Family Caregiving or Caregiving Alone: Who Helps the Helper?

by

Joanie Sims-Gould

BSc, McMaster University, 1994
BA, McMaster University, 1995
HBSW, Lakehead University, 1997
MSW, Lakehead University, 1999

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

in

THE FACULTY OF GRADUATE STUDIES

(Interdisciplinary Studies)

THE UNIVERSITY OF BRITISH COLUMBIA

April 2006

ABSTRACT

This investigation advances the understanding of family caregiving by examining the relationship between adult children caregivers and their helpers, as well as the intersections between helping, gender and kinship. Specifically, it focuses on examining "who helps whom" and extends analyses beyond the dyadic focus of caregiving in later life. The focus on helping and caregiving addresses the variety of contributions and responsibilities involving not only the 'caregiver' who was the 'target' respondent in this research, but also others identified as 'helpers' in the provision of care.

The data for this dissertation are derived from the Work and Eldercare Research group of CARNET: The Canadian Aging Research Network. Secondary analysis of CARNET data focuses on quantitative and verbatim data collected from 250 individuals with significant caregiving responsibilities to at least one older person.

The dissertation is comprised of three scholarly papers each focusing on a dimension of helping and caregiving by adult children. Study One examines the multiple relationships and contributions involved in providing care to an older relative. The research extends Kahn & Antonucci's convoys of social support model (1981) and Cantor's model of social care (1991) by disentangling some of the dimensions of helping and caregiving such as the distinction between direct and assistive help. Direct help is defined as the help given by caregivers and helpers to an older person. Assistive help is the help given to a caregiver or helper. Study Two examines the characteristics and composition of helping and caregiving families with specific attention to the intersection of gender and kinship. Findings underscore the presence and coordination of direct and assistive help, the predominance of women and kin, the importance of adult siblings and

the participation of men in helping and caregiving. Study Two also advances understandings of caregiving/helping as a family-level concept. Study Three through the analysis of three case vignettes explores several themes in helping. Themes include, the presence and importance of absent caregivers/helpers, the presence of multiple care recipients, the participation of men in helping/caregiving and the contributions of paid helpers. Conclusions highlight implications for professional practice, policy and research.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

ACKNOWLEDGEMENTS

As evidenced in my research very little happens in the context of day-to-day life without the help and contributions of other individuals. My academic journey has been no exception. The process and completion of my doctoral program has been enabled by the contributions of many individuals. To invoke the language of caregiving, I have been the very fortunate and most grateful recipient of both instrumental and affective support. It is with heartfelt gratitude that I am now able to acknowledge this support.

I have had the pleasure and honour of working with an exemplary supervisor and human being, Dr. Anne Martin-Matthews. Dr. Martin-Matthews has continually provided me with superior academic guidance while also supporting, sustaining and affirming me throughout my academic journey. Anne, I thank you for being my mentor, my supervisor and a constant fixture in my life for the past six years. I look forward to continuing our academic work and friendship.

A most sincere thank you to members of my supervisory committee. Thank you to Dr. Deborah O'Connor, Dr. JoAnn Perry and Dr. James White for providing me with indispensable academic guidance, support and confidence.

To the childcare staff at UBC. You gave me the gift of assurance to pursue my work with the knowledge that my children were being inspired.

To my dissertation support group -- my friend, Kara McDonald. Through this process, your friendship, and that of your family, has been a truly special gift.

To my family and friends. It is with your help in every corner of my life, with your inspiration, and with your dedication to seeing me achieve my goals, that I can write these acknowledgments. Words alone cannot express my gratitude.

Thank you to my grandparents (Mary & George Alexander), parents (Ruth and Richard Sims), brother and sister-in-law (Jesse Sims and Lisa Johnson), friends (Julie, Bernard, Michelle, Sarah, Dave, Doug and Gale). Thank you to my aunts, uncles, cousins, and friends across the country. Thank you to my family in England and in Southern Ontario. You have all contributed to my sense of family and sense of self. To Susan, I always carry your spirit with me.

To my husband and children -- James, Jocelyn and Julia. Thank you for being in my life, for giving me the gifts of balance, patience, certainty and success no matter what I do. It is you who give me my greatest sense of accomplishment and fulfillment. I love you more than words can express. I am so grateful for you. I am so proud of you.

In closing, my last acknowledgment comes as a dedication. It is to my mother, Ruth that I dedicate this work. This dissertation belongs to you as much as me. Without your support, your work as a mother and as a grandmother, and most of all, without your selfless approach to family, this would not have happened. You have facilitated my work and inspired my ideas. I cannot thank you and Dad enough -- I can only hope to do for my children and grandchildren as you have.

CHAPTER ONE

Introduction

Family caregiving[1] is a developing concept. Historically grounded in medicine and science, it often bears a definition fixed on measuring outcomes and determining need for formal service within a caregiver-care recipient dyad (Hagestad & Dannefer, 2001). Hagestad & Dannefer (2001) argue that social science has focused its research on aging as a micro-level process in its focus on the dyad; the study of caregiving has been no exception.

Developments driven by an interdisciplinary interest in family caregiving are beginning to construct caregiving as consisting of complex relationship processes that are multi-layered, embedded in social histories and located within specific conditions. The challenge for caregiving research is to capture the multiplicity and complexity of caregiving situations using theory and methods from a range of disciplines while not homogenizing the experience of families. This is particularly salient in the context of population aging and changing health care policy. Increasingly Canadian families are finding themselves directly and/or indirectly involved in the provision of care to an older person.

Most empirical research on caring for older adults examines caregiving as a series of chores performed in the context of a dyadic relationship between primary caregiver (most often a wife or adult daughter) and care recipient (Armstrong & Kits, 2004; Fast,

[1] Family in its broadest definition refers to a group (two or more individuals) who share friendship, blood, kinship, marriage or marriage-like ties. The use of the term family has been criticized for carrying and perpetuating hetero-normative assumptions about what it means to be 'family'. The term family caregiving is used in this dissertation, to maintain consistency with previous research on the topic and to emphasize the relational nature of caregiving contributions and relationships. Where appropriate the limitations and connotations of the term family caregiving are acknowledged.

Keating, Otfinowski & Derksen, 2004; Peek & Zsembik, 1997; Pyke & Bengtson, 1996; Sims-Gould & Martin-Matthews, 2005); conceptually this work has drawn on micro level theories of stress and coping. With so much of the focus on the activities of the primary caregiver, there has been little research on the relationships and contributions when more than one individual mobilizes to provide care to an older person (Chappell, 1992; Fast et al., 2004).

As an integral step in advancing our understanding of caregiving, the presence of multiple individuals involved in care provision for an older person must be understood. Keating, Otfinowski, Wenger, Fast & Derksen (2003) argue that a perspective on caregiving, where caregiving is examined as a series of interconnected relationships, is the solution. Similarly, Haines and Henderson (2002: 235) contend that with Canadian health care reforms placing greater emphasis on family care of older adults, it is essential to understand how families organize to provide this care, both to the older person and to one another.

The purpose of this dissertation is to demonstrate the complexity of providing care to an older person through an examination of the relationships and contributions of primary caregivers and their helpers. This research explores how the composition of helping networks, based on gender and kinship ties, translates into differences in the types of help given both to caregivers and to the older person receiving care. Drawing on previous conceptual work by Kahn & Antonucci (1981) on convoys of social support and Cantor's (1991) model of social care, this dissertation examines caregiving as a concept that exceeds its historically-based definition as a fixed, quantifiable, and micro-focused entity.

Population Aging, Healthcare and Family Caregiving

Families have both extrinsic and intrinsic reasons to provide care for older family members. Extrinsic factors for engaging in caregiving can include but are not limited to, the influence of changing health care structures and increasing emphasis on the legal responsibility of families to provide necessary care to older adults; intrinsic reasons may include but are not limited to: filial obligation and cultural expectations for family members to provide care. To date, the most influential extrinsic reasons affecting the provision of family care in Canada have been overall population aging and a changing health care system (Chappell, Gee, McDonald & Stones, 2003).

