further research efforts, nor has much energy or discussion been invested in theory development in the area as a whole. The reasons behind this absence of theory development are unclear, yet it is becoming increasingly recognized as a serious limitation and growing liability in the field (Hinrichsen & Hernandez, 1992).

This is not to imply, however, that the caregiving literature lacks causal explanations or perspectives. In fact, a number of interesting perspectives have been offered for a variety of issues. The aspect of the field which has generated the most theory driven discussion and research design is caregiver burden research. This may in part be due to the fact that this is the most extensively studied issue in the caregiving literature. Gender has also been an aspect of caregiving which has received considerable attention within the literature. The type of relationship between caregiver and care recipient is another important aspect of caregiving which has generated a number of concepts that may prove useful in better understanding and integrating our knowledge of caregiving.

Perspectives on Caregiver Burden

While no comprehensive theory of caregiver burden exists, researchers in this area have consistently adapted a number of elements from stress and coping theory. This is to be expected since the caregiving literature continues to document the high pervasiveness

of burden among caregivers (Kosberg & Cairl, 1992); in fact, researchers often use caregiver burden and caregiver stress interchangeably. For the most part, the research on caregiver burden has adopted a number of central concepts from stress and coping theory (for example, problem-focused and emotion-focused coping strategies) without embracing the larger theoretical framework. In particular, researchers have almost always omitted the subjective aspects of caregiving, those aspects that would typically be found in the appraisal portion of stress and coping theory. The irony of this omission is that appraisal is a core element of stress and coping theory, one which is presumed to mediate individuals' responses to potentially stressful circumstances and subsequent levels of well-being (or stress).

Although to a lesser extent than with stress and coping theory, other theories have been used to explore caregiver burden. For example, Cicirelli (1993) used life span attachment theory in his examination of caregiver behaviour and subsequent subjective caregiver burden. Mui (1992) used role theory to examine caregiver strain among black and white daughter caregivers. Farran et al. (1991) employed an existential model in their investigation of the experiences of family caregivers for dementia patients. Young and Kahana (1989) described a caregiver outcome model they constructed based on their research on gender and relational aspects of caregiver strain. Montgomery, Stull and Borgatta (1985) developed a model for studying burden which incorporates the element of time and the inter-relationship between multiple caregiver and care recipient variables.

In large part, each of these theoretical positions have been used in relative isolation. There has been no consolidated effort to develop over time a given theoretical framework and, as a result, the potential merit of any given approach is not well known.

Perspectives on Gender

The use of several theoretical perspectives has led to a variety of hypotheses regarding gender differences in caregiving. However, no dominant theory has come to prevail in this area. Instead, a number of fragmented, narrow perspectives have been articulated by different authors. Perspectives on gender in this area have tended to focus primarily upon women's higher levels of reported burden and women's greater adoption of the caregiver role.

Two alternative perspectives have received particular attention concerning the greater tendency of women to report caregiver burden: the gender socialization hypothesis, and the social role hypothesis. Underlying both of these perspectives are posited differences in role demands, supportive resources and personal dispositions that will influence the adoption of the caregiver role and any subsequent caregiver burden (Pearlin et al., 1990). Men and women can be expected to differ significantly from one another to the extent that they bring different demographic, occupational and role socialization backgrounds to caregiving (Miller & Cafasso, 1992).

The gender socialization hypothesis is based upon the notion that gender roles, represented by stable personality traits, become established as a result of potent childhood socialization experiences (Chodorow, 1978; Gilligan, 1982; Rossi, 1984). The result of

these gender-specific socialization processes is the greater tendency for women to be affiliation-oriented and men to be more orientated towards autonomy, differentiation and instrumental behaviours (Miller, 1990). As a result, women are seen as comparatively more sensitive (and potentially more vulnerable) than men with regards to relationships, role behaviours, the meaning and use of social supports, and illness behaviours (Miller, 1990). This greater sensitivity has been argued to predispose women to experience greater distress than men when problematic or stressful social relationships are involved (Kessler & McLeod, 1984). Billings and Moos (1981) outline a perspective in which men are seen as coping more effectively with life stresses in general, and this view has been extended to caregiving in particular (Barusch & Spaid, 1989). Thus, there is speculation that gender differences may exist in both the nature and consequences of caregiving.

The social role hypothesis claims that adults are involved in a continuous construction of social reality in which current social role demands constitute the primary explanation for gender differences in behaviour (Reisman, 1987). Thus, the level of involvement in caregiving, access to social resources, and the experience of "role overload" (Fitting & Rabins, 1985) are all seen as underlying gender differences in burden, rather than prior socialization and personality factors.

Feminist theories of women's identity have been cited as a theoretical basis for women's greater adoption of the caregiving role. According to this perspective, women have a relatively greater internalization of a demand to care (Graham, 1984). Women's identity is seen as primarily affiliational (Chodorow, 1978), and women tend to judge themselves according to an ethic of responsibility to others (Gilligan, 1982). Thus, for

women, addressing the needs of others (particularly close others, such as parents and/or a spouse), is necessary in order not to significantly undermine a women's self-concept (Lewis, 1987).

Adding weight to the perspectives of feminist theorists is the suggestion that formal programs may reinforce the gender-based division of caregiver responsibilities. For example, there have been reports that daughters receive the lowest level of community-based services (Evandrou, 1986; Wright, 1983). Blaxter (1976) notes that social workers and other health care professionals often assume that if a female relative is present, then no difficulties could arise with regards to the care recipient receiving adequate care. Additionally, women's lower employment earnings can also be seen as a factor which may contribute to their greater adoption of the caregiving role. Wives more so than husbands may leave their jobs to provide care to elders because of their comparatively lower earnings. Also, single women may find it more difficult to afford formal caregiving services, and thus engage in more personal caregiving themselves.

Perspectives on Caregiver-Care Recipient Relationship

As with gender in relation to caregiving, there is no over-riding theory of the role relationships between caregiver and care recipient. Given the theoretical and empirical grounds for considering the experiences of spouses and adult children as different, this is a serious limitation in the field, because the potentially distinctive information about spousal versus adult child caregivers (representing the vast majority of caregiver-care recipient relationships), cannot be adequately integrated and understood without a well-articulated

framework within which to account for such findings. However, two key themes relating to caregiving role relationships have been developed and may be useful in understanding existing empirical findings as well as guiding further investigation in this area: reciprocity and obligation.

Patterns and norms of reciprocity are fundamental components of both parent-child and spousal relationships. The emphasis in the literature on the care provided by adult children to their aging parents has acted to minimize the contributions of elderly parents to their children (Connidis, 1989). Dowd (1980) argues that the supportive relationships between parents and adult children are best viewed as exchange relationships, emphasizing the contributions of both participants. A fundamental aspect of these exchanges is a sense of reciprocity (Gouldner, 1967), and the degree of balance in the relationship can directly affect the quality of the relationship. For example, Adams (1969) found that widowed mothers were closer to their adult daughters than sons because the relationship was characterized by an exchange of assistance versus a one-way flow of help from sons. The emotional functioning of older persons has also been found to be better if their relationships are characterized by reciprocity (Black, 1985). This advantage, in addition to norms of reciprocity for couples, may significantly influence caregiving experiences for older spousal caregivers. Kelly (1981) proposes that the severe illness or disability of a marital partner creates a level of dependency which throws off the balance in the relationship, frequently leading to conflict.

Somewhat related to issues of reciprocity is the issue of obligation. Of particular relevance here are the questions of children's sense of obligation to care for their aging \

parents and spouses' feelings of obligation to care for their partners. Bengtson, Olander & Haddad (1976) introduced the term "filial obligation" as a means of describing the motivation of individuals within a family to actively care for elderly members. According to Bengtson et al., filial obligation interacts with elderly family members' dependency needs to determine the level of helping behaviour. The concept of filial obligation has been developed further by a number of individuals. For example, Blau (1973) developed the term "irredeemable obligation" as a causal explanation for adult children's strong motivation to care for their elderly parents. According to this view, children are motivated to repay their parents, yet nothing they can do will fully account for the initial gift of life and nurturing they received from their parents (Berman, 1987). Brody (1985) has argued that this is the reason why many women feel guilty about the level of care they can provide to their parents (even though the amount of care may be outstanding); they feel they are unable to return the level of care they themselves have received during childhood.

The concept of obligation has been less developed within spousal caregiving research. However, the intense obligation of one spousal partner to care for another has been identified as a potential threat to the well-being of both the caregiver and the care recipient (Connidis, 1989). As one spouse strives to fulfill his or her obligation to provide care, both individuals often become increasingly isolated socially and correspondingly restricted from the benefits and resources of outside relationships.

In addition to concepts involving obligation and reciprocity, the issue of balancing caregiving responsibilities along with other duties has also been given some consideration. A high prevalence of adult daughters who find themselves in the roles of caregiver for

their aging parents, care-taker of their children, and that of full-time employee has led to concerns about these “women-in-the-middle” (Brody, 1985). This stands as an excellent example of the ways in which gender and caregiver-care recipient relationship interact.

What is needed is to advance the consideration of these issues using an effective theoretical framework and carefully designed empirical measurements.

CHAPTER FOUR

ORIENTATION AND PURPOSE

In review, the introduction explored the need to study phenomena related to the growing elderly population. Chapter one introduced the topic of caregiving and a number of important areas that have received the most attention in this area (most notably, caregiver burden and instrumental aspects of care). In chapter two, important conceptual and methodological limitations in the existing caregiving research were identified (the most salient of which were limitations in the definition and analysis of “caregivers”). Chapter three highlighted the lack of an overarching theory in the area. However, a number of perspectives (e.g., socialization, reciprocity) were identified which have been employed in conceptual and causal issues related to caregiving. Based on this review of the literature, a number of important weaknesses in the existing research on caregiving have been identified: theoretical and conceptual limitations in the field, empirical limitations, and limitations in the selection and subsequent treatment of caregiver subjects.

One of the most important problems in the caregiving literature is the lack of theory in the field. Not only is there an absence of a central theoretical framework, but also few theoretical concepts exist. The importance of theory in formulating research designs, integrating findings and guiding further research efforts cannot be underestimated. In particular, the most rudimentary and fundamental concepts in the area, ‘caregiving’ and ‘caregiver,’ are weakly and inconsistently described and are not integrated into a larger theoretical framework. ‘Caregiving’ is used as a global label for what is actually a wide

variety of experiences, and basic questions related to the concept of 'caregiving' have not been answered, nor have they been frequently asked. An exploration and elaboration of the *concept* of caregiving is urgently needed. Beginning at the most elementary and fundamental level, questions pertaining to the boundaries around caregiving and how the caregiver role is understood by caregivers themselves need to be asked. It is important to investigate how caregivers understand or impute meaning into their role as caregiver.

Many of the issues raised regarding the conceptual limitations in the field are evident in the critical review of the area's empirical work. This is not surprising since theory and practice are inextricably linked, with shortcomings in one directly affecting the other. The operational definitions of caregivers employed in the caregiving research are based on widely varying criteria, a probable result of the lack of attention given to the conceptual constituents of "caregiving." If there is little agreement among researchers concerning the types of questions they are asking and the people of whom they are asking the questions, then there is likely to be dissonance and anomalies among the findings attained.

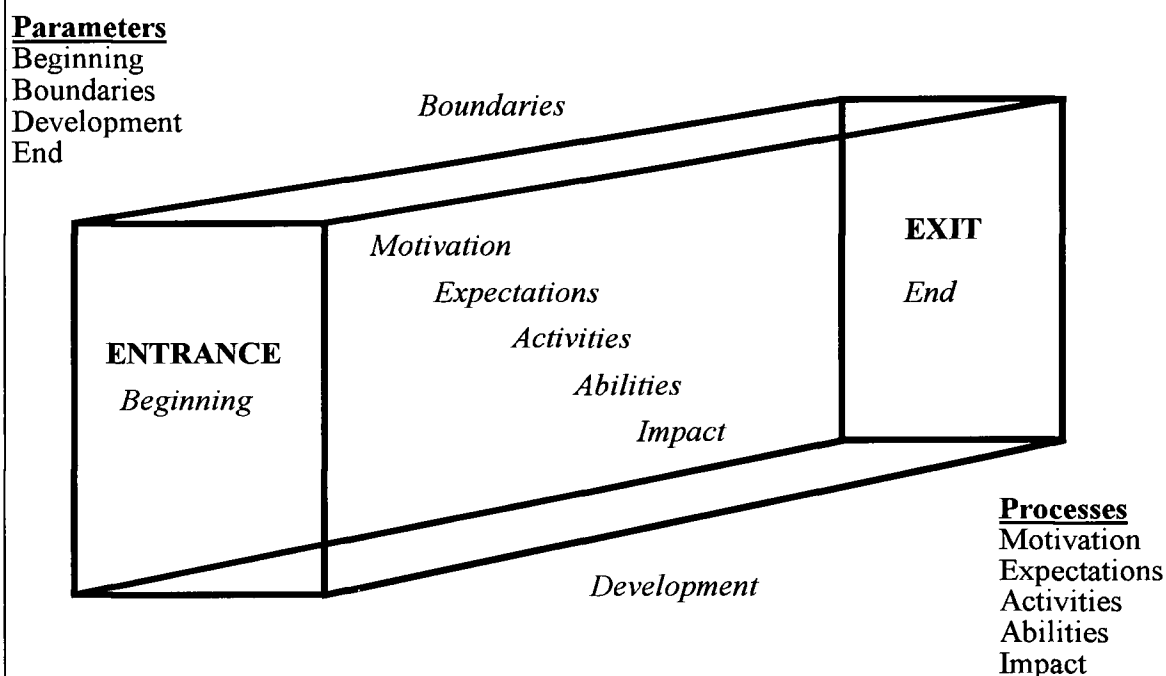
The problems associated with the variable and conceptually insubstantive nature of the operational definitions of "caregiver" are further compounded by both the frequent treatment of caregiver subject groups (e.g., women and men, spouses and adult children) as homogeneous or the selective focus on specific groups (e.g., adult daughters) which are subsequently generalized to caregivers and/or caregiving as a whole. A review of the research has revealed a number of different findings and perspectives that suggest that particular caregivers (for example, spousal and adult children caregiver, female and male

caregivers) have different experiences. In terms of both research and any practical application of that research, it is important to distinguish caregiver sub-types more clearly and analyze for potentially important distinctions between these different groups. The purpose of this study is to investigate the concept and subjective experience of caregiving from the perspective of caregivers, in addition to exploring the potentially different ways in which women and men experience caregiving.

The Caregiving Corridor

In an effort to address some of the above-noted limitations inherent in the existing caregiving literature and to advance one possible conceptual model of caregiving, the author developed a rudimentary structural framework that incorporated a number of variables and dimensions associated with the experience of caregiving. This framework, hereafter referred to as the “Caregiving Corridor,” was developed over the course of several months and began with an appreciation of what is believed to be the two primary dimensions of the concept: parameters and processes (see Figure 3 below).

Figure 3
The Caregiving Corridor



Parameters are those aspects of caregiving which tend to bracket and encapsulate the concept and experience of being a caregiver. In this investigation, there were four parameters of interest. The first was the beginning of caregiving. The literature to date has not explored the simple but fundamental notion of when caregiving begins. It is argued that knowledge of circumstances and experiences related to when caregiving begins may prove very useful in gaining a better conceptual understanding of caregiving.

The same is true for the second parameter of the Caregiving Corridor, the end of caregiving. Little research to date has explored how and under what circumstances caregivers anticipate that their role as caregiver will come to a conclusion.

The third parameter is the development aspect of the Caregiving Corridor. Existing research has almost exclusively taken a “snap-shot” view of caregiving, without focusing on aspects and dimensions of caregiving that may change over time. Given the extended periods of time some individuals act as caregivers, there are likely to be differences in their experiences that are worthy of exploration.

The final parameter of the Caregiving Corridor explored in this study was the boundary dimension of caregiving. Although much work has been done on the instrumental aspects of caregiving (as noted earlier in the 5-year review of articles in *The Gerontologist*), there has been no significant effort to examine caregiver’s perceptions of those activities they either can not or are not willing to provide. It is of interest to this study to identify what caregivers note as behaviours and/or activities they are either unable or unwilling to perform in an effort to further illuminate and detail the concept of caregiving.

The process dimension of the Caregiving Corridor includes a variety of experiences and perceptions which occur within the role of caregiver. There were five processes investigated in this study. The first was the motivation for individuals to provide care. While there is much in the literature identifying and describing what caregivers do (particularly in terms of instrumental tasks), there has been less of an effort invested in examining why they perform these behaviours (Guberman, Maheu & Maille, 1992). This is particularly salient given the central role family members play in caring for the elderly (Stone, Cafferata & Sangl, 1987; Thomas, 1987). Certainly an individual’s motivation to commence and continue providing care, particularly in the face of documented high levels

of stress (Zarit, 1989), is an important aspect of any conceptual understanding of caregiving.