Canada's population[2] is considered young in comparison with many countries in the industrialized world; however, with increases in life expectancy, the proportion of the population over the age of 65 will increase to approximately 25 percent by the year 2031 (this trend will begin to accelerate around 2011). Currently, at age 65, women in Canada can expect to live another 20 years and men another 16 years (Chappell et al., 2003). These numbers will continue to grow with improvements in medicine, nutrition and overall population health.

Increased longevity also means a substantial increase in the duration of family ties across generations. It is now common for parents and children to share 50 or 60 years together. When persons born in 1910 reached their fiftieth birthday in 1960, only 16 percent of them had at least one of their parents still alive. By comparison, when persons born in 1930 reached their fiftieth birthday in 1980, 49 percent of them had at least one of their parents still alive. Projections suggest that when persons born in 1960 reach their

[2] 13 percent of Canada's total population of 31 million people is over the age of 65 years (Statistics Canada, 2003).

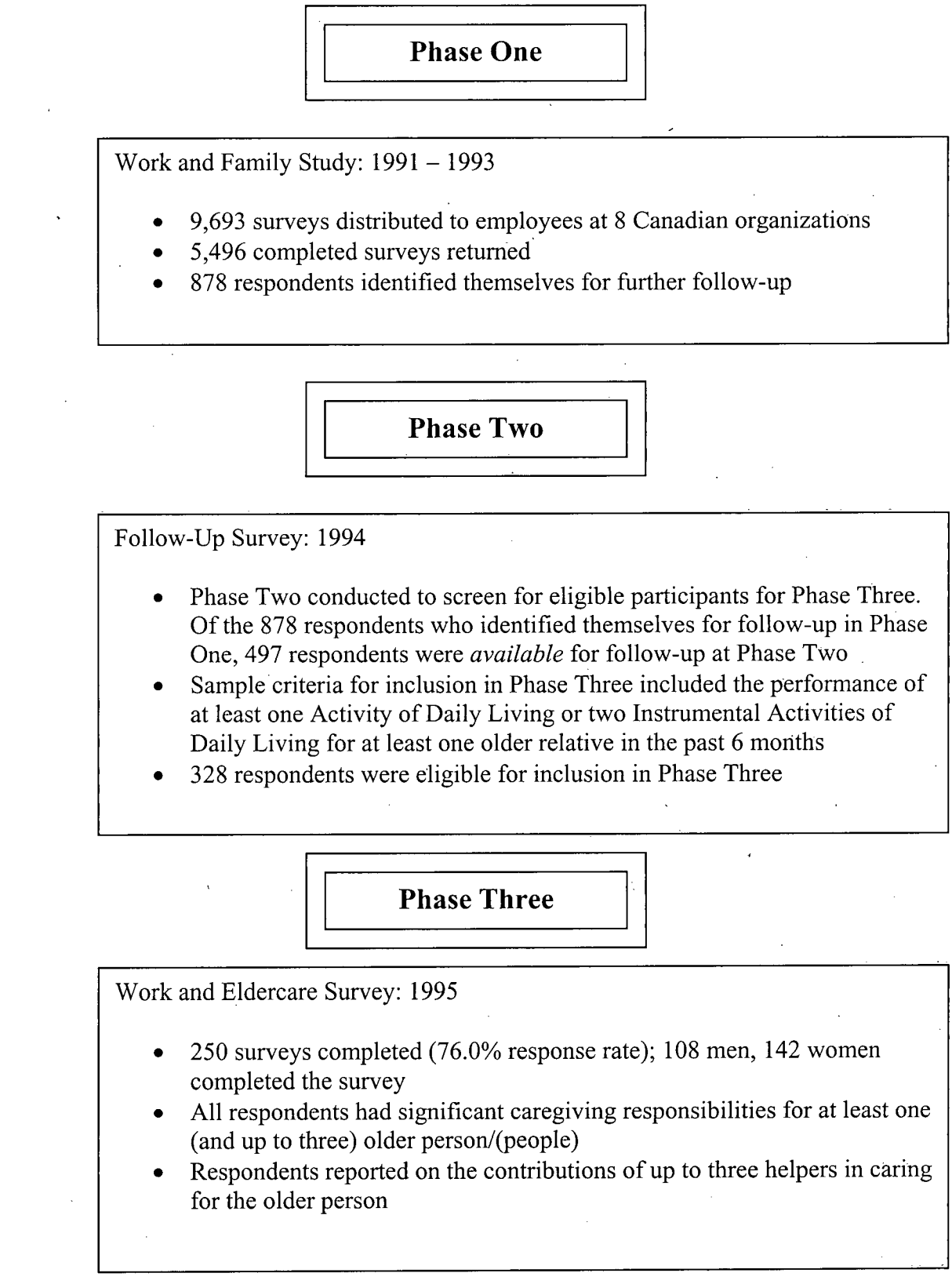
fiftieth birthday in 2010, 60 percent of them – about a fourfold increase in 100 years – will have at least one of their parents still alive to celebrate the event with them (Gee, 1990; Bengtson, 2001). As family ties endure over more years, more Canadians will find themselves involved in family care of an older relative.

Population aging is not the only feature of Canadian life that is contributing to a changing context and increased opportunity or likelihood for family caregiving. Changing health and social policies are impacting aging individuals and families. In a recent Statistics Canada report based on the 2002 General Social Survey, 2 million Canadians over the age of 45 years indicated that they provided care to an older person (Cranswick, 2003). Ward-Griffin and Marshall (2003: 189) contend that "recent changes in patterns of care provision for the elderly, including withdrawal from the formal system" have created an "increasing reliance on family care providers". Health care is still in the midst of restructuring (Romanow, 2002), and the complex and as yet unclear changes in Canadian health-care policy and delivery (Chappell et al., 2003) stand to have substantial impact on Canada's older people and those who care for them (Martin-Matthews, 1999). In a current review of the process of health reform in Canada, Chappell et al. (2003:432–33) conclude "the vision of health reform... has allowed for a shifting of the burden of care in old age from the public purse onto individuals and families even though this was not part of the rhetoric or the vision of health reform".

While much of the responsibility for care of older adults has shifted from the public purse to individuals and families, little research has addressed the presence and responsibilities of multiple members of a family in family caregiving. The bulk of caregiving research has focused on the relationship between primary caregiver and care

recipient (Fast et al., 2004; Hequembourg & Brallier, 2005; Peek & Zsembik, 1997; Sims-Gould & Martin-Matthews, 2005; Skemp Kelley, 2005) and has paid little attention to the presence and contributions of other helpers (Haines & Henderson, 2002).

Figure 1.1: Phases of the CARNET Study



Data Collection and Analysis

This dissertation is a secondary analysis of data from the Canadian Aging Research Network (CARNET) Work and Eldercare Study (N=250), a follow-up study to the CARNET Work and Family Study (N=5,496). Figure 1.1 outlines the phases of the CARNET study and addresses the steps taken to obtain the sample for the Work and Eldercare Study.

CARNET is a complex and interdisciplinary data set that has been used by numerous researchers spanning multiple disciplines and areas of inquiry (e.g. Campbell & Martin-Matthews, 2003; Connidis, Rosenthal & McMullin, 1996; Gignac, Kelloway & Gottlieb, 1996; Keefe, Rosenthal & Béland, 2000; Rosenthal, Martin-Matthews & Matthews, 1996). The data gathered in the third stage of the CARNET survey are unique in that respondents were able to report on the help they received from multiple individuals who assisted them in their caregiving responsibilities. They also provided detailed information on the help received by their older relative or friend (with information gathered on up to three individuals). The 1996 General Social Survey (GSS) of Canada, often considered the best available data for examining the social support and caregiving networks of older Canadians, does not include questions about help to the caregiver. The CARNET data are the most appropriate for this analysis in that they include measures of help to the caregiver and to the older individual(s) receiving care. The inclusion of questions on help given to the caregiver makes the CARNET data set the best choice of data for the present investigation on the contributions and relationships of multiple individuals in the context of providing care to an older individual.