Although the influence of caregiver appraisal has been studied somewhat (see Bass & Bowman, 1990), the second process dimension of the Caregiving Corridor, expectations, has been absent in past caregiving research. Yet it is argued that both the motivation to provide care and expectation surrounding both how to provide care and the perceived sufficiency of such care are important factors influencing caregiving experiences. Indeed, Role Theory includes the concept of clarity of role expectations as being an important determinant of role performance (Burr, Leigh, Day & Constantine, 1979).

Given that caregiving activities have been studied considerably in the literature (George, 1990), their inclusion as the third process in the Caregiving Corridor is important. Although caregivers have been shown to engage in a wide variety of activities (Horowitz, 1985), it is of interest to know how caregivers characterize these activities along a number of more specific dimensions (for example, activities most often provided, activities regarded as the most energy consuming).

The fourth process dimension of the Caregiving Corridor is caregiver abilities. Absent in the caregiving literature reviewed is an attempt to identify how caregivers interpret their abilities in terms of both assets and limitations in relation to their role as caregiver. Information from exploring these issues might provide important clues about how to reduce areas of potential weakness (e.g., minimize caregiver burden) and enhance areas of strength (e.g., identify important determinants of successful caregiving).

The final process aspect of the Caregiving Corridor is impact. Research has repeatedly demonstrated the high prevalence of negative aspects of caregiving (Zarit, 1989), and in fact this is likely the single most studied aspect of caregiving (George, 1994; Kosberg & Cairl, 1992). However, little has been done in exploring the potentially positive aspect of being a caregiver (see Cohen, Gold, Shulman & Zuccherro, 1994). Additionally, although some work has been done on the nature of caregiver-care recipient relationships (Black, 1985; Dowd, 1980; Adams, 1969) further investigation is warranted to explore the ways in which caregiving impacts on the earlier relationships of caregivers and care recipients.

The following is a list of the definitions for each of the dimensions of the Caregiving Corridor as conceptualized and investigated in this study:

Parameters - Parameters are those characteristics of caregiving that encapsulate or limit the caregiving experience. Caregiving takes place within the parameters of the Caregiving Corridor, but not outside of it.

Beginning - The Beginning parameter is the starting point (temporal, affective and/or situational) at which individuals first identify or recognize themselves to be caregivers.

Boundaries - The Boundaries of the Caregiving Corridor are the perceived points at which individuals describe themselves as either performing acceptable behaviours of caregiving (within a given boundary) or not performing acceptable caregiving behaviours(outside a given boundary).

Development - The Development parameter of the Caregiving Corridor captures the fluid nature of caregiving. It is the aspect that focuses on those behaviours and experiences that change over the course of time and experience.

End - The End parameter is the ending point (temporal, affective and/or situation) at which individuals identify themselves as no longer being caregivers.

Processes - Processes are those caregiving activities, experiences and perceptions that take place within the parameters of the Caregiving Corridor, (i.e., the beginning, boundaries, development and end of caregiving).

Motivation - Motivation is that aspect of individuals which inspires them to adopt and perform the role of caregiver.

Expectations - Expectations are the aspect of caregiving within which caregivers identify (1) how they know what care to provide, and (2) whether that care is meeting their own and/or the care recipients expectations for suitable or satisfactory care.

Activities - Activities are those specific tasks and behaviours performed as part of the caregiver role.

Abilities - The Abilities aspect is intended to cover personal attributes (including strengths and weaknesses) that are brought into the caregiving role.

Impact - The Impact aspect of the Caregiving Corridor is intended to capture the results, both individual and social, positive and negative, of caregiving as described by caregivers.

The Caregiving Corridor, as initially conceived, was used to guide the process of planning and executing the current study. Each of the questions employed in this study was designed to explore one or a combination of the components of the Caregiving Corridor. In addition, this structural metaphor offered an effective approach to integrating and coordinating the findings of this investigation, and may serve as a possible guide for further research investigations. Of course, this framework, as developed by the author, is only one method of conceptualizing this data - it does not represent an exhaustive list of the components or dimensions which may be deemed of interest in relation to caregiving.

Overview of Research Questions

Because the questions employed in this primarily qualitative investigation are exploratory, it is difficult to predict the nature or direction of responses. Additionally, the relationship between the responses to these questions and the other measures included in this study (in particular, demographic variables and the caregiver burden scale) will be of

interest. As above, the exploratory nature of this study makes difficult the ability to make predictions about potential variable relationships.

The first group of subjective questions utilized in this investigation explore the boundaries that caregivers identify as defining their experience of the caregiver role. For example, questions about how caregivers conceptualize when their caregiver role began, how it will end, and how it differs from the rest of the parent-child relationship are explored.

The second set of questions explores those activities identified by daughters and sons as the most frequently provided, and how they evaluate these in terms of their perceived abilities. One of the few clear predictions drawn from existing literature is that daughters will report providing more hands-on type of care, while sons will report providing more of a liaison role between aging parents and other formal services (Stoller, 1990).

The third group of questions explores how caregivers perceive their caregiving role as having changed with time, both with respect to the activities they perform and their relationship with their parents.

The fourth set of questions is designed to investigate the impact of both caregivers' and their parents' expectations of what the caregiving role would entail. What do caregivers identify as the source of expectations for their role, and are these well-defined?

The final group of questions explores how caregivers evaluate their caregiving experiences in terms of both positive and negative aspects, and in terms of the sense of

importance and meaning they derive from caregiving. Based on previous research, it is predicted that daughters will report greater burden associated with their caregiving than will sons (Miller & Cafasso, 1992). With regards to the identification of positive aspects of caregiving, limited previous research has described a number of potentially positive aspects, including having the company of the care recipient, keeping the care recipient at home and preventing institutionalization, feeling a sense of duty, and love (Cohen et al., 1994).

CHAPTER FIVE

METHOD

Recruitment of Participants

In an effort to maintain consistency with recruitment procedures used in the majority of existing caregiver research, participants were selected through letters sent to several local area caregiver support programs and through an article soliciting participants in a community newspaper. Both the letters sent to leaders of caregiver support programs and the community newspaper article outlined the study and requested that interested individuals contact the researcher by telephone for more information and/or to set-up an interview (see Appendix 1).

Participants in this study had to meet three specific criteria: (1) they must be the self-identified primary caregiver of their parent(s) aged 65 or older (indicating they provide the majority of all informal care received as measured by time spent providing care), (2) they must live within 50 kilometers/30 miles of their respective care recipient, and (3) care recipients must be living in a private residence. The first criterion was designed for compatibility with subject selection procedures utilized by a majority of caregiving research projects. The second requirement was designed to exclude caregivers who may be providing less intensive, long-distance assistance to their parents (for example, primarily providing support by telephone). The third selection criterion was employed to exclude caregivers who may be providing care for a parent or parents currently residing in an institutional setting.

Response Rate

It was initially intended to interview twenty participants, equally divided by gender (10 daughters and 10 sons), however the final number of participants was ten women and six men. Two individuals who responded to the newspaper article did not meet the eligibility requirements and were not included in the study. Although it had been hoped that a greater number of male caregivers would be incorporated into the study, time and resource limitations made this a particularly difficult objective to achieve. This difficulty in including a greater number of men in caregiving research has been identified as a problem in similar research efforts (Keith, 1995; Horowitz, 1992). Whether this ratio of female to male respondents is due to a response bias or reflects the gender ratio of caregivers in the population is undetermined.

Data Collection Procedure

Individuals interested in participating in the study were briefly interviewed by telephone to ascertain whether or not they met the subject selection criteria. Successful individuals were then invited to provide a suitable time and location to conduct the interview. Prior to commencing the interview, participants were provided with an information letter describing the project (see Appendix 1) and their rights as a participant, and were asked to sign a consent form (see Appendix 1) indicating their willingness to take part in the study. The interview sessions were tape recorded and subsequently transcribed to facilitate analysis. Interviews took place at either the subject's home or an alternative location arranged by the interviewer and the subject (for example, at the participant's place of employment). Only the interviewer and the participant were present

during the course of the interview. At the conclusion of the interview, participants were asked if they had any questions about the project, and whether or not they would like a summary of the research project mailed to them following the completion of the study, all of whom accepted.

Measures

Data were collected during a personal interview which took approximately 30 minutes to 1 hour to complete. The interview schedule was divided into four parts (see Appendix 2). Parts 1 and 2 requested demographic information about the caregiver and care recipient. Additionally, Part 2 asked caregivers to assess who else provided informal care to the care recipient and what percentage of the total amount of informal care they themselves provided. Part 3 of the interview was composed of a number of qualitative questions that inquired into the ways in which subjects perceived and experienced their role as caregivers. Question 2c of this section of the interview also asked subjects to work with the interviewer in arranging a series of task cards (related to the types of caregiving tasks performed by the subject) from the most energy-consuming to the least energy-consuming tasks. All of the questions to this point in the interview were devised by the author for the purposes of this study. Finally, Part 4 of the interview involved presenting subjects with eleven questions (the General Burden Scale - Chiriboga, Weiler & Neilsen, 1990) each of which were rated on a scale ranging from 'never' to 'nearly always.'

Prior to being used in the study, the interview was pre-tested with two test subjects (one daughter and one son) in order to evaluate the appropriateness of the interview's design, content and method of presentation, (for example, the clarity of

questions and length of time required to complete the interview). With the exception of three changes of wording, the interview was found to be effective for the purposes of this study in that it elicited responses that addressed the study's research questions.

Parts 1 & 2 - Demographic Information

Demographic information about the caregiver included questions about caregiver's sex, age, marital status, ethnic identity, estimated annual household income, number of years of education, living arrangements and employment status. Demographic information about the care recipient included questions about the care recipient's sex, age, marital status, ethnic identity, estimated annual income, and living arrangements. These demographic variables are similar to the descriptive information commonly gathered by other studies investigating caregiving (for example, Williamson & Shulz (1993), Black (1985), Folkman & Lazurus (1980)). Additionally, the inclusion of these demographic variables was intended as means of comparing the situations of women and men participants in the study. Participants were asked to identify others who provided informal care to the care recipient and the percentage of the total amount of informal care they themselves provided. These questions were included to explore the "primary caregiver" classification and the availability of other potential caregivers.

Part 3 - Caregiver's Subjective/Qualitative Perspective

The following is a presentation of the dimensions of the subjective experience of caregiving that were explored. It is important to note that different sections of the interview schedule often combined different components of the Caregiving Corridor. In order to link each of the questions back to the Caregiving Corridor, an identifier in a

square bracket is located at the end of each brief statement identifying the intended purpose of the question (e.g., [motivation]). (Note: italicized text following a question indicates a prompt to be used if further elaboration of a question was deemed necessary, for example, if a participant was having difficulty understanding or formulating a response to a given question.)

I. Boundaries

The questions in the boundary/barrier section of the interview were included to explore different components and dimensions of the caregiver role (for example, the beginning and end, the limits of performing care, and the impact of care provision). The questions in this section were as follows:

- 1a. If you had to identify a point at which you first perceived yourself as a caregiver for your parents, what would that be? (*When did your relationship with your parents change with your becoming the caregiver for your parents? When and in relation to what circumstances did you first become a caregiver for your parent(s)*)
 - Explores the events, circumstances and/or experiences associated with the transition into the caregiver role. [beginning; boundaries]
- 1b. How long have you been a caregiver for your parent(s)?
 - Determines the amount of time over which caregiving has been performed. [development; boundaries]
- 1c. Why are you doing this for your parent(s)? (*What motivates you to be a caregiver for your parent(s)?*)
 - Explores the motivation or driving force behind caregiving. [motivation]
- 1d. Is there anyone else who could provide care to your parent(s), and how did you come to be the primary caregiver?
 - Explores factors of selection in becoming a primary caregiver. [beginning]

1e. In your caregiver role, are there things you feel you can not or won't do?

- Explores the boundaries (e.g., physical, psychological) within which caregiving takes place. [boundaries]

1f. When do you feel your role as caregiver for your parent(s) will end?

- Explores events, circumstances and/or experiences associated with the anticipated termination of the caregiver role. [end; boundaries]

II. Nature of Care Provision

The questions in this section of the interview were included in response to the predominantly instrumental approach taken by many researchers exploring caregiving. The purpose of this section was to provide a link between investigative approaches evident in much of the existing caregiving research (e.g., caregiver task checklists) and some novel approaches to examining caregiving tasks which are utilized in this study. This section was designed to allow subjects to describe the specific types and amounts of assistance provided by adult daughters and sons caring for their parents. In addition, caregivers' sense of their own abilities to perform the caregiver role were investigated. The specific questions in this section were:

2a. What do you do as a caregiver for your parent?

- Acquires an unstructured accounting of the nature of subjects' caregiving. [activities]

2b. If at all, which of the following broad types of care do you typically provide?

- (1) ☐ food services (cooking and clean-up)
- (2) ☐ shopping (food and clothing)
- (3) ☐ house work (house cleaning and laundry)
- (4) ☐ home maintenance (inside and yard work)
- (5) ☐ transportation (for doctor's visits)
- (6) ☐ personal finances (banking and bill payment)

- (7) ☐ personal care (dressing and bathing assistance)
- (8) ☐ emotional care (listening and talking)
- (9) ☐ advice and decision making (regarding short-term and long-term decisions)
- (10) ☐ interacting with health care agencies (arranging homemakers, appointments)
- (11) ☐ health care assistance (with medications, help with exercise)
- (12) ☐ coordinating social activities (social events, visits, letter writing)

- Includes a comprehensive caregiving tasks checklist based on a review of the most prevalent caregiving activities included in the literature.
- Intended to identify specific tasks should the subject be vague or unspecific in response to Question 2a. [activities]

- 2c. Of those types of care you do typically provide, how would you arrange the associated task cards from the most energy-consuming to the least energy-consuming of the different tasks?

- Identifies a subjective ordering of the various tasks performed that were the most demanding on their resources. [activities]

This question involved having subjects indicate how the types of caregiving tasks they commonly performed (represented on individuals task cards) should be physically arranged from the most energy-consuming task to the least energy-consuming.

- 2d. Do you feel your abilities are sufficient to perform the role of caregiver for your parent(s)? What are your strengths and weaknesses in caring for your parents?

- Explores the perceived relationship between subjects' abilities and caregiving responsibilities. [abilities]

III. Development

The developmental section of the interview was included as a means of acquiring information about how caregiving experiences, both in terms of activities performed and feelings about the parent-child relationship, change over time. This developmental aspect of caregiving has been notably absent in previous caregiving research. The questions included in this section were:

- 3a. How have your activities as a caregiver (for example, those we discussed earlier) changed since you first became a caregiver for your parent(s)?
- Explores the potentially changing nature of caregiving activities. [development; activities]
- 3b. How have your feelings about your parent(s) changed since you first became their caregiver? (*How do you feel your relationship with your parent(s) has changed?*)
- Explores how feelings about caring for an aging parent change over time. [development]

IV. Expectations

This section of the interview was included in recognition of the relationship and social context in which caregiving occurs. Questions were designed to focus on the role expectations and evaluation play in caregiving experiences. The questions in this section were:

- 4a. Were there clear expectations for how to be a caregiver? (*How did you know what was expected of you as a caregiver? How did you know what to do?*)
- Explores what caregivers identify as guiding their caregiving behaviour; in addition, examines if there are prescriptions for the caregiver role. [expectations, beginning]
- 4b. Do you feel you are living up to your own expectations as a caregiver?
- Explores the association between caregivers' performance and their expectations for providing care. [expectations]
- 4c. Do you feel you are meeting your parent(s) expectations as their caregiver?
- Explores the association between caregivers' performance and their perception of their parents' expectations. [expectations]

V. Evaluative

This section of the interview included evaluative questions regarding caregiver's conceptions of the importance of their caregiving, both the positive and negative aspects

of providing care, and what being a caregiver for their parents meant to them. While previous research has explored negative aspects of caregiving, little attention has been paid to the potentially positive rewards of caregiving. Questions in this section were as follows:

5a. What do you see as the most important thing or things you do as a caregiver for your parent(s), and why?

- Assesses subjective evaluations of the most important aspect(s) of parental care provision. [activities]

5b. Are there any pleasurable or rewarding aspects of caring for your parent(s)? If so, what are they? (*What, if any, satisfaction do you get from caring for your parents?*)

- Explores sources of pleasure or satisfaction derived from the caregiving experience. [impact]

5c. Are there any problematic or upsetting aspects of providing care to your parent(s)? If so, what are they?