In the most recent edition of the Sourcebook of Family Theory and Research, Radina & Downs (2005) note that analysis of secondary data is a valuable approach for maximizing the potential of a data source. Similarly, in their work on methods for studying marriages and families, Miller, Rollins & Thomas (1982) note that secondary analyses of extant data can make important contributions to the generation of new knowledge while being economical and less time consuming than primary data collection. Secondary analysis of data also helps to contribute to the prevention of 'research survey fatigue' particularly with vulnerable populations (Miller et al., 1982).

As with any secondary analysis of data, there are constraints imposed by the original sampling strategies and/or questions (Radina & Downs, 2005). Several characteristics of the CARNET Work and Eldercare Study influence the nature of the original sample and have implications for the research focus of this dissertation. First, the CARNET Work and Eldercare Study focused on individuals currently employed. As such, respondent caregivers had an average age of 43.3 years (SD 7.10). This average age dictates that the sample consists predominantly of adult children caregivers and not spousal caregivers. The focus of this dissertation is therefore on adult children's caregiving, not on spousal caregiving. Second, the average annual personal income for participants involved in CARNET was $50,000 – 59, 999. The results of studies using CARNET data must therefore be interpreted cautiously as the sample does not represent individuals in low-income brackets. Third, the final phase of the CARNET study (N=250) is not representative of the current Canadian ethno-cultural context. Future work on the contributions of multiple individuals within the context of caregiving would benefit from examining caregiving within and between different cultural and ethnic

contexts. Fourth, in order to be included in the Work and Eldercare Study, respondents had to have provided assistance to at least one older person (in the past 6 months) with one Activity of Daily Living (ADL)[3] or two Instrumental Activities of Daily Living (IADL). While there is significant and important inquiry into whether task-based criteria such as ADL and IADL measures adequately capture the range of activities in which caregivers engage, caregiving in this study is operationalized as the performance of at least one ADL or two IADLs. Threads of the debate on the operationalization of what constitutes caregiving and how caregiving is measured are explored where applicable through this dissertation.

Data for this dissertation were analyzed using the statistical software package SPSS. Quantitative survey data and written responses to long answer questions were used in analyses as well as in the development of descriptive vignettes. Both the quantitative data and the analysis of vignettes informed the examination of the contributions of multiple individuals involved in family caregiving.

The dissertation is comprised of three scholarly research papers each focusing on a dimension of helping and caregiving, employing different theoretical and methodological approaches[4]. The studies draw on secondary data to extend our understanding of family caregiving in a way not previously done in order to shape future research questions about family caregiving. Study One examines the multiple

---

[3] Katz, Ford, Moskowitz, Jackson & Jaffee (1963) developed this well-known and well-used task typology. Since its development it has been used extensively in health and health related research. ADLs include: feeding, bathing, dressing, toileting, help with medication; and, IADLs include: transportation, shopping, doing errands, laundry, household chores, meal preparation, home maintenance and yard work.

[4] According to the University of British Columbia requirements for doctoral theses "a thesis may contain a brief introductory statement followed by off-prints of published articles under certain conditions". This dissertation, adopting a modified journal style model, includes an introduction, three papers and a conclusion. Each of the three papers, or chapters, is ultimately intended for publication in a scholarly book or journal. Each paper includes reference to methodology, theory and responds to a unique set of research questions.

relationships and contributions involved in providing care to an older relative and addresses the benefits of expanding the focus in caregiving research from the primary caregiver to 'family' caregiving; Study Two examines the characteristics and composition of helping and caregiving families with specific attention to the intersection of gender and kinship. Study Three, through the analysis of three case vignettes, explores themes in helping in the context of family caregiving. The conclusion highlights implications for professional practice at the policy and research levels.

References

Armstrong, P. & Kits, O. (2004). One hundred years of caregiving. In Grant, K. R., Amaratunga, C., Armstrong, P., Boscoe, M., Pederson, A. & Willson, K. (Eds.), Caring For/Caring About: Women, Home Care and Unpaid Caregiving, (43 - 73). Aurora, Ontario: Garamond Press.

Bengtson, V. L. (2001). Beyond the nuclear family: The increasing importance of multigenerational bonds. Journal of Marriage and the Family, 63(1), 1 – 16.

Campbell, L. D. & Martin-Matthews, A. (2003). The gendered nature of men's filial care. Journal of Gerontology: Social Sciences, 58B(6), S350-S358.

Cantor, M. H. (1991). Family and community: changing roles in an aging society. The Gerontologist, 31(3), 337 – 346.

Chappell, N. L. (1992). Social Support and Aging. Toronto: Butterworths.

Chappell, N.L., E. M. Gee, L. McDonald and M. Stones (Eds.). (2003). Aging in Contemporary Canada. Toronto: Prentice Hall.

Connidis, I. A., Rosenthal, C. J. & McMullin, J. A. (1996). The impact of family composition on providing help to older parents: A study of employed adults. Research on Aging, 18(4), 402-429.

Cranswick, K. (2003). Caring for an aging society. Statistics Canada, from http://www.statcan.ca/english/freepub/89-582-XIE/index.htm

Fast, J., Keating, N., Otfinowski, P. & Derksen, L. (2004). Characteristics of family/friend care networks of frail seniors. Canadian Journal on Aging, 23(1), 5 – 19.

Gee, Ellen M. (1990). Demographic change and intergenerational relations in Canadian families: findings and social policy implications. Canadian Public Policy, 16(2), 191–199.

Gignac, M., Kelloway, K. E., & Gottlieb, B. H. (1996). The impact of caregiving on employment: a mediational model of work-family conflict. Canadian Journal on Aging, 15(4), 525 – 542.

Hagestad, G. O. & Dannefer, D. (2001). Concepts and theories of aging: beyond microfication in social science approaches. In Binstock, R. H. & George, L. (Eds.). Handbook of Aging and the Social Sciences, 5th Edition, (3 - 21). San Diego: Academic Press.

Haines, V. A. & Henderson, L. J. (2002). Targeting social support: a network assessment of the convoy model of social Support. Canadian Journal on Aging, 21(2), 243 – 256.

Hequembourg, A. & Brallier, S. (2005). Gendered stories of parental caregiving among siblings. Journal of Aging Studies, 19(1), 53 – 71.

Kahn, R. L. & Antonucci, T. C. (1981). Convoys of social support: a life-course approach. In March, J. G., Kiesler, S. B., Morgan, J. N., & Oppenheimer, V. K. (Eds.), Aging: Social Change, (383 – 405). New York: Academic Press.

Katz, S., Ford, A. B., Moskowtiz, R. W., Jackson, B. A. & Jaffee, M. W. (1963). Studies of illness in the aged. The index of ADL: a standardized measure of biological and psychological function. Journal of the American Medical Association, 185, 914 – 919.

Keating, N. C., Otfinowski, P., Wenger, C., Fast, J. E. & Derksen, L. (2003). Understanding the caring capacity of informal networks of frail seniors: A case for care networks. Ageing & Society, 23(1), 115-127.

Keefe, J., Rosenthal, C. J. & Béland, F. (2000). The impact of ethnicity on helping older relatives: Findings from a sample of employed Canadians. Canadian Journal on Aging, 19(3), 317- 342.

Martin-Matthews, A. (1999). Widowhood: dominant renditions, changing demography and variable meaning. In Neysmith, S. M. (Ed.). Critical Issues in Social Work with the Elderly. Columbia University Press.

Miller, B. C., Rollins, B. C. & Thomas, D. L. (1982). On methods of studying marriages and families. Journal of Marriage and the Family, 44(4), 851 – 873.

Peek, C. W. & Zsembik, B.A. (1997). The changing caregiving networks of older adults. Research on Aging, 19(3), 333 – 362.

Pyke, K. D. & Bengtson, V. L. (1996). Caring more or less: Individualistic and collectivist systems. Journal of Marriage & Family, 58(2), 379 – 383.

Radina, M. E. & Downs, K. J. M. (2005). Asking new questions of existing qualitative data. In Bengtson, V. L., Acock, A. C., Allen, K. R., Dilworth-Anderson, P. & Klein, D. M. (Eds.), Sourcebook of Family Theory & Research, (63 – 64). Sage: Thousand Oaks.

Romanow, R. (2002). Building on Values: The Future of Health Care in Canada. Government of Canada. http://finalreport.healthcarecommission.ca/

Rosenthal, C. J., Martin-Matthews, A. & Matthews, S. H. (1996). Caught in the middle? Occupancy in multiple roles and help to parents in a national probability sample of Canadian adults. Journal of Gerontology: Social Sciences, 51B(6), S274-S283.

Sims-Gould, J. & Martin-Matthews, A. (in press, 2005). Caregivers, Helpers, and Family: Family Caregiving Research in a Canadian Context. In Paoletti, I. (Ed.), Family Caregiving to older disabled people: relational and institutional issues. Nova Science Publisher.

Skemp Kelley, L. (2005). Minor children and adult care exchanges with community-dwelling frail elders in a St. Lucian village. Journal of Gerontology: Social Sciences, 60B(2), S62 – S73.

Ward-Griffin, C. & Marshall, V. W. (2003). Reconceptualizing the relationship between "public" and "private" eldercare. Journal of Aging Studies, 17(2), 189 - 208.

CHAPTER TWO

Study One: Who Helps the Helper?[5]

Family caregiving is an important and popular gerontological research topic (Keating, Fast, Frederick, Cranswick & Perrier, 1999; Martin-Matthews, 2000) as evidenced in its proliferation in gerontology and family studies literature since the early 1970's (Allen, Blieszner & Roberto, 2000; Walker & Pratt, 1995). In a decade review (1990-2000) published in the Journal of Marriage & Family (Allen et al., 2000), thirty-three percent (N=296) of articles in a representative sample of academic gerontological publications focused exclusively on caregiving to older family members.

Although there has been a plethora of research on caregiving, the emphasis has been on understanding the activities of the primary caregiver and not on understanding the contributions of other caregivers (Haines & Henderson, 2002; Marshall, Matthews & Rosenthal, 1993; Matthews, 2002; Piercy, 1998; Pyke & Bengtson, 1996). Despite ample evidence demonstrating that adult children are filially responsible (Matthews & Rosner, 1988; Globerman, 1996) very little is known about how these adult children contribute together to caregiving in response to the needs of an older parent/relative.

To date, those studying families have focused almost exclusively on studying family roles, not family relationships or family contributions; there has been particular paucity of literature that examines family contributions as relative and interconnected (Matthews, 2002). This statement can be extended to research on family caregiving where the activities of the primary caregiver are well documented, but there is little if any information on whether primary caregivers receive help. Connidis (2001: 257) contends,

[5] A version of this chapter entitled "Family Caregiving or Caregiving Alone: Who Helps the Helper" has been submitted for review to the Canadian Journal on Aging.

"like the cared for, caregivers also receive extensive help from other family members". The focus of the present study is on the "extensive help from other family members", with an emphasis on understanding the contributions of multiple individuals involved in family caregiving.

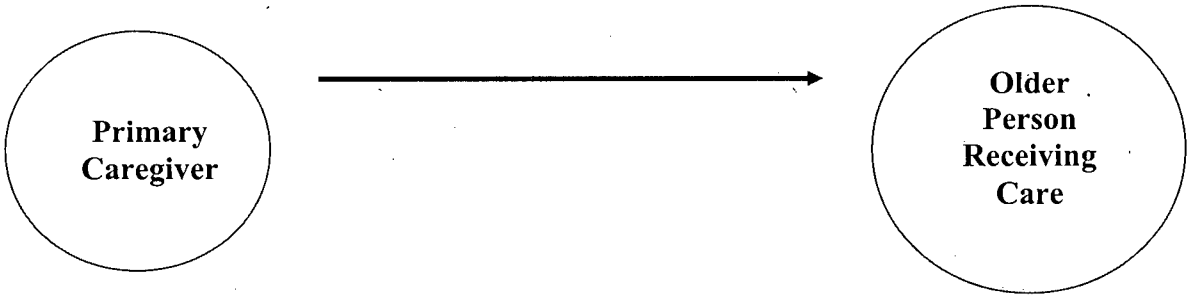
This study furthers the current understanding of caregiving through an analysis of Canadian data examining the relationships and contributions of various family members involved in providing care to an older adult. Within the analysis, a distinction is made between those who are caregivers and those who are "helpers", and their differential responsibilities within family caregiving. The research is based on the premise that family caregiving research must extend beyond an examination of primary caregivers to an exploration of multiple individuals with multiple responsibilities.

Dyads to Families: Framing the Research

The relationships, contributions and exchanges within intergenerational families have long been of interest to researchers (Boss, 2005). The concept of caregiving to an older relative, however, has only dominated the research vernacular within the past fifteen years (Martin-Matthews, 2004). Prior to this, the concept of caregiving most frequently appeared in medical literature referring to activities of medical or formal caregivers such as nurses. This medical orientation has defined much of the discourse around aging (Katz, 1996; Warren, 1998). Studies of family caregiving have been no exception. It is not surprising that family caregiving research has predominantly focused on understanding the caregiving dyad and the resultant impact or stress (often called burden) experienced by individual caregivers. Most often studies of caregiving focus on variables related to the health status of the older person in order to understand the impact

of the caregiving experience on the caregiver. Figure 2.1 depicts the relationship most commonly studied in the context of caregiving to an older person.

Figure 2.1: Common Conceptualization of Caregiving in Research



While studies of stress and burden have dominated the caregiving literature, the application of theory from multiple disciplines has contributed to improved understandings of caregiving. Specifically, life course perspectives (Allen et al., 2000; Bengtson & Allen, 1993; George, 1993; Hareven, 1994; Pearlin & Skaff, 1996), feminist models (Allen & Walker, 1992; Allen et al., 2000; Opie, 1994; Withers Osmond & Thorne, 1993) and ecological perspectives (Bubolz & Sontag, 1993; Dupuis & Norris, 1997; Sumsion, 1999) have contributed to the development of different ways of understanding and interpreting the caregiving experience. Although theory from multiple disciplines is used in family caregiving research, the majority of studies concentrate on the relationship between primary caregiver[6] and care receiver. As a result of the dyadic focus, very few conceptual frameworks have been explicitly developed to examine the relationships and contributions of multiple individuals in the context of family caregiving. With few identified theoretical guides in family caregiving research for examining the contributions of multiple individuals, this study relied on network models.

[6] Primary caregiver is the term most frequently assigned to the person who is providing the most care to their older relative.

Who Helps?

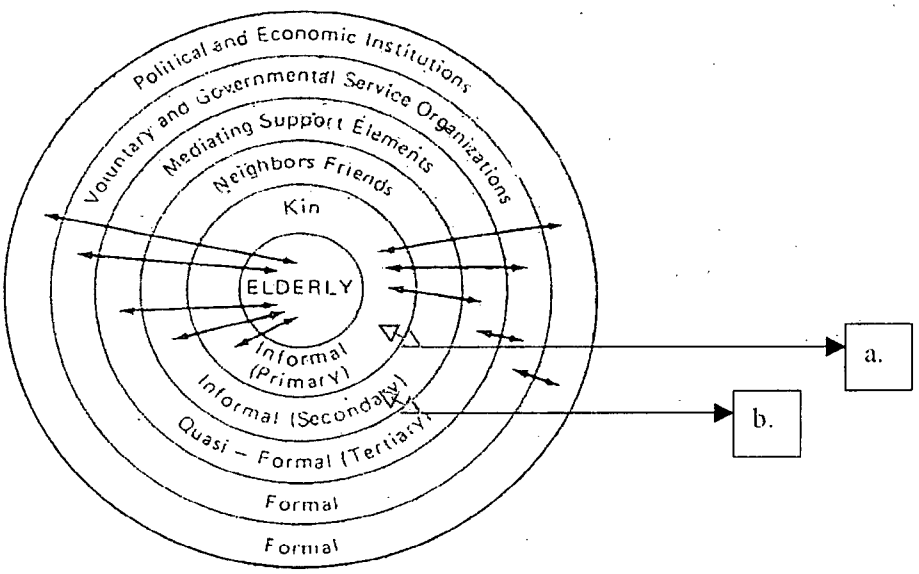
Social network research has been instrumental in establishing who is involved in the lives of older adults and in establishing network types. Kahn & Antonucci (1981:392) suggest that the study of social networks is "highly relevant for specifying the formal properties...properties of the network as a whole and properties of the separate dyadic links between the focal person and each of the network members". In his research on social networks, Milardo (1988: 14) argues that families live in an elaborate system of interactions characterized by ties of varying complexity and strength, but as social scientists we know little about the character of these personal relationships. In particular, there is a dearth of information regarding the character of these relationships and contributions when multiple individuals mobilize to provide care to an older person. In the present study of family caregiving networks, Kahn & Antonucci's (1981) convoys of social support and Cantor's (1991) social care model, two types of network models, contribute to the development of a conceptual model for examining the contributions of multiple individuals involved in the provision of care to an older adult.