- Explores sources of difficulty or conflict resulting from the caregiving experience. [impact]

5d. What does being a caregiver mean to you? (*How do you think of yourself as a caregiver? Over all, how would you describe what it is you do for your parents and how you feel about it?*)

- Provides an unrestricted opportunity for caregivers to describe and assign a conceptual meaning to their role as caregiver for their parents. [Caregiving Corridor as a whole]

Part 4 - *Caregiver Burden*

A quantitative measurement of caregiver burden was included in this study for two reasons. First, the measure utilized allows for this study to be integrated with those studies that have included similar measures of caregiver burden. The findings of other studies using this measurement technique will make it possible to draw comparisons with this

study and much of the existing caregiving literature. Second, it is of particular interest to this study to identify the ways in which traditional measures of caregiver burden relate to findings from the exploratory, subjective questions incorporated in this study. This section of the interview schedule relates to the 'impact' component of the Caregiving Corridor.

The level of burden experienced by caregivers was measured based on subjects' verbal responses to the 11-item General Burden Scale developed by Chiriboga, Weiler & Neilsen (1990), which has an acceptable level of established reliability ($\alpha = .90$). This 5-point Likert-type scale is composed of items which are rated from 'never' to 'nearly always.' The questions comprising the eleven items are:

- (1) Do you feel because of the time you spend with your parent(s) that you don't have enough time for yourself?
- (2) Do you feel stressed between trying to care for your parent(s) and trying to meet other responsibilities for your family or work?
- (3) Do you feel that your parent(s) currently affect your relationship with other family members or friends in a negative way?
- (4) Do you feel strained when you are around your parent(s)?
- (5) Do you feel your health has suffered because of your involvement with your parent(s)?
- (6) Do you feel that you don't have as much privacy as you would like because of your parent(s)?
- (7) Do you feel that your social life has suffered because you are caring for your parent(s)?
- (8) Do you feel you will be able to take care of your parent(s) much longer?
- (9) Do you feel you have lost control of your life since your parent(s)' illness?
- (10) Do you just wish you could pass the care of your parent(s) to someone else?
- (11) Overall, how burdened do you feel caring for your parent(s)? (Chiriboga, Weiler & Neilsen, 1990)

Qualitative Analysis

Based on participants' responses to the subjective/qualitative questions, attempts were made to identify distinct categories using thematic content analysis procedures and techniques derived from principles of Grounded Theory (Strauss & Corbin, 1990).

Responses were coded for a given question, identifying any distinctive language, themes, and concepts that emerged. The resulting coded information was organized into categories, which were in turn refined and modified to best reflect the overall data gathered. This primarily involved using a coding worksheet (see Appendix 3) to combine similar response types to achieve higher order categories (i.e., broader categories which included various but closely related response types). The final procedure involved a review of all data in which attempts were made to situate responses within categories, as either 'present' or 'absent,' or along a continuum, (for example, high or low sense of responsibility). Additionally, categories were not mutually exclusive. In a number of cases, individual participant's responses to a particular question were identifiable as belonging in more than one category. In these instances, responses were coded for all applicable categories. As a result, the percentage of respondents who fell into each of the response categories for a particular question do not necessarily sum to one-hundred percent. The final stage of analysis involved re-ordering the categories for each question on a hierarchical basis from most to least prevalent. This was done for convenience sake in an effort to facilitate the identification and subsequent review of the most prevalent responses to each question and section of the study.

CHAPTER SIX

RESULTS

Characteristics of the Sample

A summary of the key characteristics of the participants in the study is presented in Table 1 and the following text. For a detailed listing of all caregiver and care recipient demographic information gathered, refer to Appendix 3.

Table 1 - Characteristics of Caregiver Participants

Variable	Daughters N=10		Sons N=6		Total N=16	
	Mean	SD	Mean	SD	Mean	SD
Caregiver Age	52.2	8.5	53.2	6.4	52.6	7.6
Caregiver Income	2.8	1.5	3.3	1.7	3.0	1.5
Caregiver Education*	14.1	2.4	17.2	2.0	15.2	2.7
No. of Care Recipients	1.0	0	1.0	0	1.0	0
No. Other Caregivers	1.6	1.6	0.7	0.5	1.2	1.3
% Care Provided	88.8	15.4	88.3	14.7	88.6	14.7
Years Caregiving	6.5	4.2	8.7	4.1	7.3	4.2
No. Tasks Performed	7.6	2.7	8.7	3.4	8.0	2.9
General Burden Score	2.6	0.7	2.0	0.4	2.4	0.7

* Significant, $t(14) = 2.62$, $p=.02$

Approximately forty-four percent of caregivers were married or in common-law relationships, thirty-seven-and-a half percent were divorced and twelve-and-a-half percent were single. It is interesting to note that the only never-married participants in the study were men, 33.3% of men in the study. The average, annual household income for

caregivers was between \$40,000 and \$59,000. The only statistically significant differences to emerge between daughters and sons was in the number of years of education $t(14) = 2.62, p=.02$, with sons reporting more years of education ($M=17.2, SD=2.0$) than daughters ($M=14.1, SD=2.4$). Seventy-five percent of caregivers reported their ethnicity as Canadian, with the remainder reporting European ethnicity. Regarding caregivers' residence, 31.3% reported living with a spouse or partner, 25% were living with their parents, and 18.8% reported living alone. Fifty percent of the sons in the study reported living alone, while all of the daughters reported residing with at least one other person. The majority of caregivers reported working full-time (62.5%), while 18.8% were working part-time and 12.5% categorized themselves as retired. All participants in the study reported being the primary caregiver for only one elderly parent. In response to being asked to identify others who regularly contributed care to the care recipient, participants identified a mean number of 1.2 ($SD=1.3$) other care providers. Participants also reported providing care to the care recipient for a mean number of 7.3 years ($SD=4.2$).

The ages of care recipients in the study ranged from 72 to 94, with a mean age of 83.4 ($SD=7.0$). The majority of care recipients were female (93.8%); the only male care recipient included in the study was cared for by his son. Eighty-seven-and-a-half percent of care recipients were widowed, one care recipient was married and one was single. Almost all recipients' average, annual household income was reported as being less than \$19,000. Fifty percent of care recipients' ethnicity was reported as Canadian, followed by British (18.7%), and one care recipient each classified as Chinese, Danish, Hungarian,

Polish and Ukrainian. Most care recipients lived alone (43.8%), followed by living with their children (31.3%), their children and grandchildren (18.8%), or with their spouse (6.3%).

The following presentation of results follows the order of information as gathered using the interview schedule employed in this study. In addition, unless otherwise noted the results of qualitative analysis are present in order, from the most prevalent to the least prevalent type of responses. Where a reference is made to a specific participant in the study, the participant is identified by a number and letter combination which corresponds to their participant number (1 is the first and 16 is the last) and their sex (F for female and M for male). This labeling convention was used extensively during data collection and analysis and provides a means of linking some of the participants' responses in differing sections of the study's results.

BOUNDARIES

Beginning. In response to the question, "If you had to identify a point at which you first perceived yourself as a caregiver for your parent, what would that be?" participants identified several content and process issues. Content issues concerned relatively specific events. The most prevalent content issue to emerge, identified by 75% of participants (7 women, 5 men), was the onset of caregiving due to a parent's health crisis, including both physical and cognitive changes or limitations. A typical example of this is evident in participant 12M's statement:

“Around eighty [my mother] had a stroke and that was a health crisis point. It was a fairly major stroke, but she did recover somewhat. Although, I noticed that her mental state had suffered.”

To a lesser extent, a major life event or change other than health occasioned the onset of the caregiving role. Twenty-five percent of participants (2 female, 2 male) identified a number of such events, including retirement, relocation and the loss of other parent. For example, participant 11M responded to the question saying:

“I guess when my father died in 1962. That brought it home to me that I have no brothers or sisters, and I’m going to be looking after Mom in a sense of being involved in her decisions. Then in 1982 she had her first stroke and lost the use of her left arm and hand.”

For two participants (1 female, 1 male), there was a recognition of the scope of issues related to them as caregivers (i.e., a realization of the responsibility undertaken) and the implicit role reversal or realignment of roles. As participant 1F states:

“It was kind of her struggling with the fact that she couldn’t do it anymore, and that really shifted things. Up until that point she had been the parent for me, and then all of a sudden I had to become the parent for her.”

Process issues had more to do with the ways in which participants experienced the transition into their role as caregiver. These issues assumed two forms - participants either described the sudden and unexpected nature of the onset of caregiving (the most common form) or the gradual transition into the caregiver role. Examples of both of these follow. Participant 3F responded:

“...we thought she had the flu, but in fact nobody knows what it is and she hasn’t come out of it. So she aged ten years in one day.”

In contrast, participant 9F described her transition into the caregiver role by saying:

“When my Dad went into the hospital, [my Mother] had to come live with me because she couldn’t live on her own. And when he passed away then she just stayed on with me.”

Motivation. In assessing what motivates them to act as caregiver for their parents, participants identified a variety of considerations. The most prevalent theme contributed by 69% of the participants (9 female, 2 male) can be described as their desire to adhere to a strongly felt moral principle that it is their “duty,” “obligation,” or “responsibility” to provide care for their increasingly dependent parents. Participant 11M expressed this sentiment by saying:

“I care for my mother out of an appreciation for the things she did for me... and out of a sense of duty that was instilled in me. I feel that it’s an obligation and duty that I should fulfill. There’s kind of two sides to it.”

As participant 6F’s statement that she provides care for her aging mother “because she’s my mom” indicates, there is an assumption by many of the participants that such care is both expected and demanded as a natural part of the parent-child relationship. Closely allied with this notion is the sentiment expressed by 38% of participants (3 female, 3 male) that their decision to act as caregiver for their parents was motivated by a sense of indebtedness for the care and assistance previously bestowed upon them by their parents.

For example, participant 5F states:

“She did it for me. She was a single parent raising me. I want to do it because we are each other’s family. I want to do it because I owe her that.”

A second prevalent theme identified by 56% of participants (4 female, 5 male) was the affection of the caregivers for their parent. While some spoke of their friendship with their parent, others used terms such as “admiration,” “love,” and a desire to provide their parent with a semblance of “dignity” in describing what motivates them to act as their parent’s caregiver.

Finally, 31% of the participants in the study (4 female, 1 male) attributed their motivation to care for their aging parents to a lack of available alternative caregivers. As participant 2F said:

“I guess logically there’s nobody else. But I wouldn’t think of abandoning her. I mean, there’s no thought that I would do that.”

Two participants made particular mention of the fact that they were only-children and as a result could envision no other alternatives for their parents’ care.

Designation as Primary Caregiver. Two main themes emerged from participants’ responses to the question of how they came to be their parent’s primary caregiver. The majority of participants, fourteen of the sixteen (9 female, 5 male), identified a lack of alternative caregivers as the central reason for their becoming their parent’s primary caregiver. However, within this category of responses exists some variation in why alternative caregivers were not available. Thirty-eight percent of participants (3 female, 3 male) attributed the lack of alternative caregivers to structural barriers preventing other family members from providing any additional care; for example, due to geographic distance, work and/or family responsibilities of other potential caregivers. Participant 13M responded:

“We both lived in Vancouver, whereas my siblings live five hundred miles away and they were not at all able to do it. They were married at that time with young children and I don’t think that would have been an option.”

In contrast, an equal number of participants (5 female, 1 male) noted that although other individuals were in a position to provide care, they were unwilling to do so. For example, participant 8F said:

“[My mother] has some brothers and sisters, and we did ask them if they wanted to play some kind of role in caring for her, but they quite clearly didn’t want to really do anything.”

All of the participants who were only-children mentioned this lack of alternatives as a reason behind their assumption of the role of primary caregiver for their parents.

The responses of 19% of the participants (2 female, 1 male) formed a second theme of participants’ explanation as to how they came to be their parents’ primary caregiver. These individuals cited distinct aspects of their relationship or family history with their parents. Participant 16M responded:

“Yes, there are other members of the family, but that doesn’t necessarily mean that they are going to do anything. I became [my father’s] primary caregiver because I don’t step all over his toes.”

Participant 9F said:

“I was always really close to my Mom, and my sister lived out of town. We’re all pretty close, but I guess I was just closer than [my sisters], and [my parents] trusted me and I think felt more secure with me.”

And participant 1F stated:

“There’s always been not only an unspoken, but also a verbal expectation that I would be there.”

Barriers. Asked if there were things they felt they could not or would not do in caring for their parents, participants’ responses were primarily concerned with issues related to themselves rather than issues related directly with their parent’s care needs. The responses of 25% of participants (3 female, 1 male) formed the most prevalent theme of participants’ unwillingness to make specific sacrifices in their own lives. Several participants noted their strong reluctance to commit more time to caring for their parents,

citing the necessity of saving time for themselves and attending to their own well-being.

As participant 11M mentioned:

“I don’t want to get into having to go and care for her everyday, because that would be too much for me. It can be too much... too confining and detrimental to my own well-being.”

Other sacrifices participants stated they were unwilling to make included leaving their job and sharing a household with their parent.

A second set of responses focused on the participant’s parents and involved the desire not to interfere with their parent’s independence and/or sense of control. As participant 1F stated:

“I won’t do things she can do for herself. I learned a lesson very early on about kind of rushing in and doing things for her. That made her quite angry and also made her feel less adequate.”

One female and two male participants also noted their desire not to deal with issues and tasks related to physical care, particularly personal hygiene. Twenty-five percent of participants (1 female, 3 male) stated that there was nothing they felt they either could not or would not do in caring for their parents.

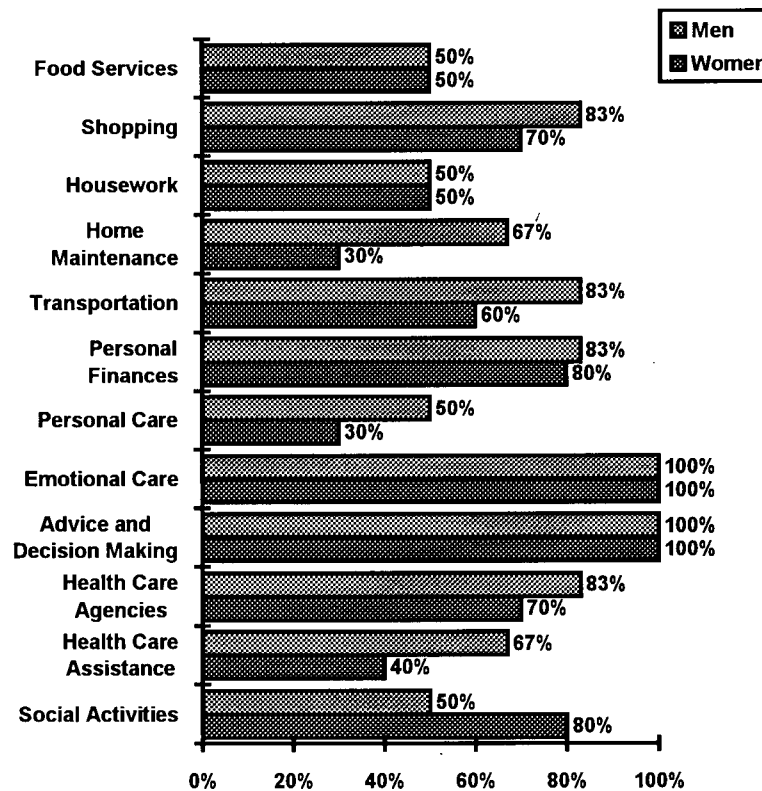
End. Asked when they felt their “role as caregiver for [their] parent will end,” 81% of participants (9 female, 4 male) responded that their caregiver role would end with the death of their parent. However, two of these same participants (both male) also stated that if facility placement became a necessity, their caregiving role would end at that point. Two participants (1 female, 1 male) did report their expectation that their caregiving role would end when their parent was ultimately placed in a facility. One male participant reported that his caregiving role would end when his mother regained her independence.

NATURE OF CARE PROVISION

Performance of Activities. In response to the question “What do you do as a caregiver for your parent?” a wide variety of responses emerged. The most prevalent categories, listed from most to least frequently mentioned, included instrumental tasks (for example, errands, household maintenance, transportation and personal finances), emotional and social care (for example, providing companionship, talking and facilitating external social contact), and managing care (for example, managing tasks and difficulties of daily living, managing professional assistance). Also, 19% of participants (2 female, 1 male) mentioned that they were involved in providing total physical care for their parents. Additionally, one female participant described her role as requiring her to do what her mother directed her to do, while another described her role as involving her to fill-in whatever her mother needed but could not achieve alone.