Kahn & Antonucci's (1981) convoys of social support and Cantor's (1991) social care model both reject the idea of a single caregiver, suggesting that care is provided by a "convoy" or network of individuals (see Figure 2.2). The models emphasize caregiving as a care system comprised of multiple individuals (Antonucci, 1990; Antonucci & Aykiyama, 1995; Cantor, 1991). The two models are consistent with recent academic research on caregiving that suggests that the care of older relatives often involves multiple individuals (Fast, Keating, Otfinowski & Derksen, 2004). The convoy model, with attention to social ties and social relations, conceptualizes caregiving based on

relationships. It provides a framework for understanding who is involved in the provision of care and what they contribute. Antonucci & Aykiyama (1995: 356) argue that "individuals move through their lifetimes surrounded by people who are close and important to them and who have a critical influence on their life and well-being." The convoy model metaphorically describes an individual's movement through the life cycle "surrounded by a set of other people to whom he or she is related by the giving or receiving of social support" (Kahn & Antonucci, 1981: 393).

Cantor's (1991) model of social care and related theory of hierarchical compensatory support (1979) extend the convoy model by suggesting that certain individuals take primacy over others and as a result are more likely to provide care. For example, Cantor suggests that an older person receiving care is likely to use the formal system as a last resort; family care takes precedence over formal care. The two models of support provide a framework for mapping the critical influence of multiple individuals within family caregiving. The two models are different from other types of network analysis in that they do not seek to understand distance or strength of relationships but rather they provide a template for examining how individuals are connected to one another by relationships and through collaborative contributions.

Figure 2.2: Convoys of Social Support



Adapted from:
Cantor, M. J. (1991). Family and community: changing roles in an aging society. The Gerontologist, 31(3), 337 – 346.

Figure 2.2 depicts Kahn & Antonucci's (1981) convoy of social support model and Cantor's (1991) model of social care. Figure 2.2 shows the various levels or rings of support around the older person receiving care. The primary caregiver is shown in the first ring, helpers in the second ring. The black two-way arrows show the flow of contributions to and from the older person to the primary caregiver, helper etc. This model improves the conceptualization of caregiving beyond that depicted in Figure 2.1, but is still limited in the way in which it depicts how groups of individuals mobilize to provide care for an older person. The model does not account for how helpers support a primary caregiver or one another (arrows a. & b. added by this author). This exclusion has created a gap in family caregiving research. Little is known how individuals, acting

together with the purpose of providing care to an older person, mobilize to care by providing care directly to that person, and/or by helping one another. In particular, the assistance to 'one another' is not understood.

This study uses an adapted version of Kahn & Antonucci's (1981) model and Cantor's (1991) social care model. The adapted model, shown in Figure 2.2, includes arrows a. and b. These arrows (a. and b.) identify the assistance received by primary caregivers from helpers, as well as between helpers. The conceptual diagram of help in caregiving, shown in Figure 2.3, provides a detailed depiction of support to the older person receiving care and also between caregivers/helpers. The assistance provided by caregivers who are not the primary caregivers is called 'help'[7] and those who provide this help are defined as 'helpers'.

The diagram shown in Figure 2.3 also shows a distinction between direct help and assistive help. This is a distinction not previously made in caregiving research. Direct help is help given to the older person by helpers (those individuals who are not the primary caregiver) and assistive help is help given to the caregiver.

[7] The terms help and helpers are used to distinguish helpers from primary caregivers. Help therefore refers to the assistance provided to the caregiver, between helpers and to the older person by an individual or individuals who are NOT the primary caregivers.

Figure 2.3: Help in Caregiving

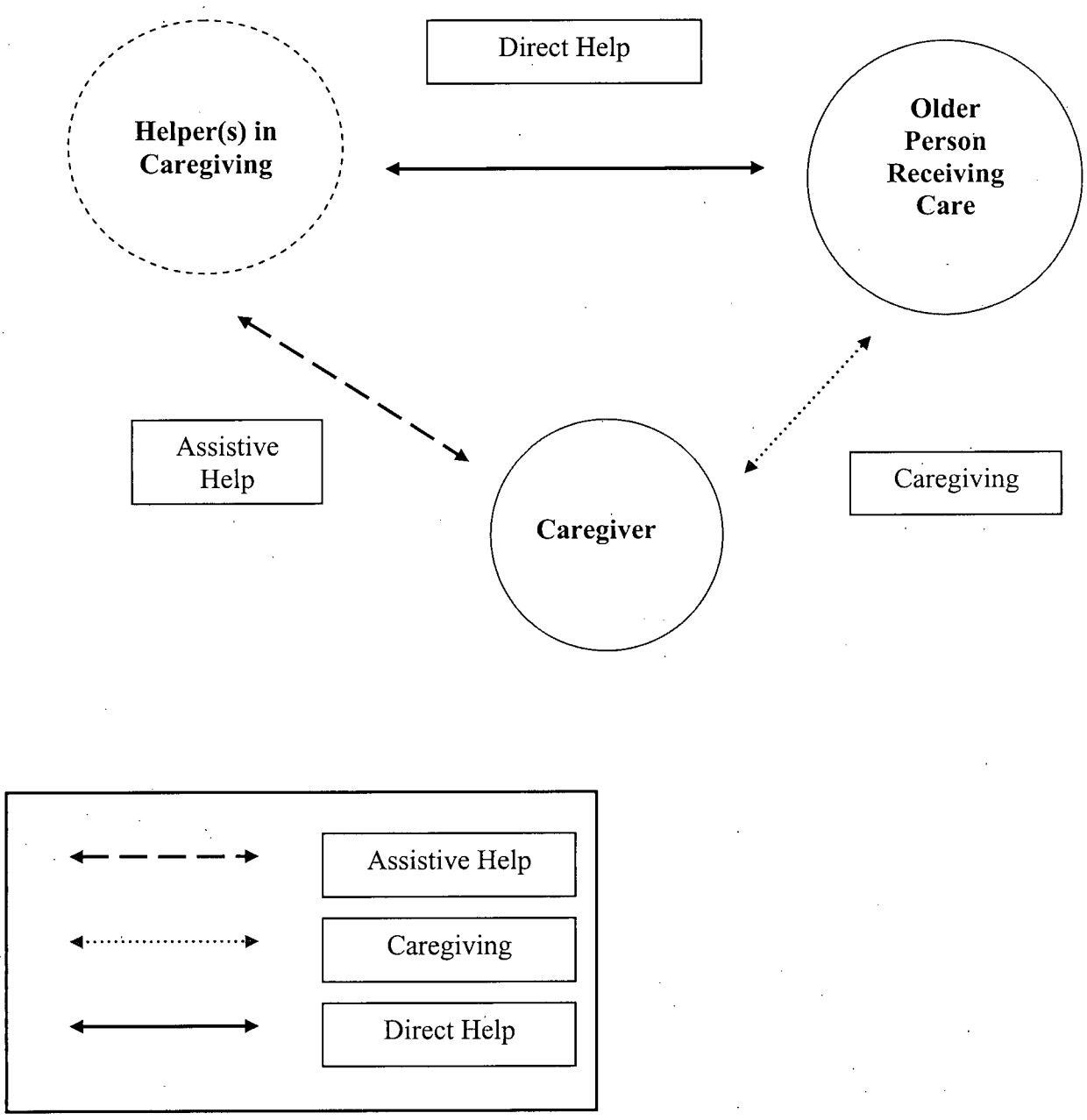


Figure 2.3 depicts the different types of help to be measured in this study. The dotted arrow highlights the relationship most commonly discussed in caregiving research – the care given by the primary caregiver to the older person receiving the most care (highlighted in Figure 2.1). The dashed arrow highlights assistive help extended from helpers to caregiver. The solid black arrow represents direct help given by helpers to the older person receiving care. This diagram extends previous work on caregiving in that it includes helpers and assistive and direct help in caregiving. It must be noted that while reciprocity exists within the relationships between helpers and caregivers, and is depicted in Figure 2.3 through the use of bi-directional arrows, the reciprocal nature of the relationship is not a focus of this study.