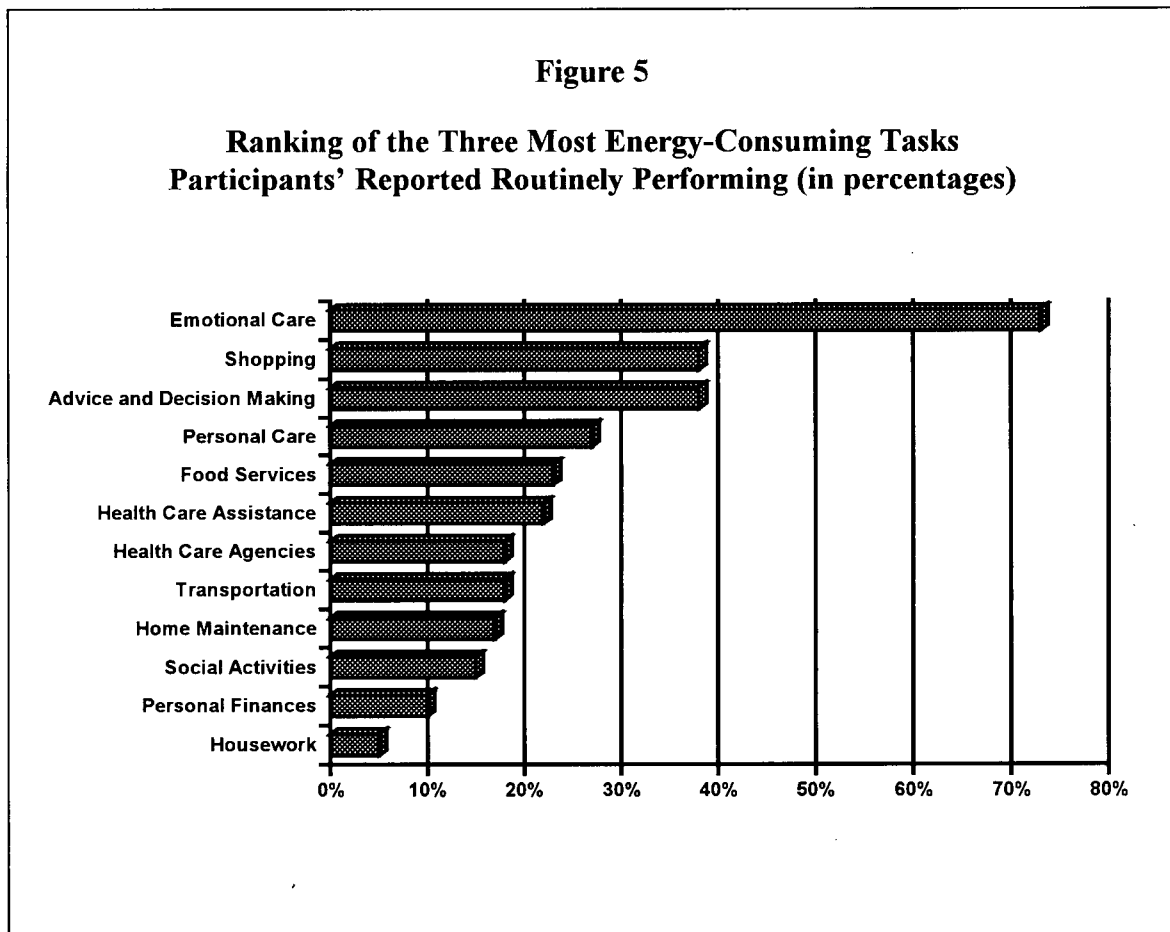
Caregiving Tasks Checklist. Figure 1 below summarizes the different types of care (as presented in the questionnaire) men and women in the study reported routinely providing for their parents. The most common tasks performed by participants in the study were emotional care and advice and decision making. Overall, participants identified a mean of 8 ($SD=2.94$) tasks performed, with a range from 3 to 12. Additionally, it is worth mentioning that t-tests revealed no significant differences in either the type or number of tasks performed by male and female participants in the study.

Figure 4
Percentage of Men and Women Participants Who Reported
Providing Different Types of Care



Most Energy Consuming Tasks. Following the identification of tasks routinely performed, each participant was asked to indicate how to arrange those tasks from the most to least energy consuming. Since participants identified a variable number of tasks, only the three most consuming tasks were analyzed, given that all participants identified at least three from the list. Figure 2 presents the percentage of participants who identified each task as being within the three most energy consuming tasks they perform. Emotional care was the most mentioned type of care, followed by advice and decision making, shopping and personal care. As with the identification of types of care provided, t-tests

revealed no significant gender differences with respect to the participants' ranking of the most energy consuming tasks they perform.



Abilities: Sufficiency. In addressing the question as to whether or not they perceived their abilities to be sufficient to perform their role as caregiver, 88% of participants (8 female, 6 male) responded "yes." However, one female participant noted that previously her abilities seemed insufficient to deal with the demands placed on her in caring for her mother. She stated:

"At this level of care, yes. But a year-and-a-half ago I would have to say I was really pushed to the wall. There was a bad time from when she had the initial strokes through her extended hospital stay. She was afraid to be alone and it was very difficult."

One female participant also reported that she was unable to determine whether she felt her abilities were sufficient to care for her mother. One participant stated she felt her abilities were insufficient, citing her perception that she could not give her mother enough mental stimulation as she perceived necessary.

Abilities: Strengths. Asked to identify their strengths in being a caregiver for their parent, participants reported a variety of positive attributes. Thirty-one percent of participants (4 female, 1 male) mentioned their management skills as an asset, both in relation to their parent's and their own lives. As an example, participant 3F stated:

“I mean, it's not just taking care of your parent. It's holding down a job, being a single parent, and being a member of your community... There are a lot of priorities that need juggling all the time, and you always have to be assessing and re-assessing to try and make sure that everybody gets their needs met.”

Another 31% of participants (2 female, 3 male) simply identified their personal circumstances (for example, their own good health or flexible work schedule) and willingness to help as assets in being a caregiver. Twenty-five percent of participants (4 female, 0 male) noted their knowledge, particularly of the physical aspects of providing care, as a key strength in caring for their parent. Three of the six men in the study mentioned that “patience” was an important strength in their ability to care for their parents. Other individuals responses included “a sense of personal boundaries,” religion, a sensitivity to their parent's needs, and a good relationship with their parent. Only one male participant was unable to identify any strengths in his role as caregiver for his mother.

Abilities: Weaknesses. When asked if they could identify any weaknesses they had in caring for their parents, participants' responses generally fell into three categories:

personal ability issues, boundary issues, and relationship issues. Personal dispositions that were considered weaknesses included:

- physical and emotional limitations,
- the recurring emergence of negative emotions (most notably impatience),
- difficulty in maintaining one's own sense of well-being,
- worrying too much,
- lacking a sufficient ability to socially interact with their parent, and
- negative feelings about being the primary caregiver.

Several participants also noted boundary-related issues as representing a weakness in their parent care. One participant noted her tendency to assume too much responsibility for her mother's well-being. Two other participants (2 female) mentioned their tendency to assume too much control over their parent. As an example, participant 5F responded:

“Sometimes I over-react a bit emotionally, and try and take control of her life instead of trying to help her control hers. I get angry sometimes over the issue of how much control she is willing to take.”

Three other participants noted the difficulty they had in separating their lives from caring for their parents and the resulting inability they experienced in sufficiently caring for themselves.

Finally, one female participant mentioned financial limitations as being a weakness in her ability to properly care for her mother. Two men in the study reported no identifiable weaknesses in their ability to carry-out the role of caregiver.

DEVELOPMENT

Activities. Fifty percent of the participants in the study (4 female, 4 male) noted that the number of tasks they perform in carrying for their parents had increased since they had first become their parent's caregiver. Additionally, 44% of participants (5 female, 2 male) noted that caring for their parent had become more difficult and/or demanding since they first adopted the role, while 19% of participants (3 female, 0 male) mentioned that providing care had become easier. For example, participant 12M described his mother's increasing sleep difficulties as resulting in a negative "shift in the focus of my schedule towards my mother and away from my work." In comparison, participant 1F notes:

"Shopping now is far more routine. [My mother] has kind of established her own little routine around my visits, and it's become easier."

Only one female participant noted no change in the activities she performed as caregiver for her elderly mother.

A number of participants offered additional ways in which their activities as caregivers had changed over time. Nineteen percent of participants (1 female, 2 male) described the ways in which their parents' care management had altered. Participant 1F expressed that "earlier [care] was more fragmented." Participant 11M mentioned that he was now "learning to prioritize" the many aspects of caring for his mother, and participant 15M noted that he was now providing "less direct contact and more management" in caring for his mother.

Although this question was concerned primarily with the activities involved in caring for their parents, several participants also mentioned a number of psychological

changes they had experienced. Participant 1F spoke of having established more limits for herself in caring for her mother:

“Earlier I felt I should be there all the time, and really felt bad that I wasn’t.”

Participant 4F described an increased acceptance of caring for her mother rather than changes in the nature or type of care she provided:

“It’s not that things have gotten better, rather I have become more accepting of her limitations.”

Relationship. In response to the question, “How have your feelings about your parents changed since you first became their caregiver?” participants’ responses fell into two categories: issues related to changing roles and issues related to changes in affect. Only participant 14M was unable to identify any changes in his relationship with his mother since he became her primary caregiver.

Nineteen percent of the participants (3 female, 0 male) noted that a reversal of roles had taken place in which they had effectively become the ‘parent’ in the relationship, with their aging parent akin to a dependent child. This circumstance was often described with a high degree of discomfort. Participant 9F stated:

“The roles are reversed. She thinks of me as her mother... She’s quite confused right now and she’s totally dependent upon me. I feel kind of sad because I wish I had *my* mother back.”

Two female participants spoke of the transition of their parents from “mother” to “individual.” This is exemplified by participant 1F’s statement:

“I see her as a separate person now. She’s not my mother, she’s this delightful woman in her eighties that’s doing really well. And I no longer feel the same... I’m more objective about the relationship.”

Similarly, participant 3F mentioned:

"I have a much better sense of who she is, what she values, and what her fears are. I think the nature of the relationship has changed. If nothing else it has knocked a few corners off of us."

With respect to changes in affect, the most prevalent response, noted by 38% of the participants (2 female, 4 male), was a perceived increase in the closeness of their parent-child relationship. Participant 5F states:

"I feel very close to her now. We're best friends in many ways."

In contrast, five participants (4 female, 1 male) noted an increase in negative affect in their relationship with their parent. These individuals described their relationship with their parent as negatively affected by feelings of frustration, fatigue, overwhelming involvement, resentment, impatience, and a sense of being trapped in the relationship. As participant 2F states:

"You feel real despair sometimes. [When] all of a sudden my mother needs me, I have to drop everything else... and run up to her place to do whatever it is that has to be done. I think the other thing is that it's constantly in the back of my mind."

EXPECTATIONS

Expectations About How to be a Caregiver. Responses to the questions "Were there clear expectations for how to be a caregiver?" and "How did you know what to do?" generally fell into three categories: participants whose expectations and behaviour evolved over time and circumstances, participants who were unable to identify from where they had drawn guidance, and participants who identified past personal and/or professional experiences as a source of direction in caring for their parents.

Seventy-five percent of the participants (7 female, 5 male) described a variety of approaches to caring for their parents that evolved from the beginning of their efforts. For example, participant 2F spoke of:

“...never having any hesitation... but I didn’t really know what to do. It’s called ‘learning on the job.’”

Participant 3F commented on working through “a negotiated process” with her mother in establishing how to best provide care, and participant 10F in her response echoed a common sentiment:

“Basically I tied my own needs to taking care of hers... It’s like a child. You become observant, watching closely and looking for cues to how she’s doing.”

Thirty-eight percent of the participants (4 female, 2 male) were unable to identify how they came to care for their parents. For these individuals an especially strong sense of unpreparedness was associated with their initial adoption of the caregiver role. Participant 4F mentioned this by stating:

“I really didn’t know what I was getting into. I had no idea. I just bumbled around initially.”

A number of participants also identified past experiences as having been a significant aspect of how they came to act as caregiver for their parents. Participant 13M identified having learned a great deal of practical skills from his mother as he grew up, and having lived independently for many years as being important factors in deciding how he would care for his aging mother. Participant 5F noted her experiences in watching her mother caring for her grandparents as having influenced her own approach to caring for her mother. And participant 6F and 8F noted their work history in the health care field as having been instrumental in their approach to providing care to their parents.

Caregiver Expectations. Asked simply, “Do you feel you are living up to your own expectations as a caregiver?” 44% of participants (5 female, 2 male) answered in the affirmative. Another 38% of the participants (3 female, 3 male), answered “yes,” but expressed that they could be doing more and/or better in caring for their parents. Two participants (1 female, 1 male) also answered “yes,” but qualified their answers by saying that previously they did not feel they were meeting their own expectations in caring for their parents. And participant 10F stated that she was failing to meet her own expectations because she felt she was not giving her mother enough attention. This participant felt strongly that she should be communicating more with her mother, but describes engaging her mother in conversation as increasingly difficult because:

“Talking to mum is really not that enjoyable - it’s quite an ordeal. You’re doing all the talking and not really getting any input.”

Care Recipient Expectations. In response to the question: “Do you feel you are meeting your parent’s expectations as their caregiver?,” 63% of participants (6 female, 4 male) responded “yes.” However, two participants (1 female, 1 male) expressed the fact that earlier this had not been the situation. As participant 1F responded:

“I think I am now. I think for a long time I disappointed her, but over time she has branched-out and [developed] some good friendships with others.”

Two other participants (1 female, 1 male) noted that although they felt they were currently meeting their parent’s expectations, this may not be the case in the future. Both these participants expressed concern about the impact that facility placement might have on their parent’s perception of how well their children were caring for them. Finally, participants

2F and 4F stated that they were not meeting their parent's expectations for care.

Participant 2F stated:

"I think she would like to have me spending more time [with her]. She would be pleased if she didn't have home makers and it was me instead."

Participant 4F responded:

"No, I don't fulfill her expectations. She feels that whatever it is, I'm not doing enough of something - otherwise she would be walking. She's holding me responsible."

EVALUATION

Most Important Aspect of Care. In response to the question, "What do you see as the most important thing(s) you do as a caregiver for your parent and why?" two interwoven themes emerged: compensation and protection.

The themes of compensation and protection consisted of participants providing care and assistance to counteract the limitations experienced by their parents, as well as their efforts to protect what their parents value most about their lives. Thirty-one percent of participants (4 female, 1 male) mentioned providing a sense of connectedness with others and the "outside world" as being among the most important things they did in caring for their parents. An additional 31% of participants (2 female, 3 male) identified their efforts in preventing their parents from having to enter a facility as the most important aspect of their caring for their parents. Participant 13M described this as:

"It's just doing what I'm doing, being there for her in her hour of need so to speak. I couldn't see her in a facility - I wouldn't wish that upon her."

Other important aspects of providing care included providing emotional support, a sense of security, a sense of purpose and financial protection.

Rewards. When asked to identify any pleasurable or rewarding aspect of providing care for their parents, only participant 14M was unable to identify any positive aspect of providing care. Thirty-eight percent of participants (4 female, 2 male) noted how they took great pleasure in their parent's happiness. For example, participant 9F responded:

"Yes, I do. Just seeing that she's happy and when she laughs. That makes me feel good... Making something that she really likes or getting something that she's really happy about."

Thirty-one percent of participants (4 female, 1 male) mentioned how much they positively enjoyed their parent's company and companionship. Nineteen percent of participants (1 female, 2 male) noted the rewarding aspect of keeping their parents out of an institutional setting. Two female participants made mention of the satisfaction they received in reciprocating the care their parent had previously bestowed upon them. And 19% of participants (1 female, 2 male) mentioned that they derived a strong sense of satisfaction from simply doing what they perceived as necessary and doing it well. For example, participant 15M attributes his satisfaction in caring for his elderly mother to "doing what I think is the right thing to do."

Difficulties. A variety of responses emerged in response to the question, "Are there any problematic or upsetting aspects of providing care to your parents?" Forty-four percent of participants (5 female, 2 male) identified the loss of personal freedom as being the most difficult aspect of caring for their parents. For example, participant 2F mentioned:

"There are a lot of problems... having to do with all of this intrusion on my own life, and the limitations and frustrations I've had to accept as part of caring for my mother."

Thirty-one percent of participants (3 female, 2 male) noted their frustration at the overwhelming, multiple responsibilities they dealt with as the most problematic aspect of caregiving. Thirty-one percent of participant (5 female, 0 male) also cited their own worrying (i.e., about their parent's future, providing sufficient care, possible emergencies) as the most upsetting aspect of caring for their parents. Other problematic aspects of caregiving identified by individual participants included personal financial loss (due to inability to work and make pension contributions), witnessing declines in parent's health and well-being, difficulty in negotiating family conflicts (e.g., between mother and husband), and the redundancy of routine tasks.

Meaning of Caregiving. Although most participants found it difficult to answer this question, a number of interesting themes emerged. Forty-four percent of participants (5 female, 2 male) mentioned both the difficulty and the personal sacrifices involved in adopting the role of primary caregiver for their parents. Participant 8F stated:

"It's one of the hardest things to do."

Participant 16M stated:

"I feel that by being a caregiver you have to give a part of your life away. I don't know if you want to say 'throw it away,' but you have to give it and that part of your life is gone."

Another strong theme to emerge was one of commitment in conjunction with a strong sense of interconnectedness between caregiver and care recipient. Participant 10F responded:

"I could do things for mom... I could not do for a stranger."

Participant 4F described her role as caregiver for her mother by saying:

“In a way I’m living the life of [someone who has suffered a stroke].”

Participant 12M described his performance in the caregiver role by saying:

“I guess it has a lot to do with being given a challenge... The satisfying thing is that I’m meeting the challenge and giving her a good life, at least as long as she’s able to receive that good life. Looking back over my life, it’s one of the primary things I’m proud of doing.”

Twenty-five percent of participants (4 female, 0 male) also noted the importance of the emotional dimension of caregiving, above and beyond the instrumental aspects of caring for their parents. As participant 5F stated:

“I am her caregiver and she has been a caregiver for me. I guess it’s supporting someone in whatever they need, which is emotional as much as anything else.”

The process of acting as manager for their parents’ lives was mentioned by nineteen percent of the participants (2 female, 1 male). Participant 11M said:

“All aspects of [my mother’s] being, the legal, the medical, the physical, they’re my responsibility now, to make sure that all areas are being addressed.”

Participant 2F spoke of the benefit in having increasingly accepted the situation and becoming “more objective about it and less emotional” in terms of managing her mother’s care.

Two participants (1 female, 1 male) mentioned their caregiving as primarily being concerned with preventing their parents from being placed in a facility. Participant 9F stated:

“[Mother] is dead-against facilities... now she can be around her family.”

Participant 14M said that he acts as his mother’s caregiver because:

“I don’t think it’s humane to send her into an institution. Because I too will feel that way when I’m seventy, and I don’t want to teach my children to do the same thing.”

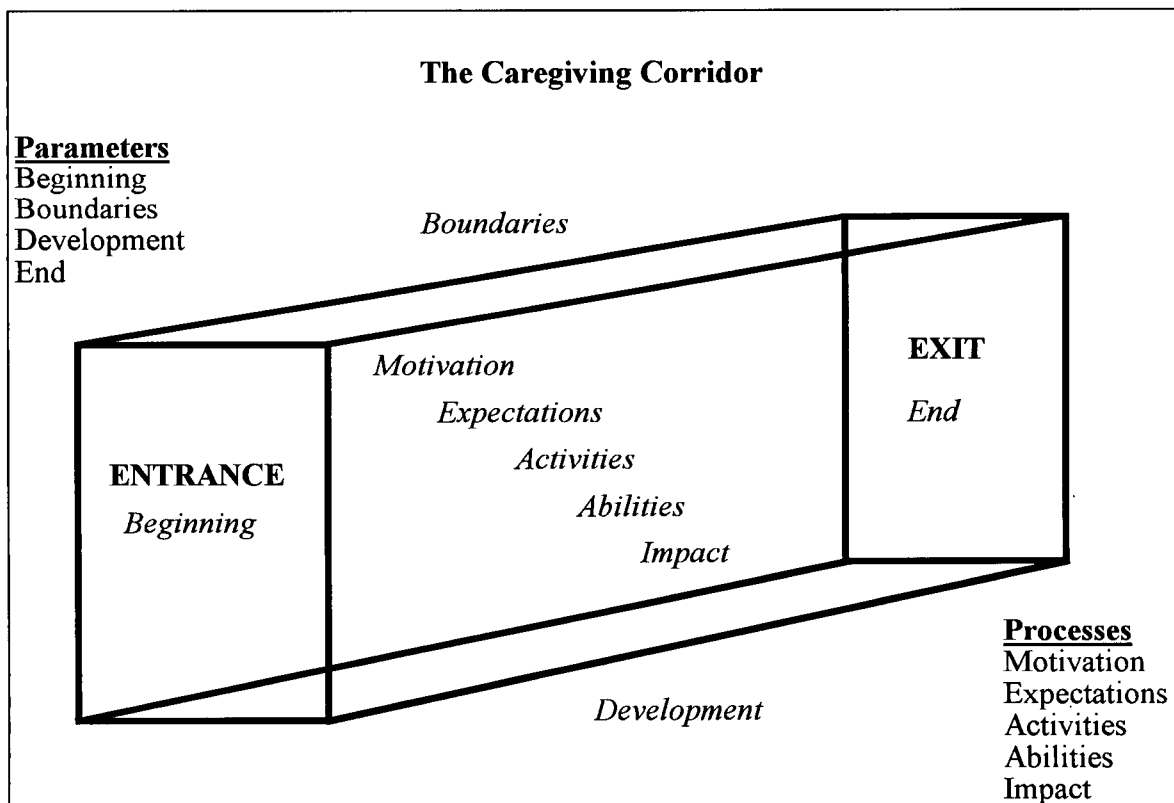
CAREGIVER BURDEN

The results of the 5-point, 11-item General Burden Inventory, were within expected values, ranging from 1.18 to 4.0, with a mean of 2.39 and standard deviation of .71. Of particular interest, and as predicted, the burden scores of female participants ($M=2.63$, $SD=.76$) were considerably higher than those of the male participants ($M=1.98$, $SD=.41$). However, a statistical test of these two means failed to reach significance, $t(14)=1.9$, $p=.078$.

CHAPTER SEVEN

DISCUSSION

The following section is a discussion of the most prevalent themes and noteworthy findings to emerge from this study. This section uses the Caregiving Corridor as a framework for reviewing and discussing the results of this investigation. (For the sake of convenience, Figure 3 is reproduced below as a visual reference of the Caregiving Corridor.) In addition, several topics of particular interest integrating both the literature review and the study's findings are presented. These topics include gender differences, caregiver burden and satisfaction, instrumental and emotional aspects of caregiving, developmental perspectives, and the conceptual meaning of caregiving.



PARAMETERS

Beginning. The most common occurrence which demarcated the entrance of participants into the role of caregiver and the Caregiving Corridor was a negative parental health event. In recounting when they had first become caregivers for their parents, most participants noted a sense of both suddenness and unpreparedness that accompanied the beginning of their role. And for others, entrance into the caregiver role took place within the context of an urgent and stressful circumstance, involving their parents' health and the difficulty participants reported experiencing in attempting to integrate this new role into their existing lifestyle. Both of these themes highlight the existence of a key period in which a program aimed at assisting caregivers might best be employed. Such a program might involve specific one-on-one counseling and/or a more general educational strategy designed to make available practical information and strategies for adapting to the demands of caregiving at a time when individuals are just beginning to provide regular care.

For the majority of subjects, the initial designation as primary caregiver of their parents resulted from a lack of available alternatives, often due to an inability or an unwillingness on the part of others to provide care. Although several participants identified aspects of their relationship history with their parents (for example, explicit parental expectations for care, a strong sense of closeness), none of the participants indicated a desire to begin providing routine care for their parents in the presence of viable alternatives. For many participants, it appears that their adoption of the caregiver role was understood as the best alternative in an undesirable situation. However, these findings

counter the contemporary belief that the elderly are commonly abandoned (Connidis, 1989; Horowitz, 1985). It would be interesting in future research to explore in more detail what family dynamics are involved in the selection process of primary caregivers. There may be important links between how individuals become caregivers and the ways in which they subsequently provide care and are impacted in their journey through the Caregiving Corridor.

Boundaries. The boundaries participants identified as encompassing their caregiver role generally fell into two categories. The first related to participants' desire to limit the level of personal sacrifices they would endure in caring for their parents. Although most participants expressed a strong willingness and commitment to continue providing a high level of care for their parents, they also expressed the need to set some restrictions on their involvement in order to ensure their own sense of well-being. Further research on the kinds of programs (e.g., respite, counseling, educational) which might best assist caregivers achieve a successful balance between their own and their care recipient's needs seems warranted.

The second category of boundaries concerned an effort on the part of several participants to limit interference with their parent's sense of independence and control. Although several participants mentioned the relative ease of addressing their parents' needs using their own judgment alone, many had come to recognize the importance of allowing their parents as much input in decisions and tasks as they were able and willing to make. This is consistent with the findings of one study that described successful caregiving relationships as characterized by an "exchange relationship" versus a one-way flow of

assistance (Gouldner, 1967). As has already been mentioned in the literature (Barer & Johnson, 1990), a greater inclusion of the experiences and perceptions of care recipients seems imperative to gaining a better understanding of the dynamics involved in caregiving relationships.

Development. Although the range in duration of caregiving in this study did not significantly differentiate participants' experiences, there is good reason to include developmental aspect as an important parameter in the Caregiving Corridor framework. This is based primarily on this study's recognition of the changing nature of caregiving over time. It seems likely that individuals who have recently become caregivers (and who may be in an initial "transition stage") will differ notably from individuals who have been providing care for several years (and thus, may have developed extensive and integrated caregiving routines). It remains to be seen whether distinct "stages" of caregiving may emerge as a relevant conceptual approach to understanding caregiving. Further stage specific cross-sectional and especially longitudinal research on caregiving may identify important ways in which caregiving experiences both change and remain consistent over time and in relation to specific experiences and/or caregiving circumstances.

End. Eighty-one percent of participants in this study responded that their role as their parent's caregiver would end when their parent died. The immediacy and bitter-sweet nature of the responses to this question testify to the commitment of the caregivers in this study, as well as the significance and magnitude of the caregiver role in the lives of these individuals. Few other roles or positions are so bordered by such profound limits as life and death. However, it is important to note that these findings were based on caregiver's

expectations about when their role would end rather than based on first hand experiences. Further research is needed in order to explore when caregivers actually identified their role as caregiver as having reached some form of identifiable conclusion.

PROCESSES

Motivation. The finding that a strong sense of duty motivates the participants in this study to care for their aging family members is similar to the results of another study which explored this issue from an exclusively female perspective (Guberman, Maheu & Maille, 1992). Participants in this study tended to describe their beliefs as being a natural part of their familial, and more specifically, their parent-child relationship. It is interesting to note that while participants believed that caregiving was a natural part of their relationship, many did not naturally know what to do for their parents, particularly when they first began providing care. Similarly, while a significant number of participants reported affection as being a significant part of their motivation to care for their parents, almost a third of participants also noted a lack of available alternatives as being a major motivating factor. Implicit in many participants' responses was an abhorrence of abandoning their parents (particularly if this involved institutionalizing them), regardless of the inherent difficulties they have experienced in providing care. This finding further highlights the high degree of complexity involved in many individuals' caregiving experiences.

Expectations. The questions looking directly at expectations in this investigation served to illuminate two themes which are evident in other portions of the study's findings. The first pertains to participants' responses which indicate that they did not have

clear expectations for how to be a caregiver when they first adopted the role. Instead they describe themselves as having developed their role as caregiver over the course of time and various experiences. This highlights the idea mentioned earlier in relation to the beginning of caregiving that the caregiver role is not closely tied with well-defined and widely held notions of what it means to be a caregiver and what specifics are involved in carrying-out the role. However, with increasing numbers of elderly in the population and with the increasing move by governments to off-load health care responsibilities to communities (Rosenthal, 1994), this absence of knowledge about the caregiver role may soon be changing. It will be interesting to see whether a greater social recognition and understanding of caregiving comes about as a result of collective individual experiences, government or community education, the media, or some other social force.

The second aspect of expectations investigated in this study involved participants evaluating whether or not they were meeting both their own and their parents' expectations regarding the care being provided. Although the majority of participants felt they were meeting both sets of expectations, of additional importance, several participants mentioned that earlier this had not been the case or that they might not be able to meet their parents' expectations in the future. These types of responses emphasize the fluid and changing nature of caregiving over time, a theme which is evident in other aspects of this investigation (e.g., in relation to activities performed, the establishment of boundaries, relationship changes), but have yet to be explored in-depth in the caregiving literature.

Activities. It is interesting to note the wide variety of responses that emerged from the questions about what activities participants routinely performed, with individual

responses seemingly based on specific parental needs (e.g., transportation) and participants' individual resources (e.g., professional experience and training), rather than on preconceptions about what caregivers generally should do in providing care. That is, in describing what tasks they performed in the course of caring for their parents, participants did not refer to general expectations about what 'caregivers' should do, but rather what their particular parents' needs were and their own individual resources. This trend in the subjects' responses may reflect a larger trend in general society, characterized by a lack of general discussion of the nature of the caregiving role. It is not surprising that many of the participants reported tremendous difficulty in initially adapting to their role as caregiver given the general lack of awareness of the caregiving role that this author has noted in our society.

A number of interesting points emerged from the caregiving tasks checklist. The first of these was the predominance of emotional care/advice and decision making in relation to the other tasks included on the list. All sixteen participants identified these two categories of tasks (the only two categories identified by all participants) as being provided on a regular, routine basis. What is of particular interest is the disproportionate focus the existing caregiving literature has allocated to instrumental caregiving tasks (i.e., shopping, housework, etc.); the results of this study seem to indicate that it may be beneficial to further study non-instrumental aspects of care provision. This point is further supported by the finding that the single most energy-consuming task participants identified was providing emotional support to their parents. Perhaps this is not surprising given that emotional care and advice and decision making are not clearly time-delineated tasks (for

example, several participants mentioned that even when not engaged in specific tasks they tended to worry about the care recipient).

In terms of possible gender differences, female and male participants did not significantly differ in either the number (see Chapter 6, Table 1) or nature (see Chapter 6, Figure 4) of tasks identified. If anything, male participants reported performing slightly more routine tasks than did female participants (although this difference was not significant). Again, this finding is contrary to expectations based on the results of previous research which indicated that men performed fewer tasks overall and that those tasks they did take on tended to be managerial rather than hands-on (Stoller, 1990). This anomaly may be due in part to this study's exclusive inclusion of primary caregivers, those individuals providing the majority of informal/unpaid care to their respective care recipients. It may be the case that previous research has included male caregivers who would not identify themselves as primary caregivers and/or who provided relatively lower levels of care.

Interestingly, few participants identified specific tasks, such as those from the tasks checklist when they discussed what was the most important thing they did in caring for their parents. Instead, participants tended to frame their responses in terms of broader goals. Keeping their parents connected with the outside world and preventing their parents from placement in a facility emerged as the two most important goals participants reported. Inherent in these responses was a strong sense of psychological and emotional connectedness between participants and their parents: the intent and activities of the caregivers seemed to be based on their perceptions of their parents' remaining aspirations

in life. Here again, participant's approach to caregiving is not based on a socially prescribed set of activities carried out by caregivers in general, but by a strong and relatively unique relationship with their parents. This kind of perspective on caregiving adds increased incentive to further explore care recipients perspectives and experiences in relation to caregiving, and the relationship between caregivers and care recipients and the history of their relationship dynamics.

Participants noted that both the number and the nature of tasks they performed in their caregiver role changed with time. Several participants noted that the tasks they performed had become more difficult over time as their parents' abilities had been further compromised. They also noted that the way they managed and prioritized their care provision changed, with their gradually adopting a more routine and structured approach to care provision. All of these responses are evidence of the dynamic, fluid nature of caregiving, one to which individuals adapt and re-adapt, both physically (i.e., with respect to tasks performed), and psychologically, over the course of the caregiver role. Unfortunately, much of this dynamic nature of caregiving has been missed in the previous research on caregiving. This kind of finding forces a re-examination of the extent and appropriateness of using caregiving tasks checklists which tend to capture current behaviours, experiences and demands at one time only.

Abilities. Asked to identify their perceived strengths in being their parents' caregiver, several participants identified good management skills in addition to their personal circumstances and willingness to provide care as representative of their greatest strengths in caring for their parents. Such responses are strikingly similar to the responses

many participants gave in describing how they came to be their parents' primary caregiver, and this again highlights the idea that many individuals become caregivers and continue to provide care out of circumstance as much as out of a strong personal desire to assume the role. If circumstance rather than personal disposition dictates much of who becomes a caregiver and how they carry out their role, this may have important implications for programs designed to educate and assist caregivers. For example, counselors and educators may need to focus more on how an individual becomes a caregiver and conceptualizes the role in addition to what he or she does in providing care.

It appears as though the amount and type of care provided must also be carefully considered within the context of the relationship between caregiver and care recipient. One weakness mentioned by several participants concerned issues of control in their relationship with their parent, and more specifically, their tendency to assume too much control over their parents during the course of providing care. These types of descriptions fit well within the 'boundary' aspect of the Caregiving Corridor. Issues of control are one aspect of those boundaries participants identified as important guidelines within which they provided care for their parents. Previous approaches to caregiving research have tended to adopt a 'snap-shot' view of caregiving, one which fails to capture the ongoing process of mediation and negotiated compromise between caregiver and care recipient. It remains for future research to investigate the ways in which caregivers and care recipients carry out these kind of negotiations and the impact different strategies may have on both.