How Do Helpers Help?

Abel and Nelson (1990: 4) describe the character of caregiving relationships as "encompassing both instrumental tasks and affective relations". Instrumental tasks are defined as those tasks necessary to the physicality of daily living (feeding, bathing, taking medication etc.) while affective relations include emotional and social support. In determining the contributions of multiple individuals in caregiving, an essential step is to understand the "character" of help given and received, that is, whether help involves instrumental tasks, affective relations or both. Understanding the type and character of caregiving tasks has been common in family caregiving research and has most often relied on Katz' (1963) distinction of tasks as Activities of Daily Living and Instrumental Activities of Daily Living. Research on caregiver tasks has been essential in developing an appreciation for the nature and extent of primary caregiver contributions. However, a focus on primary caregiver tasks does not contribute to an understanding of whether other

individuals participate in the provision of care, either directly to the older person or indirectly by giving assistance to the caregiver. Building on previous caregiving research on the tasks of primary caregivers, this study examines the contributions of helpers to both the primary caregiver (assistive help) and the older person receiving care (direct help). As stated, the distinction between assistive help and direct help has not previously been made in the literature and has the potential to extend our understanding of the multiple and differential contributions involved in caring for an older adult.

What Predicts Help?

In gerontological caregiving research a number of factors have been found to influence the likelihood of caregiving. Health status of the older person receiving care has been shown to be one of the most significant predictors of care received (Keating et al., 1999; Navaie-Waliser, Spriggs & Feldman, 2002). Age and marital status of the older person, have also been shown to influence the incidence and frequency of tasks associated with receiving caregiving assistance (Fast et al., 2004). Therefore in understanding differences and similarities in helping and caregiving, it is important to determine whether certain factors such as: health status, age, and/or marital status of the older adult receiving care, and the activities of the primary caregiver influence the likelihood of receiving a specific type of help in caregiving.

Research Questions

Guided by a review of literature and drawing on the available conceptual frameworks for studying the relationships and contributions of multiple individuals involved in caregiving, this paper focuses on the development of a picture of 'helpers' in family caregiving where the nature or character of help, who is delivering it and the predictors of certain types of help are examined. The research was guided by the following questions:

- Who helps the caregiver?
- How do helpers help (i.e. what are they doing)?
- Do helpers provide predominantly direct help to the care recipient or assistive help to the caregiver?
- Are there factors that predict the help given by helpers?
    - For example, are the contributions from direct helpers influenced by the activities of the respondent caregiver?

Methods

Design

The CARNET Work and Family Study conducted from 1991-1992 involved the distribution of surveys to 9,693 employees in eight Canadian organizations[8]. The organizations do not represent a random cross-section of Canadian employees, but efforts were made to select organizations representing different employment sectors, including government agencies, financial services, manufacturing, health services and educational institutions (Gottlieb, Kelloway & Fraboni, 1994; Gignac, Kelloway & Gottlieb, 1996).

Personal meetings (by individuals involved in the initial data collection of the Work and Family Study) were conducted with employers to describe and explain the purpose of the study. Once an organization agreed to participate, employees were mailed an information letter describing the study. They were also mailed a questionnaire comprised of standardized scales from previous research as well as items developed specifically for this study (Gottlieb, Kelloway & Fraboni, 1994). In six (of eight) of the organizations participants over the age of 35 were over-sampled to increase the likelihood of identifying people currently providing assistance to a relative aged 65 or older (Gottlieb, Kelloway & Fraboni, 1994; Gignac, Kelloway & Gottelieb, 1996).

A variety of methods were used to distribute and collect the survey in accordance with the preferences of participating organizations (Gottlieb, Kelloway & Fraboni, 1994). The questionnaire was self-administered and took approximately 35 to 45 minutes to complete. A notice was mailed one week after the survey was distributed to each company to remind all respondents who had not returned a questionnaire to please do so. Across all participating organizations, a total of 5, 496 usable surveys were returned,

[8]Most of the organizations were located or had headquarters in the province of Ontario; they were situated in both urban and rural environments.

yielding an overall response rate of 57 per cent in the first wave of the study (1991-1992). At this stage, 878 respondents identified themselves as being available for further follow-up studies and provided follow-up contact information.

The second phase of the research, conducted in 1994, involved a follow-up with the respondents who had provided contact information in stage one. Of the 878 who provided follow-up contact information, 497 could be located. This second stage was conducted as a screening step to identify individuals for inclusion in stage three. Individuals were asked a variety of questions regarding the provision of care to an older adult, including: "Do you provide assistance with personal care (i.e. feeding, bathing, etc.)?", "Do you provide assistance with household chores/maintenance?", "Do you provide assistance with finances?", "Do you provide emotional support ?" In order to be included in the third phase of the study the respondent had to be providing care to at least one relative and assisting with one Activity of Daily Living (feeding, bathing, dressing, etc.) or two Instrumental Activities of Daily Living (home maintenance, transportation, shopping, etc.). As a result of this screening 328 of the 497 individuals surveyed were identified for inclusion in the third and final stage of CARNET, The Work and Eldercare Study.

Of the 328 individuals to whom the survey was sent, 250 individuals (108 men and 142 women) completed the survey questionnaire. The respondents reported on various aspects of care provision for up to three elderly family members; they also provided information on caregiving contributions for up to three 'helpers". The third stage of research was conducted in order to examine patterns of formal service use and the frequency, type and duration of help provided by caregivers and those who they

identified as providing 'help' in family caregiving in a sample of employed Canadians. These 250 respondent caregivers form the sample for the present secondary analysis.

Sample

Table 2.1: Sample Characteristics

	N	%	M	SD
Respondent Characteristics				
Gender				
Male	108	43.2		
Female	142	56.8		
Marital status				
Married or common-law	217	87.1		
Separated or divorced	19	7.6		
Widowed	2	0.8		
Never married	11	4.4		
Only Person Providing Care				
Yes	31	13.5		
No	199	86.5		
Am the person providing the most care				
Yes	135	54.0		
No	114	45.6		
Age			43.3	7.10
Older Person Characteristics				
Overall Physical Health			2.67	.82
Poor	41	17.8		
Fair	84	36.5		
Good	94	40.9		
Excellent	11	4.8		
Overall Emotional Health			2.38	.90
Poor	30	13.0		
Fair	63	27.4		
Good	101	43.9		
Excellent	36	15.7		
Age			76.5	8.16

Table 2.1 shows select sample characteristics of respondents and older individuals identified as receiving care in the CARNET Work and Eldercare Study. Eighty four percent of respondent caregivers indicated that they were married or living common-law. Thirteen percent of respondents indicated that they were the only person providing help to their older relative while eighty six percent indicated that they received assistance from others. Respondents in this study (N=250) averaged 43.3 years of age (SD = 7.10). The majority of older individuals in the CARNET Work and Eldercare Study are identified by the respondent as being in fair (36.5%) or good (40.9%) overall physical health and fair (27.4%) or good (43.9%) overall emotional health. The individuals receiving care in this study averaged 76.5 years of age (SD = 8.16).