While thirteen participants indicated they were meeting their own expectations for providing care, a number of these individuals expressed that they could also be doing more

for their parents. This sense of not doing enough care is akin to Brody's (1985) concept of "irredeemable obligation" in which adult children feel as though their efforts, although substantial, are inadequate in comparison to the level of care they have received from, and in a sense, are indebted to their parents. Ten participants responded that they were meeting their own parents' expectations for care. However, several participants noted that either they were not previously meeting their parents' expectations or might not meet their parents' expectations in the future (particularly in relation to issues such facility placement). These responses demonstrate participants' sensitivity to the developmental nature of caring for their parents and the potential for change in the nature of their caregiving experiences over time. It's clear that there is much to be learned from future studies of caregiving that focus on the nature and role of change over the course of caregiving.

Impact. Several participants described these relationship changes in terms of a reversal of roles, with participants characterizing themselves as the new parents in the relationship and their parents as dependent children. Such a reversal of roles made many of the caregivers extremely uncomfortable. They did not feel this was an appropriate or desirable type of relationship for them to have with their parents and several appeared to grieve over the loss of their former relationship. Although parent-infant role relationships may have similarities with the caregiver role, there are clearly limits to the similarities, such as greater unpredictability, the presence of an extensive relationship history and an increasing dependency on the part of the care recipient. Other participants spoke of a relationship change which served to replace parent-child roles with a less role-prescribed

sense of one another. Recognition of these kinds of relationship changes may form the basis of more effective educational and counseling programs designed to assist caregivers. Additionally, the impact of caregiving was described by six participants as having resulted in a greater sense of closeness and positive affect between themselves and their parents, a trend which has been missed by previous research on caregiving.

Asked if they could identify any positive or rewarding aspects of caring for their parents, most participants identified either their pleasure in being a part of their parents' happiness or their enjoyment of their parents' company and companionship. Such responses further support the recognition of a high degree of connectedness between these individuals and their parents. In many respects, it is as though participants and their parents are living vicariously through each other's lives. Three participants also mentioned that keeping their parents out of an institution was the most rewarding aspect of providing care, an issue which was quite salient for a number of participants in the study. The theme of avoiding institutional placement was evident in a number of sections of this investigation, including participants' motivation to provide care and their identification of the most rewarding aspect of providing care. This finding might offer some explanation for the documented low numbers of elderly in Canada living in institutions (Statistics Canada, 1990). It remains to be investigated just what it is about facility placement that is so abhorrent to many caregivers, and whether the resistance to facility placement come more so from caregivers themselves or the recipients of their care.

Caregiver burden, as measured by the General Burden Inventory, revealed a level of difficulty in providing care consistent with previous studies employing this construct

(Choi, 1993; Gwyther & George, 1986; Zarit, Reever, & Peterson, 1980). Of particular interest, a previously identified trend in which women report higher burden scores than men was also partially supported in this study. It is curious to note that while the majority of findings from this study indicate that male and female caregivers perform and experience their role as caregiver in strikingly similar ways, the widely used measure of caregiver burden employed in this study indicated that men and women differed (although not statistically - which is perhaps not surprising given the limited number of participants and the consequent conservative test of the hypothesis) with regards to their reports of burden. In assessing difficulties caregivers experienced from an open-ended approach, the most prevalent themes to emerge from both female and male participants related to a loss of personal freedom, frustration at the inherent difficulties in orchestrating all of the various tasks in their parents' and their own lives, and a continual sense of both conscious and unconscious worrying that was associated with caregiving. These findings provide more potential target issues which can be addressed by those professionals involved in educating and assisting familial caregivers.

Issues of Interest

Gender Differences

Very few differences were observed between women's and men's responses during the course of the interviews. This is not to say that no attention was given to the possibility of differences in the ways female and male participants responded (for example,

with regards to the language participant's used and the issues they raised in responding to specific questions).

The results of one scale that did suggest a difference between women and men, the General Burden Inventory, were predicted based on previous research utilizing the same or similar caregiver burden scales. While this difference was not significant, it was in the predicted direction and it is possible that significance could be reached with a larger sample. Yet there is still considerable question as to why women and men typically differ in these scales. This study found that female participants did not report providing more tasks or tasks differing in nature from those reported by men in the study, and this finding ran contrary to predictions based on previous research (Stoller, 1990) that indicated that women tended to provide more hands-on types of care, while men tend to provide more managerial types of assistance. And in fact, men reported providing slightly more tasks, and identified a relatively lower number of other caregivers providing regular assistance to the care recipient. Overall, both women and men in the study tended to provide whatever types of assistance were deemed necessary, an approach previously identified by Cantor (1980). With respect to the open-ended question about what participants felt was the most difficult about providing care, the responses of women and men in the study were very similar.

The explanation for women's higher burden scores in the literature is still open to question. The present study suggests the possibility, prompted by observations taken from the participant interviews, that women are relatively more emotionally open and sensitive to the interpersonal aspect of their relationship with their parents. In contrast, men seemed

more emotionally guarded in discussing the negative impact of caring for their parents, possibly out of a concern that extolling upon the difficulty they experience may appear as a personal weaknesses. This explanation may be supported by the fact that one-third of men in the study did not report any weakness in their ability to provide care, while all of the female participants identified at least one weakness. In addition, although both women and men listed emotional care as both the most energy-consuming and one of the most important aspects of care they provide, men may have adopted a greater emotional distance in their relationship with their parents and, in the process, reduced the extent to which they are impacted by the prevalent, emotionally intense aspects of caregiving. An alternative explanation is that the General Burden Inventory and similar Likert-type burden scales may be somehow biased, either in the subject of the questions or the means in which they are employed, so that women generally score higher than men. Such an explanation is supported by the finding that the responses to the open-ended question about caregiving difficulties were extremely similar for the women and men in this study.

Of more relevance to this discussion of gender in caregiving was the finding that, overall, differences between male and female subjects were minimal. For the most part, daughters and sons approach, perform and are impacted by caregiving in markedly similar ways. In part, this may be due to the relatively high level of mental, physical and emotional involvement common to the *primary* caregiver role. This may be evidence of a “ceiling effect,” in which at the upper levels of care provision women and men do not differ. It may be the case that previous caregiving studies have used selection processes which resulted in the inclusion of sons (and perhaps male caregivers in general) who do not

provide the same high level of care as demonstrated by the primary caregivers selected to take part in this study. While men and women may bring somewhat different experiences and viewpoints into caregiving, such differences may be lost in the complex, dynamic and frequently overwhelming process of caregiving. The customized approach often necessitated by a particular caregiver's abilities and parent's circumstances in conjunction with the lack of a clear definition or stereotype of caregiving may result in the caregiver role acquiring greater salience than other existing roles such as gender.

Caregiver Burden and Satisfaction

The results of this study support previous research (George, 1994) in that, to a large extent, negative feelings of burden were a common consequence of being a caregiver. The overwhelming and unpredictable nature of providing care for their aging parents tended to result in extended periods of high stress for many participants. The fact that five participants noted their tendency to worry about their parents as a central difficulty emphasizes the continual personal involvement, beyond just instrumental aspects of care provision, inherent in caregiving for many individuals. In participants' descriptions of the meaning of caregiving, the most common response involved the difficulties and personal sacrifices associated with being a caregiver, a finding which highlights the high personal cost of caregiving for many individuals and supports the development of initiatives designed to reduce the stress and strain commonly experienced by caregivers.

While research has repeatedly demonstrated the high level of difficulty experienced by many caregivers, it is important to balance the negative side of caregiving by exploring

the nature of identifiable, positive aspects of caregiving. This study found that caregivers generally derived great satisfaction from a variety of experiences while providing care, most notably, their parents' expressions of happiness and companionship. While understanding determinants of caregiver burden is important, a potentially beneficial description of what comprises "successful caregiving" may be revealed by further investigating what positive dimensions of caregiving exist. From an applied, therapeutic perspective, it may be equally important to reduce the negative aspects as it is to enhance the positive dimensions of caregiving. From a conceptual perspective, it is important to reinforce the idea that the negative and positive aspects of caregiving are not opposite poles of a single dimension, but are better conceptualized as orthogonal to each other.

Instrumental and Emotional Aspects of Caregiving

Although instrumental aspects of caregiving have received a great deal of attention in previous research, this study found that emotional care was the most prevalent activity caregivers performed. Additionally, emotional care was listed as the most important type of care participants provided, and was mentioned as an important dimension of the meaning of caregiving by several participants. The finding that the emotional dimension of caregiving is so salient suggests a re-focusing of attention towards understanding the process by which emotional care is given, received and evaluated. In many respects, the emotional aspect of caregiving represents the central essence of caregiving, the dimension on which caregivers described being the most strongly impacted. This study found that emotional care was closely linked to the strong sense of connectedness and integration

that existed in the relationships between participants and their parents. It remains to be explored what significant variations in the nature and/or level of emotional care may imply for the larger caregiving experience. For example, do female and male caregivers provide differing levels and/or types of emotional care, and what impact might this have on care recipient's perceived level of well-being?

Developmental Perspective

This results of this study strongly suggest that future caregiving research should pay more attention to the role time and experience plays in caregiving. Evidence of the dynamic, changing nature of caregiving emerged from several areas of this investigation. Participants often described their entrance into the caregiver role as a process involving a variety of novel (and often stressful) experiences and changing perceptions, rather than as a specific event. Similarly, participants spoke of the gradual establishment of boundaries around their role as caregiver, changes in the activities they performed over time, variations in the extent to which they felt they were meeting their own and their parent's expectations, and often dramatic changes in the nature of their relationship with their parents over the course of providing care. All of these examples of duration-associated changes in participants' caregiving experience endorse the relevance and importance of including temporal variations in future investigations of caregiving and within any theory development in the area. The structure of the Caregiving Corridor emphasizes the temporal nature of the caregiving experience by depicting it with a beginning, a series of processes encompassed by boundaries, and an end. Of course, it is possible that further

temporal stages and distinctions within the duration of the caregiving process may be identified. For example, the 'end' may be re-defined in recognition that emotional work and its aftermath may continue into bereavement.

The Conceptual Meaning of Caregiving and the Caregiving Corridor

As most participants in the study would attest to, establishing a clear and delimited conceptual description of caregiving is a difficult task. The broad or superordinate goal of this study was to explore the concept of caregiving from a number of dimensions. In assessing what contributions this study makes to further understanding the concept of caregiving, it is worthwhile to separate the concept of caregiving into operational and theoretical discussions.

A review of the caregiving literature found that the operational treatment of "caregiver" or "primary caregiver" varied considerably from one study to another and typically was only minimally or not at all described. The results of this study provide one possible explanation for this prevalent approach to operationalizing caregiving. There appears to be no firm set of objective tasks that designate an individual as a caregiver. Instead, individuals seem to construct themselves as caregivers based on their willingness and ability to provide care, the availability of alternatives, their relationship with their parents, their parents' unique needs and circumstances, and a dynamic approach to providing care that evolves and changes during the course of being a caregiver. In this circumstance, broad definitions regarding the nature and type of caregiving seem relatively unavoidable.

One advancement which seems feasible with respect to enhancing operational definitions in caregiving research, involves the greater specificity with which the label "primary caregiver" is employed. For example, this study found that primary caregivers recruited through a method consistent with much of the existing research provided a mean of 88.8% of the total, informal care received by their care-recipient. It seems plausible that either a similar percentage of care be provided in future studies, or that an agreed upon level of care will be associated with the use of the label "primary caregiver." The value of this kind of standardization lies in the potential for greater comparability between studies and the greater strength and relevance of findings.

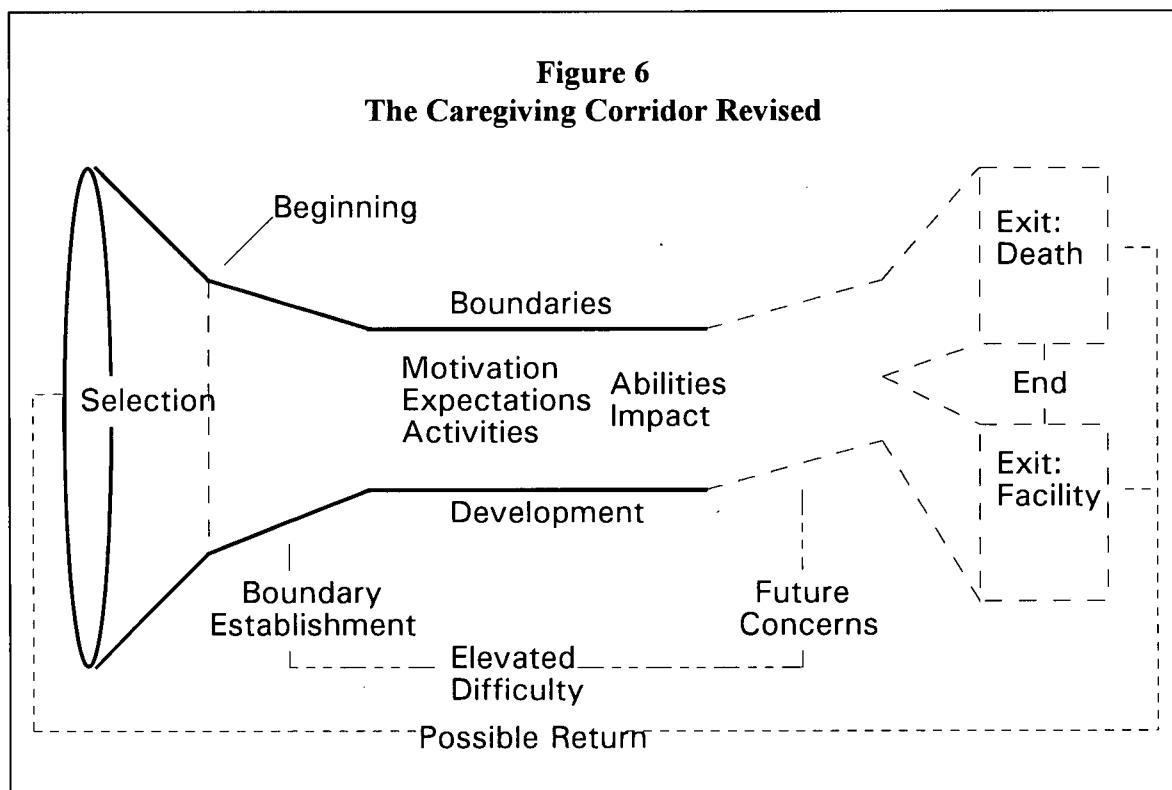
Another constructive advancement in operationally defining caregivers would involve a greater recognition and presentation of diversity among caregivers. This may involve a greater elaboration of caregiver types (for example, female and male, children and spouses), personal resources available to caregivers (for example, other individuals assisting with care), in addition to a possible description based on the development of stages of caregiving (for example, identifying what stage a given sample falls within).

The lack of theory in caregiving research also emerged as a pervasive theme from the review of the existing caregiving research. The establishment of a theory of caregiving is one of the most important challenges facing researchers in this field. Ideally, a theory of caregiving should serve two important functions: (1) integrate existing and future knowledge, and (2) provide guidance for future research. The development of the Caregiving Corridor may begin to address these two tasks without necessarily being considered a theory. Previous research may be positioned within the Caregiving Corridor

according to the parameters and process dimensions incorporated into the research. For example, a study exploring the ways in which adult daughters initially adapt to caregiving may be compared with similar studies looking at different stages of caregiving along the Caregiving Corridor. Alternatively, spousal and adult children caregivers of both sexes may be compared at any one point along the Caregiving Corridor, and along any one or combination of processes involved in caregiving (i.e., motivation, activities, impact). In this manner, previous research may be integrated and possibly re-interpreted according to the patterns and relationships that appear using the Caregiving Corridor as a guiding framework.

The Caregiving Corridor itself may be modified by new information collected.

Figure 6 below outlines one interpretation of the ways in which the Caregiving Corridor may be modified in response to some of the results of this study.



In Figure 6 above, the selection process which leads to the beginning of the caregiver role is depicted as a funnel. What is important to note is that the shape of the funnel differs for different individuals who subsequently become a primary caregiver. Results of this study indicated that some caregivers were able to clearly identify others who could have provided care (wide funnel), while others (e.g., only children) identified few if any others who could have provided care to the care recipient (narrow funnel). In almost all instances, however, participants in this study identified a selection period in which they instead of alternative individuals became the primary caregiver.

This study found that the beginning of caregiving is strongly associated with a sense of anxiety and unpreparedness, and this is depicted in Figure 6 as an incline intended to symbolize the period of relative, elevated difficulty reported by most participants in initially adapting to the caregiver role. In addition, Figure 6 depicted a narrowing of the boundaries associated with caregiving. This is in response to many participants' reporting that both the boundaries they set for themselves in terms of protecting their own well-being and the boundaries they established with their care recipients relating to maintaining some degree of parental self-control developed and improved over time. Several participants noted that these two aspects of boundaries were particularly troublesome during the initial adoption of the caregiver role. However, over time as both they and their care recipient directly and/or indirectly negotiated a more adaptive relationship and routine, these boundary issues became more clarified and correspondingly less difficult.

The results from this study also suggest that the exist transition from the Caregiving Corridor might best be depicted as 'up hill,' a difficult stage in caregiving

similar to the initial adoption process. The difficulties participants identified in relation to future concerns about caregiving related to a number of possible scenarios, including their ability to maintain their own well-being, increasing disability of the care recipient, and how their caregiver role would end, either with the death of their parent or with a highly undesirable institutional placement of an elderly parent. Of particular salience was the concern that several participants expressed about the possibility of having to place their parent in a facility, and the anticipated negative effect that would have on themselves, their parent and their joint relationship.

One additional revision evident in Figure 6 is not based on the results of this study, but does have particular implications for the Caregiving Corridor. For some individuals the Caregiving Corridor might be circular in nature, rather than linear. With the possible illness and dependency of an additional parent or elderly family members, some individuals might return and re-enter the Caregiving Corridor to experience the role as caregiver in markedly different ways. For example, an individual re-entering the Caregiving Corridor might experience less difficulty during the initial adaptation phase of the role, and in relation to establishing adaptive and effective boundaries.

In addition, The Caregiving Corridor, as initially conceived, is not exclusively tied to elder caregiving and could also be used to explore other types of caregiving relationships. For example, studies exploring parental caregiving may benefit from employing the Caregiving Corridor as both a framework to guide research as well as a means of organizing and interpreting findings. It remains to be seen whether future

research designs and findings serve to modify and strengthen the Caregiving Corridor, or vice versa.

The specification that an effective theory of caregiving should direct further research efforts may also be at least partially met by the Caregiving Corridor. For example, the concept of caregiving boundaries directs researchers to further explore the ways in which individuals establish psychological and physical limits and markers in defining their role as caregivers. Similarly, the dynamic nature of caregiving as represented by individuals moving through the Caregiving Corridor provides another aspect of caregiving deserving of future research attention and resources. For example, how do the parameters (e.g., boundaries, duration) and processes (e.g., abilities, impact) of caregiving change and interact with one another as one moves through the Caregiving Corridor? How do different individuals (i.e., women, men, spouses, adult children) experience and describe the Caregiving Corridor differently?

One possible limitation of the Caregiving Corridor stems from the idea that a truly effective theory and encompassing framework for the study of caregiving must necessarily incorporate caregiver and care recipient experiences and perceptions (see Barer & Johnson, 1990). Many dimensions of the Caregiving Corridor have already been shown to equally involve caregivers and the recipients of their care. For example, the beginning of caregiving, the establishment of boundaries, and the rewarding aspects of providing care all involve a high degree of connectedness between both caregiver and care recipient. There will be many challenges for those interested in developing a meaningful theory of caregiving and these will involve incorporating an expanding literature with an effective

conceptual framework capable of unifying a wide range of individuals, circumstances and experiences.

CHAPTER EIGHT

LIMITATIONS AND CONTRIBUTION

Limitations of the Study

One potential liability in this study involves the manner in which caregivers were selected for participation. Although the issue of definitional vagueness has been of central concern in reviewing the caregiving literature, paradoxically this study utilizes the same operational definitions of caregivers as the majority of studies on this topic. While this may be interpreted as a weakness of the study, it is argued to be a necessary step in achieving a greater understanding of the concept of caregiving. The rationale is that there is more to be gained by linking and relating the findings of this study to the majority of existing research on caregiving, regardless of definitional vagueness. In exploring the variations (e.g., by gender) in caregiver's experiences, it is useful to be able to tie this back to existing studies in the field.

The small size of the sample included in this study represents another limitation of this investigation. As a result of the relatively small number of participants, statistical analysis of numerical data (i.e., General Burden Index) was dramatically limited. Similarly, the results of qualitative analyses performed need to be considered within the context of the overall, small size of the sample, in addition to the relatively smaller number of male participants who took part. However, since several measures yielded results consistent with previous findings and the method of participant recruitment was similar to many

other caregiving studies, it is believed that this study is can be considered to be fairly representative of caregivers studied in the majority of existing research.

Another of the limitations of this study is the lack of incorporation of the care recipient's perspective. Ideally, it would be desirable to gather information from pairs of caregivers/care recipients on many, if not all, of the measures utilized in this study. In this way it would be possible to ascertain the extent to which these two sides perceive the nature and functioning of their relationship. It would be interesting, for example, to investigate the satisfaction level of care recipients in connection with the obligation and burden levels of caregivers. However, although this limitation has been previously identified as a problematic issue in the area (Barer and Johnson, 1990) and not subsequently addressed in any significant manner, structural and resource limitations in this study prohibited an inclusion of care recipients' perceptions and experiences.

Contribution to the Field

The primary contribution of this study was to elucidate and gain a greater understanding of the concept and experience of 'caregiving' and 'caregivers' based on participants' descriptions of their feelings, thoughts, opinions and experiences in relation to caregiving. As has been noted repeatedly above, previous operational definitions and a lack of theoretical development regarding core concepts in caregiving have lead to serious concerns about the validity and comparability of much of the research in this area. This study aspired to establish some of the central parameters around the phenomena of caregiving, (for example, when and how it begins, what is involved psychologically and

instrumentally), and the ways in which these may vary as a function of the prevalent types of caregivers (females and males, the experiences of adult children).

In addition to exploring new aspects and perspectives on caregiving, this study may have important implications for future studies in the area. For example, from an operation perspective, a better understanding of the concept of 'primary caregiver' has emerged in terms of percentage of overall care provided and number of others providing care. Additionally, the salience of the fluid nature of caregiving has been highlighted by this investigation. There is reason to argue that future caregiving studies should more carefully outline not only who they are studying, but also the stage at which individuals are providing care.

From a conceptual and theoretical perspective, this study serves to better illuminate both the concept of caregiving and the range of experiences individuals have in performing the role of caregiver. Both the Caregiving Corridor and one possible stage model of caregiving (outlined in Figure 6) also provide potentially important means of conceptualizing and integrating existing findings and guiding further research and development in this area. The concept of caregiving is undoubtedly complex, and has only begun to be illuminated by this study. However, using structured interviews, a qualitative approach to analysis and focusing on some fundamental dimensions of caregiving, this study has made an important contribution to further understanding the concept and experience of familial caregiving of the elderly.

REFERENCES

- Adams, B. N. (1969). The middle-class adult and his widowed or still-married mother. *Social Problems*, 16, 50-69.
- Argyle, M., & Furnham, A. (1983). Sources of satisfaction and conflict in long-term relationships. *Journal of Marriage and the Family*, 45, 481-493.
- Barer, B. M., & Johnson, C. L. (1990). A critique of the caregiving literature. *The Gerontologist*, 30, 26-29.
- Barusch, A. S., & Spaid, W. M. (1989). Gender differences in caregiving: Why do wives report greater burden? *The Gerontologist*, 29, 667-676.
- Barush, G., & Barnett, R. C. (1983). Adult daughters' relationships with their mothers. *Journal of Marriage and the Family*, 45, 601-607.
- Bengtson, V. L., Olander, E. B., & Haddad, A. A. (1976). A model of the variables that influence solidarity between the older and middle generations. In D. J. Mangen and W. Peterson (Eds.), *Research Instruments in Social Gerontology*. Minneapolis: University of Minnesota Press.
- Berman, H. J. (1987). Adult children and their parents: Irredeemable obligation and irreplaceable loss. *Journal of Gerontological Social Work*, 10, 21-34.
- Billings, A. G., & Moos, R. H. (1981). The role of coping responses and social resources in attenuating the stress of life events. *Journal of Behavioral Medicine*, 4, 139-157.
- Billings, A. G., & Moos, R. H. (1984). Coping, stress and social resources among adults with unipolar depression. *Journal of Personality and Social Psychology*, 46, 877-891.
- Black, M. (1985). Health and social supports of older adults in the community. *Canadian Journal on Aging*, 4, 213-226.
- Blau, Z. (1961). Structural constraints on friendships in old age. *American Sociological Review*, 26, 429-439.
- Blaxter, M. (1976). *The meaning of disability*. London: Heinemann.
- Brody, E. M. (1985). Parental care as a normative family stress. *The Gerontologist*, 25, 19-29.

- Brody, E. M., Litvin, S. J., Hoffman, C. & Kleban, M. H. (1992). Differential effects of daughters' marital status on their parental care experiences. *The Gerontologist*, 32, 58-67.
- Burr, W. R., Leigh, G. K., Day, R. D. & Constantine, J. (1979). Symbolic interaction and the family. In W. R. Burr, R. Hill, F. I. Nye and I. L. Reiss (Eds.), *Contemporary Theories About the Family*. New York: The Free Press.
- Cantor, M. (1980). The informal support system: It's relevance in the lives of the elderly. In E. Borgatta & N. McCloskey (Eds.), *Aging and Society*. Beverly Hills: Sage Publications.
- Cantor, M. (1983). Strain among caregivers: A study of experience in the U.S. *The Gerontologist*, 23, 597-604.
- Chadorow, N. (1978). *The reproduction of mothering*. Berkley: University of California Press.
- Choi, H. (1993). Cultural and noncultural factors as determinants of caregiver burden for the impaired elderly in South Korea. *The Gerontologist*, 33, 8-15.
- Cicirelli, V. G. (1983). A comparison of helping behaviour to elderly parents of adult children with intact and disruptive marriages. *The Gerontologist*, 23, 619-625.
- Cicirelli, V. G. (1991). *Family caregiving: Autonomous and paternalistic decision making*. Newbury Park, CA: Sage.
- Cicirelli, V. G. (1993). Attachment and obligation as daughters' motives for caregiving behaviour and subsequent effect on subjective burden. *Psychology and Aging*, 8, 144-155.
- Cohen, C. A., Gold, D. P., Shulman, K. I., & Zuccherro, C. A. (1994). Positive aspects in caregiving: An overlooked variable in research. *Canadian Journal on Aging*, 13, 378-391.
- Collins, C., Stommel, M., King, S., & Given, C. W. (1991). Assessment of the attitudes of family caregivers toward community services. *The Gerontologist*, 31, 756-761.
- Connidis, V. G. (1989). *Family Ties and Aging*. Vancouver: Butterworths Canada.
- Dowd, J. J. (1980). *Stratification among the aged*. Monterey, CA: Brooks/Cole.
- Duncan, M. T. & Morgan, D. L. (1994). Sharing the Caring: Family caregivers' views of their relationships with Nursing Home Staff. *The Gerontologist*, 34, 235-244.

- Evandrou, M., Arber, S., Dales, A., & Gilbert, G. N. (1986). Who cares for the elderly? Family care provision and receipt of statutory services. In C. Phillipson, M. Bernanrd, & P. Straug, (Eds.), *Dependency and interdependence in old age: Theoretical perspectives and policy alternatives*. London: British Society of Gerontology.
- Farran, C. J., Keane-Hagerty, E., Salloway, S., Kupferer, s., & Wilken, C. S. (1991). *The Gerontologist*, 31, 483-489.
- Finch, J., & Groves, D. (1980). Community care and the family: A case for equal opportunities? *Journal of Social Policy*, 9, 487-514.
- Fitting, M., & Rabins, P. (1985). Men and women: Do they give care differently? *Generations*, Fall, 23-26.
- Folkman, S., & Lazurus, R. S. (1980). An analysis of coping in a middle-aged community sample. *Journal of Health and Social Behavior*, 21, 219-239.
- Gallagher-Thompson, D. & DeVries, H. M. (1994). "Coping with frustration" classes: Development and preliminary outcomes with women who care for relatives with dementia. *The Gerontologist*, 34, 548-552
- George, L. K. (1990). Caregiver stress studies - There really is more to learn. *The Gerontologist*, 30, 580-581.
- George, L. K. (1994). Caregiver burden and well-being: An elusive distinction. *The Gerontologist*, 34, 6-7.
- Gilligan, C. (1982). *In a different voice: Psychological theory and women's development*. Cambridge, MA: Harvard University Press.
- Gore, S., & Mangione, T. W. (1983). Social roles, sex roles, and psychological distress: Additive and interactive models of sex differences. *Journal of Health and Social Behaviour*, 24, 300-312.
- Gouldner, A. J. (1967). Reciprocity and autonomy in functional theory. In N. J. Demerath III and Richard A. Peterson (Eds.), *System, change and conflict*. New York: Free Press.
- Graham, H. (1984). Caring: A labour of love. In J. Finch & D. Groves, (Eds.), *A labour of love: Women, work and caring*. London: Routledge, Kagan Paul.
- Guberman, N., Maheu, P., & Maille, C. (1992). Women as family caregivers: Why do they care? *The Gerontologist*, 32, 607-617.

- Gwyther, L., & George, L. (1986). Caregivers for dementia patients: Complex determinants of well-being and burden. *The Gerontologist*, 26, 245.
- Hinrichsen, G. A., & Ramirez, M. (1992). Black and white dementia caregivers: A comparison of their adaptation, adjustment, and service utilization. *The Gerontologist*, 32, 375-381.
- Horowitz, A. (1992). Methodological issues in the study of gender within family caregiving relationships. In J. W. Dwyer & R. T. Coward (Eds.), *Gender, families, and elder care* (pp. 132-150). Newbury Park, CA: Sage.
- Horowitz, A. (1985). Family caregiving to the frail elderly. In C. Eisdorfer (Ed.), *Annual Review of Gerontology and Geriatrics, Volume 5*, New York: Springer.
- Horowitz, A., Siloverstone, B. M., & Reinhardt, J. P. (1991). A Conceptual and empirical exploration of personal autonomy issues within family caregiving relationships. *The Gerontologist*, 31, 23-31.
- Kelly, H. H. (1981). Marriage relationships and aging. In James G. March (Ed.), *Aging: Stability and change in the family*. Toronto: Academic Press.
- Kesler, R., & McLeod, J. D. (1984). Sex differences in vulnerability to undesirable life events. *American Sociological Review*, 49, 620-631.
- Kieth, C. (1995). Family caregiving systems: Models, resources, and values. *Journal of Marriage and the Family*, 57, 179-189.
- Kingson, E. R., & O'Grady-LeShane, R. (1993). The effects of caregiving on women's social security benefits. *The Gerontologist*, 33, 230-239.
- Knight, B. G., Lutzky, S. M., and Macofsky-Urban, F. (1993). A meta-analytic review of interventions for caregiver distress: Recommendations for future research. *The Gerontologist*, 33, 240-248.
- Kosberg, J. I., & Cairl, R. E. (1992). Burden and competence in caregivers of Alzheimer's disease patients: Research and practice implications. *Journal of Gerontological Social Work*, 18, 85-96.
- Lawton, M. P. (1972). Assessing the competence of older people. In D. Kent, R. Kastenbaum, & S. Sherwood (Eds.), *Research planning and action for the elderly*. New York: Behavioral Publications.
- Lazurus, L., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer Publishing.

- Lee, G. R., & Ellithorpe, E. (1982). Intergenerational exchange and subjective well-being among the elderly. *Journal of Marriage and the Family*, 44, 217-224.
- Lewis, J. (1987). *Daughters caring for mothers*. Technical report to the Rockefeller Foundation, London School of Economics.
- Miller, B. (1990). Gender differences in spouse caregiver strain: Socialization and role explanations. *Journal of Marriage and the Family*, 52, 311-322.
- Miller, B., & Cafasso, L. (1992). Gender differences in caregiving: Fact or artifact? *The Gerontologist*, 32, 498-507.
- Mittelman, M. S. et al. (1993). An intervention that delays institutionalization of Alzheimer's disease patients: Treatment of spouse-caregivers. *The Gerontologist*, 34, 730-740.
- Montgomery, R. J. V., Stull, D. E., & Borgatta, E. F. (1985). Measurement and the Analysis of Burden. *Research on Aging*, 7, 137-152.
- Mui, A. C. (1995). Caring for frail elderly parents: A comparison of adult sons and daughters. *The Gerontologist*, 35, 86-93.
- Mui, A. C. (1992). Caregiver strain among black and white daughter caregivers: A role theory perspective. *The Gerontologist*, 32, 203-212.
- Mullan, J. T. (1992). The bereaved caregiver: A prospective study of changes in well-being. *The Gerontologist*, 32, 673-683.
- Nissel, M. (1984). The family costs of looking after handicapped elderly relatives. *Aging in Society*, 4, 185-204.
- Norland, J. A. (1994). *Focus on Canada: Profile of Canadian seniors*. Ottawa: Statistics Canada and Prentice Hall Canada Inc..
- Pearlin, L. I., Mullin, J., Semple, J., & Skaff, M. (1990). Caregiving and the stress process: An overview of concepts and their measures. *The Gerontologist*, 30, 583-594.
- Pearlin, L. I., & Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behaviour*, 19, 2-21.
- Rankin, E. D., Haut, M. W., & Keefover, R. W. (1992). Clinical assessment of family caregivers in dementia. *The Gerontologist*, 32, 813-821.