Table 2.1 also highlights the distinction between two types of respondent caregivers. In this study there are two types of respondents: primary caregivers and helpers. Respondents who answered 'yes' to the question 'are you the person who provides the most care' are primary caregivers; those who responded 'no' are helpers.

Thus, this study contains information from two types of respondents: those who are primary caregivers and those who are helpers. In addition, therefore, the study contains information on two types of helpers, those who are themselves respondents and those helpers being described by the respondents. This sample is unique in that there is the dual perspective where helpers are able to report on the contributions of primary caregivers as well as on other helpers

Measures

Measures include dependent variables, independent variables, control variables and explanatory variables. Appendix 1. (p. 150) provides a copy of the survey instrument. Means and standard deviations for dependent and independent variables are located in Table 2.7 (correlation matrix).

Dependent Variables.

Help Provided to Older Person by Helpers (Direct Help). To determine the type and frequency of help provided by helpers, respondents were asked five different questions. In a successive series of questions respondents were asked, "Within the past six months, how often *has this person* (helper one, helper two, helper three) helped your older relative/friend with feeding, bathing, dressing, toileting, or taking medication (personal care)?; second, by providing transportation, doing shopping and/or errands (general care)?; third, with laundry, household chores, meal preparation, home maintenance or yard work (household care)?; fourth, with moral or emotional support (emotional support)?; and fifth, with money management, or negotiating on behalf of their older relative (financial support)?". Respondents were asked to check the appropriate response category for each question, in relation to each helper, to indicate frequency of helping with that particular type of activity (0=never, 1= once or twice in the last 6 months, 2= every 1 or 2 months, 3=2-3 times a month, 4=once, 5=once a week, 6= several times a week, and 7= daily). Items were reverse coded for this measure as the original coding was counter intuitive with, 1=daily, 2=several times a week, 3=once a week, 4=2-3 times a month, 5=once every 1 or 2 months, and 6=once or twice in the last

6 months, 7=never. Univariate analyses show the responses are almost normally distributed for general care (SK .12, SE .17; K -1.1, SE .34)[9], household care (SK -.44, SE .17; K -1.2, SE .35) and emotional support (SK .21, SE .17 ; K -1.2, SE .35). When the values for skew and kurtosis are divided by their standard error[10], general care is not skewed (.71) but slightly kurtotic (-3.2), household care is not skewed (-2.6) but slightly kurtotic (-3.4) and emotional support is not skewed (1.2) but slightly kurtotic (–3.4). Personal care (SK –1.1, SE .17; K -.43, SE .34) is skewed (-6.4) but not kurtotic (-1.3) and financial support (SK –1.2, SE .17; K 2.5, SE .35) is skewed (7.0) and kurtotic (7.1). In both instances this is due to low response rates to the questions, very few respondents indicated that their relatives were receiving direct help with personal care or financial support. The measures regarding general care, household care and emotional although not normally distributed are not skewed but are slightly kurtotic. The measures used in the questions regarding type and frequency of help use Katz's (1963) classification of ADLs (feeding, bathing, dressing, toileting, help with medication) and IADLs (transportation, shopping, doing errands, laundry, household chores, meal preparation, home maintenance and yard work) a well-known categorical distinction for caregiving tasks. Although there is academic debate on the classification of tasks in caregiving, the ADL and IADL distinctions developed by Katz are currently the most well tested and widely used categories of tasks.

Help Provided to Respondent by Helpers (Assistive Help). To examine patterns of assistive help (the help provided to the respondent caregiver who then in turn provides help to the older relative) respondents answered the question: "In the last six months has

[9] SK denotes skew, SE standard error and K for kurtosis.
[10] When skew and kurtosis values are divided by their standard error, if the coefficient is greater than 3.0 or less than –3.0 it is skewed and/or kurtotic.

anyone assisted *you* in helping your elderly relatives/friend in any of the following ways: household chores, childcare, financial assistance, home/yard maintenance or repair, moral/emotional support or other?" Responses were dichotomous with a check/no check response format; respondents were asked to check each item where they received help with (household chores, childcare, financial assistance, home/yard maintenance or repair, moral/emotional support, other). If they selected 'other', respondents were asked to write down the nature of the help. Univariate analyses show that household support (SK .15, SE .20; K –2.0, SE .39) is not skewed (.75) but kurtotic (-5.1) and moral support (SK – 1.1, SE .20; K -.71, SE .39) is skewed (5.5) but not kurtotic (-1.8). Childcare (SK 5.9, SE .20; K 34.4, SE .39), financial support (SK 2.6, SE .20; K 4.8, SE .39) and home-yard maintenance (SK .25, SE .20; K -1.9, SE .39) have very skewed and kurtotic distributions most likely as a result of very low response rates to these questions.

Independent Variables.

Care Provided by Respondents. To determine the type and frequency of care provided, respondents were asked five different questions. These five questions form an index (not a scale) as items are not intended to be correlated. In a successive series of questions drawing Katz' distinction between ADLs and IADLs, respondents were asked, "Within the past six months, how often *have you* helped your older relative/friend with feeding, bathing, dressing, toileting, or taking medication (personal care)?; second, by providing transportation, doing shopping and/or errands (general care)?; third, with laundry, household chores, meal preparation, home maintenance or yard work (household care)?; fourth, with moral or emotional support (emotional support)?; and fifth, with money management, or negotiating on behalf of their older relative (financial support)?".

Respondents were asked to check the appropriate response category (0=never, 1=daily, 2=several times a week, 3=once a week, 4=2-3 times a month, 5=once every 1 or 2 months, and 6=once or twice in the last 6 months). Univariate analyses show that general care (SK -.36, SE .16; K -.93, SE .32) is not skewed (-2.25) or kurtotic (-2.9) and emotional support (SK .11, SE .16; K -1.2, SE .32) is not skewed (.68) but slightly kurtotic (3.7). The measures regarding general care and emotional support are reliable with the variance of responses almost normally distributed. Personal care (SK –2.8, SE .16; K 7.6, SE .32), household care (SK -.99, SE .16; K -.18, SE .32) and financial support (SK –1.4, SE .16; K 1.6, SE .32) are very skewed. The skews can be attributed to low response rates. Very few respondents indicated that they provide assistance to their relatives with personal care, household care or financial support. The measures with skewed distributions are therefore used only in descriptive statistics and not in the correlation or regression analyses.

Number of Hours of Care/Week Provided by Respondents. Respondents were asked to estimate the number of hours of help provided to their older relative in an average week or month by giving a numeric estimation (i.e. 4 hours per week or 12 hours per month) in response to the question "Overall, please estimate the number of hours of help you have provided to your older relative in an average week or month". The mean hours per week of care provided was 30 with a standard deviation of 9.31. Respondents were able to report on the amount of care provided for each of three older people.

Control Variables.

Older Person Characteristics. Age of the older person receiving care was determined by the respondent who responded to the question "How old is your relative?"

Age of the older relative was denoted by the respondent placing a numeral (i.e. 76, 84, etc.) in a blank space, followed by the word 'years'. Physical health status and emotional health status were each indicated by the respondent checking the appropriate category in response to the question "How would you rate your older relative's physical / emotional health status?" The checklist options included: 1=excellent, 2=good, 3=fair, 4=poor.

Explanatory Variables.

Respondent Characteristics. Respondent gender and marital status were identified by checking the appropriate response category (i.e. male/female, and married, common-law, separated, divorced, widowed, single/never married) in response to the questions "Are you (male / female)?" and "What is your present marital status?" Respondent age was denoted by a numeric (i.e. 42, 57, 33, etc.) in response to the question "What is your age in years?"

Primary Caregiver Identification. Respondents were asked to respond to the dichotomous (1=yes, 0=no) question "Are you the person who provides the most care to your older relative/friend?" to determine whether the respondent was the person most responsible for providing care to their older relative (often referred to in literature as the primary caregiver) or whether the respondent was a helper.