- Reisman, B. J. (1987). Intimate relationships from a microstructural perspective: Men who mother. *Gender and Society, 1*, 6-32.
- Rosenthal, C. J. (1994). Long-term care reform and "family" care: A worrisome combination. *Canadian Journal on Aging, 13*, 419-427.
- Rosenthal, C. J., Sulman, J., & Marshall, V. W. (1993). Depressive symptoms in family caregivers of long-stay patients. *The Gerontologist, 33*, 249-257.
- Rossi, A. (1984). Gender and parenthood. *American Sociological Review, 49*, 1-19.
- Scharlach, A. E., Sobel, E. L., & Roberts, R. E. L. (1991). Employment and caregiver strain: An integrative model. *The Gerontologist, 31*, 778-787.
- Seelbach, W. C., & Sauer, W. J. (1977). Filial responsibility expectations and morale among aged parents. *The Gerontologist, 17*, 492-499.
- Shanas, E. (1979). Social myth as hypothesis: The case of the family relations of old people. *The Gerontologist, 19*, 3-9.
- Skaff, M. M., & Pearlin, L.I. (1992). Caregiving: Role engulfment and loss of self. *The Gerontologist, 32*, 656-664.
- Smith, G. C., Smith, M. F., & Toseland, R. W. (1991). Problems identified by family caregivers in counseling. *The Gerontologist, 31*, 15-22.
- Statistics Canada (1990). *Portrait of Seniors in Canada* (Cat. #89-519). Ottawa, ON.
- Stephens, M. A. P., Kinney, J. M., & Ogrocki, P. K. (1991). Stressors and well-being among caregivers to older adults with dementia: The in-home versus nursing home experience. *The Gerontologist, 31*, 217-223.
- Stoller, E. P. (1983). Parental caregiving by adult children. *Journal of Marriage and the Family*, Nov., 851-858.
- Stoller, E. P. (1990). Males as helpers: The role of sons, relatives, and friends. *The Gerontologist, 30*, 228-235.
- Stone, R., Cafferata, G. L., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. *The Gerontologist, 27*, 616-626.
- Stone, R. (1991). Defining family caregivers of the elderly: Implications for research and public policy. *The Gerontologist, 31*, 724-725.
- Strauss, A. & Corbin, J. (1990). *Basics of qualitative research: Grounded Theory procedures and techniques*. Newbury Park, CA: Sage.

- Stull, D. E., Koloski, K., & Kercher, K. (1994). Caregiver burden and generic well-being: Opposite sides of the same coin? *The Gerontologist*, 34, 88-94.
- Teri, L. & Truax, P. (1994). Assessment of depression in dementia patients: Association of caregiver mood with depression ratings. *The Gerontologist*, 34, 231-234.
- Thomas, J. L. (1987). Adult children's assistance as a health care resource: The older parent's perspective. *Family and Community Health*, 9, 34-42.
- Williamson, G. M. & Schulz, R. (1993). Coping with specific stressors in Alzheimer's disease caregiving. *The Gerontologist*, 33, 747-755.
- Wolfson, C., Handfield-Jones, R., Glass, K. C., McClaran, J., and Keyserlingk, E. (1993). Adult children's perceptions of responsibility to provide care for dependent elderly parents. *The Gerontologist*, 33, 315-323.
- Wright, F. (1983). Single careers: Employment, housework and caring. In J. Finch & D. Groves, (Eds.), *A labour of love: Women, working and caring*. London: Routledge, Kagan Paul.
- Young, R. F., & Kahana, E. (1989). Specifying caregiver outcomes: Gender and relationship aspects of caregiver strain. *The Gerontologist*, 29, 660-666.
- Zarit, S. H., Reever, K., & Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *The Gerontologist*, 20, 649.
- Zarit, S. H., Todd, P. A., & Zarit, J. M. (1986). Subjective burden of husbands and wives as caregivers: A longitudinal study. *The Gerontologist*, 26, 260-266.
- Zarit, S. H. (1989). Do we need another "stress and caregiving" study? *The Gerontologist*, 29, 147-148.

Appendix 1

Ethics Approval Form, Program Contact Letter and Newspaper Article,
Participant Information Letter and Consent Form

Article describing the study that appeared in the *West End Times*,
Vol. 5, Issue 10, August 30, 1995

Caring for aging parents is subject of UBC research

An M.A. candidate in Family Studies at U.B.C. is studying the experiences of adult daughters and sons caring for an aging parent. In particular, how adult children describe and experience their role as caregiver for their parents, and the ways in which daughters and sons may differ in their experiences. Hopefully, this study will lead to a better understanding of some of the important issues involved in families caring for their aging members.

In order to carry out this research several volunteers are required. Participants need to be adult daughters (ten subjects) or sons (ten subjects) who are the primary caregiver for their parents aged 65 or older. Primary caregivers are those who are providing the greatest amount of informal/unpaid assistance to their parents. Participants will be asked to respond to a selection of questions about their experiences related to providing care for their parents. Any interviews will be conducted either at the volunteer's home or another location requested by the volunteer. The interview will take maybe 20 to 30 minutes. All responses are kept strictly confidential and of

course volunteers can refuse to participate or withdraw at any time without consequence. If you know of anyone who might be interested in participating in this study they may call David Watt at (604) 731-9763.

* * * *

The Network's new Shopping Service for seniors and others

Seniors

by Gordon Lewis

who are unable to get out to do their own shopping will begin on Tuesday, Sept. 5.

Volunteers will take your phone-in order at the new Safeway store on Davie Street on Tuesdays and Fridays, mornings only. Our volunteers will do your shopping and the groceries will be delivered to your home later that day. The number to call is 669-5177.

* * * *

Next Tuesday, September 5th is 10% discount day for seniors at Capers. Seniors will get 10% off all orders, free coffee and nibbles.

* * * *

Next Wednesday, Sept. 6, "Be-Well Drop In" begins again at the community centre. Drop In starts at 1 p.m. with weight and blood pressure checks. At 3 p.m. Ellen Lefevre will talk about New Directions in health care.

Appendix 2
Interview Schedule

SUBJECT ID ☐☐☐

CAREGIVER INTERVIEW

PART I - INFORMATION ABOUT CAREGIVER

1. Sex: ☐ Male ☐ Female
2. Age: _____ (in years)
3. Marital status: ☐ Single ☐ Married ☐ Common-law ☐ Separated ☐ Divorced ☐ Widowed
3. With which ethnic group do you most identify: _____
4. Estimated annual household income: ☐ \$0-19,999 ☐ \$19-39,999 ☐ \$40-59,999 ☐ \$60-79,999 ☐ \$80-99,999 ☐ \$100,000 or more
5. Number of years of education:
- 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19
- High
School
6. Do you live: ☐ Alone ☐ With spouse/partner ☐ With spouse and child(ren) ☐ With child(ren) only ☐ With friends ☐ With Parent(s) ☐ Other _____
7. Employment status: ☐ Full-time ☐ Unemployed (Seeking work) ☐ Part-time ☐ Unemployed (Not seeking work) ☐ Retired

PART III - SUBJECTIVE PERSPECTIVE

I. Boundaries

- 1a. If you had to identify a point at which you first perceived yourself as a caregiver for your parents, what would that be? (*When did your relationship with your parents change with your becoming the caregiver for your parents? When and in relation to what circumstances did you first become a caregiver for your parent(s)*)
- 1b. How long have you been a caregiver for your parent(s)?
- 1c. Why are you doing this for your parent(s)? (*What motivates you to be a caregiver for your parent(s)?*)
- 1d. Is there anyone else who could provide care to your parent(s), and how did you come to be the primary caregiver?
- 1e. In your caregiver role, are there things you feel you can not or won't do?
- 1f. When do you feel your role as caregiver for your parent(s) will end?

II. Nature of Care Provision

- 2a. What do you do as a caregiver for your parent?
- 2b. If at all, which of the following broad types of care do you typically provide?
 - (1) ☐ food services (cooking and clean-up)
 - (2) ☐ shopping (food and clothing)
 - (3) ☐ house work (house cleaning and laundry)
 - (4) ☐ home maintenance (inside and yard work)
 - (5) ☐ transportation (for doctor's visits)
 - (6) ☐ personal finances (banking and bill payment)
 - (7) ☐ personal care (dressing and bathing assistance)
 - (8) ☐ emotional care (listening and talking)
 - (9) ☐ advice and decision making (regarding short-term and long-term decisions)
 - (10) ☐ interacting with health care agencies (arranging homemakers, appointments)
 - (11) ☐ health care assistance (with medications, help with exercise)
 - (12) ☐ coordinating social activities (social events, visits, letter writing)
- 2c. Of those types of care you do typically provide, how would you arrange the associated task cards (*see attachment) from the most energy-consuming to the least energy-consuming of the different tasks?

- 2d. Do you feel your abilities are sufficient to perform the role of caregiver for your parent(s)? What are your strengths and weaknesses in caring for your parents?

III. Development

- 3a. If at all, how have your activities as a caregiver (*for example, those we discussed earlier*) changed since you first became a caregiver for your parent(s)?
- 3b. If at all, how have your feelings about your parent(s) changed since you first became their caregiver? (*Do you feel your relationship with your parent(s) has changed? If so, in what ways?*)

IV. Expectations

- 4a. Were there clear expectations for how to be a caregiver? (*How did you know what was expected of you as a caregiver? How did you know what to do?*)
- 4b. Do you feel you are living up to your own expectations as a caregiver?
- 4c. Do you feel you are meeting your parent(s) expectations as their caregiver?

V. Evaluative

- 5a. What do you see as the most important thing or things you do as a caregiver for your parent(s), and why?
- 5b. Are there any pleasurable or rewarding aspects of caring for your parent(s)? If so, what are they? (*What, if any, satisfaction do you get from caring for your parents?*)
- 5c. Are there any problematic or upsetting aspects of providing care to your parent(s)? If so, what are they?
- 5d. What does being a caregiver mean to you? (*How do you think of yourself as a caregiver? Overall, how would you describe what it is you do for your parents and how you feel about it?*)

PART IV - CAREGIVER STRESS/BURDEN

The following is a list of statements which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way, for example, never, rarely, sometimes, quite frequently, or nearly always.

1. Do you feel because of the time you spend with your parent(s) that you don't have enough time for yourself?

☐ never

 ☐ rarely

 ☐ sometimes

 ☐ quite frequently

 ☐ nearly always

2. Do you feel stressed between trying to care for your parent(s) and trying to meet other responsibilities for your family or work?

☐ never

 ☐ rarely

 ☐ sometimes

 ☐ quite frequently

 ☐ nearly always

3. Do you feel that your parent(s) currently affect your relationship with other family members or friends in a negative away?

☐ never

 ☐ rarely

 ☐ sometimes

 ☐ quite frequently

 ☐ nearly always

4. Do you feel strained when you are around your parent(s)?

☐ never

 ☐ rarely

 ☐ sometimes

 ☐ quite frequently

 ☐ nearly always

5. Do you feel your health has suffered because of your involvement with your parent(s)?

☐ never

 ☐ rarely

 ☐ sometimes

 ☐ quite frequently

 ☐ nearly always

6. Do you feel that you don't have as much privacy as you would like because of your parent(s)?

☐ never

 ☐ rarely

 ☐ sometimes

 ☐ quite frequently

 ☐ nearly always

7. Do you feel that your social life has suffered because you are caring for your parent(s)?

☐ never

 ☐ rarely

 ☐ sometimes

 ☐ quite frequently

 ☐ nearly always

8. Do you feel you will be able to take care of your parent(s) much longer?

☐ never

 ☐ rarely

 ☐ sometimes

 ☐ quite frequently

 ☐ nearly always

9. Do you feel you have lost control of your life since your parent(s)' illness?

☐ never ☐ rarely ☐ sometimes ☐ quite frequently ☐ nearly always

10. Do you just wish you could pass the care of your parent(s) to someone else?

☐ never ☐ rarely ☐ sometimes ☐ quite frequently ☐ nearly always

11. Overall, how burdened do you feel caring for your parent(s)?

☐ never ☐ rarely ☐ sometimes ☐ quite frequently ☐ nearly always

Task cards for use with Part III, Question 2c.

FOOD SERVICES
(cooking and clean-up)

SHOPPING
(food and clothing)

HOUSE WORK
(house cleaning and laundry)

HOME MAINTENANCE
(inside and yard work)

TRANSPORTATION
(for doctor's appointments)

PERSONAL FINANCES
(banking and bill payment)

PERSONAL CARE
(dressing and bathing assistance)

EMOTIONAL CARE
(listening and talking)

ADVICE AND DECISION MAKING
(regarding short- and long-term decisions)

**INTERACTING WITH HEALTH CARE
AGENCIES**
(arranging homemakers, appointments)

HEALTH CARE ASSISTANCE
(with medications, help with exercise)

**COORDINATING SOCIAL
ACTIVITIES**
(social events, visits, letter writing)

Appendix 3

Demographic and Descriptive Characteristics of the Sample, Coding Worksheet

CAREGIVERS

	Daughters N=10		Sons N=6		Total N=16	
Variable	Mean	SD	Mean	SD	Mean	SD
Caregiver Age	52.2	8.5	53.2	6.4	52.6	7.6
Caregiver Income	2.8	1.5	3.3	1.7	3.0	1.5
Caregiver Education*	14.1	2.4	17.2	2.0	15.2	2.7
No. of Care Recipients	1.0	0	1.0	0	1.0	0
No. Other Caregivers	1.6	1.6	0.7	0.5	1.2	1.3
% Care Provided	88.8	15.4	88.3	14.7	88.6	14.7
Years Caregiving	6.5	4.2	8.7	4.1	7.3	4.2
No. Tasks Performed	7.6	2.7	8.7	3.4	8.0	2.9
General Burden Score	2.6	0.7	2.0	0.4	2.4	0.7

* Significant, $t(14) = 2.62$, $p=.02$

Caregivers' Marital Status (in percent)

	Single	Married	Common-Law	Divorced	Widowed
Daughters	0.0	20.0	30.0	40.0	10.0
Sons	33.3	33.3	0.0	33.3	0.0
Total	12.5	25.0	18.8	37.5	6.3

Caregivers' Ethnicity (in percent)

Canadian	British	Polish	Scandinavian
75.0	12.5	6.3	6.3

Caregivers' Residence (in percent)

	Alone	Spouse / Partner	Children	Parents	Children, Parents	Parents, Spouse, Children
Daughters	0.0	40.0	10.0	20.0	20.0	10.0
Sons	50.0	16.7	0.0	33.3	0.0	0.0
Total	18.8	31.3	6.3	25.0	12.5	6.3

Caregivers' Employment Status (in percent)

	Full-Time	Part-Time	Retired	Unemployed
Daughters	50.0	30.0	10.0	10.0
Sons	83.3	0.0	16.7	0.0
Total	62.5	18.8	12.5	6.3

CARE RECIPIENTS

	Daughters N=10		Sons N=6		Total N=16	
Variable	Mean	SD	Mean	SD	Mean	SD
Recipient Age	82.7	6.4	84.7	8.4	83.4	7.0
Recipient Income	1.3	.7	1.0	0.0	1.2	0.5

Care Recipient's Sex (in percent)

	Male N=1	Female N=15
Daughters	0.0	100.0
Sons	16.7	83.3
Total	6.3	93.8

Care Recipient's Marital Status (in percent)

	Single	Married	Widowed
Daughters	10.0	10.0	80.0
Sons	0.0	0.0	100.0
Total	6.3	6.3	87.5

Care Recipients' Ethnicity (in percent)

Canadian	British	Chinese	Danish	Hungarian	Polish	Ukrainian
50.0	18.7	6.3	6.3	6.3	6.3	6.3

Care Recipients' Residence (in percent)

	Alone	Spouse / Partner	Children	Children, Grandchildren
Daughters	40.0	10.0	20.0	30.0
Sons	50.0	0.0	50.0	0.0
Total	43.8	6.3	31.3	18.8

CODING WORKSHEET

Question No. _____

[illegible]

PARTICIPANT(S) ID	CATEGORY LABEL	DESCRIPTION

NOTES

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.