Helper Identification. The identification of direct helpers (those individuals whom the respondent caregiver identifies as providing help to the older person by the respondent caregiver) was determined by asking respondent caregivers, "Who else helps this relative?" Respondents were asked to identify the person providing help to the older relative/friend by noting their relationship to the older person receiving care. Examples of responses included: brother, son, relatives spouse, respondents spouse, respondents

sister, home support worker, foot care provider, etc. Respondents were able to identify up to three helpers involved in providing help to the older relative/friend.

The identification of assistive helpers was determined by respondents who were asked "Who helps you?" Respondents were asked to check as many categories as applicable. Categories included: your spouse, your daughter(s), your son(s), your sister(s), your brother(s), other family members, friends, caregiver support group, respite care, other (specify). Respondents were able to identify assistive helpers for up to three relatives that they (the respondent) were providing care for.

Total Direct Help. Several summative indices were developed to measure the total amount of direct help provided by helpers to the older relative or friend receiving care. These indices were developed as there was no question regarding total amount of help received (for all types of help) by the older adult receiving care from the helper(s). The indices were developed to give an overall total score for help received in the absence of a direct measure of total help.

Respondents were asked five separate questions, "Within the past six months, how often *has this person* (helper one, helper two, helper three) helped your older relative/friend: first, with feeding, bathing, dressing, toileting, or taking medication (personal care)?; second, by providing transportation, doing shopping and/or errands (general care)?; third, with laundry, household chores, meal preparation, home maintenance or yard work (household care)?; fourth, with moral or emotional support (emotional support)?; and fifth, with money management, or negotiating on behalf of their older relative (financial support)?". Respondents were asked to check the appropriate response category (0=never, 1= once or twice in the last 6 months, 2= every 1

or 2 months, 3=2-3 times a month, 4=once, 5=once a week, 6= several times a week, and 7= daily). Items were reverse coded for this measure as the original coding was counter intuitive with 7=never, 1=daily, 2=several times a week, 3=once a week, 4=2-3 times a month, 5=once every 1 or 2 months, and 6=once or twice in the last 6 months.

For each of the types of help (personal care, general care, household care, emotional support, financial support) there is a range of possible answers ranging from 0 (never) to 7 (daily) with a total maximum score of 35. A sum of the individual types of help creates an overall index for total amount of direct help provided by helpers. An alpha reliability was computed for the second and third index to ensure that respondents were answering the same question in each index for each of the two and three helpers; for example, that general care was interpreted similarly for helper one, helper two and helper three. An alpha reliability was not needed for the first index, as it was for one helper only.

The first index, One Helper, (N=197), was created by adding the 'help scores' for each type of care provided by helper one to create an overall score (maximum 35). The range for this index was 5.0 – 35.0 with a mean of 23.6 and a standard deviation of 7.2.

The second index, Two Helpers, (N=111), was created by adding the amount of care for each type of care provided by helper one and helper two (personal care, general care, household care, emotional care, financial care) to create an overall total score for two helpers (maximum 70). The range for this index was 22.0 – 70.0 with a mean of 48.7 and a standard deviation of 12.4 and a reliability alpha of .87.

The third index, Three Helpers, (N=55), was created by adding the amount of care for each type of care provided by helper one, helper two and helper three (personal care,

general care, household care, emotional care, financial care) to create an overall total score for three helpers (maximum 105). The range for this index was 33.0 – 105.0 with a mean of 71.9 and a standard deviation of 16.1 and a reliability alpha of .92.

Analysis

The survey data, including written responses to open ended questions, allowed for the development of descriptive caregiving vignettes. In addition to the development and analysis of vignettes, SPSS (statistical software) was used to generate frequency data. Cross tabulations and chi-squares were used to determine the presence of significant differences between type of help given by helpers as reported by primary caregivers and helpers.

Ordinary Least Squares (OLS) regression was conducted using SPSS to address the question of whether the type of help provided by direct helpers is related to the type and amount of care provided by the respondent caregiver. Ordinary Least Squares regression was selected as the analytical tool for this investigation, as the dependent variables used were continuous with almost normal distribution of responses. Dependent variables included: the type of help (general, household, emotional) provided by the helper. Financial help and personal care were not used as dependent variables as they had extremely skewed distribution of responses. Independent variables included: the type of help provided by respondent caregivers (general, household, emotional). Health (overall and emotional) status of the older relative, and marital status and age of the older relative were entered as control variables.

Results

Who Helps?

The first research question, 'who is a helper?' must be addressed in two steps, first by determining who is the primary caregiver, and then who is/are the helper(s). This is necessary as in the dataset used in this analysis, the respondent caregiver is not necessarily the primary caregiver (see measures section for more detail). Another distinction that must be made is between direct help (help to the older family member) or assistive help (by referring to help given to the primary caregiver who then assists the older adult).

Table 2.2: Characteristics of Primary Caregivers and Helpers

	Respondent Caregiver Is the Primary Caregiver N=135		Respondent Caregiver Is Not the Primary Caregiver (Helpers) N=114	
	N	%	N	%
Gender				
Male	51	37.8	57	49.6
Female	84	62.2	58	50.4
Marital Status				
Married	107	79.9	98	85.2
Common-law	9	6.7	3	2.6
Separated	4	3.0	4	3.5
Divorced	8	6.0	3	2.6
Widowed	0	0	2	1.7
Single/Never Married	6	4.5	5	4.3
Only Person Providing Help				
No	103	81.7	103	100
Yes	23	18.3	0	0
Number of Helpers*				
One	56	54.0	29	30.0
Two	27	26.0	31	32.0
Three	21	20.0	36	38.0
Identification of Person Receiving Most Care				
Spouse	3	2.2	0	0
Mother	79	58.5	55	49.1
Father	15	11.1	7	6.3
Mother-in-law	12	8.9	21	18.8
Father-in-law	1	0.7	3	2.7
Grandmother/Grandfather	4	2.9	7	6.3
Aunt/Uncle	4	3.0	9	8.1
Parents/Parents-in-law	-	-	1	0.9
Friend/Neighbour	3	2.2	3	2.7
Other Family	1	0.7	1	0.9
Number of Older People Providing Care For				
One	127	94.0	104	91.2
Two	53	39.2	66	58.0
Three	9	6.7	24	21.0

* In this table "help" and "helpers" refers to the assistance given directly to the older person. One helper refers to only one helper, two helpers refers to only two helpers.

Table 2.2 shows characteristics of respondent caregivers who provide the most care (primary caregivers) and those who do not (helpers). Of the 250 individuals who responded to the survey, 54% indicated that they were the primary caregiver while 46% indicated they were not. The primary/respondent caregiver group (primary caregivers)

differed from the respondent/not primary caregiver groups (helpers) in gender composition and marital status. Sixty two percent (62.2%) of primary caregivers were female, 37.8% men. Fifty percent (50.4%) of respondents who were helpers were female, 49.6% men. The vast majority of respondent caregivers/helpers are married, with slight differences between the caregiver and helper categories; 79.9% of primary caregivers are married while 85.2% of helpers are married.

Respondent primary caregivers differed from respondent helpers in the frequency distribution of reporting one helper, two helpers, or three helpers. This was determined by examining the frequency with which respondents (both respondent caregivers and helpers) listed themselves as having one, two, or three helpers. In the case of the primary caregiver, 82% indicated receiving help; the frequency of having one, two and three helpers was 54%, 26% and 20%. In the helper group, 92% indicated having help; the frequency of having one, two and three helpers was 30%, 32% and 38%. In both respondent groups, while the identification of helpers varied, mothers were the person most often being cared for.

In the CARNET survey, respondents had the opportunity to provide information on up to three older adults to whom they were providing care. Of those who identified themselves as primary caregivers 94.0% indicated caring for one older person, 34.2% indicated providing care to two older people and 6.7% indicated providing care to three older individuals. Of those who were helpers, 91.2% indicated providing care to one older person, 58% indicated providing care to two older people, while 21% indicated providing care to three older individuals.

Table 2.3: Helper Identification

	Respondent Caregiver Is the Primary Caregiver (Primary Caregiver) N=135		Respondent Caregiver Is Not the Primary Caregiver (Helpers) N=114	
	N	%*	N	%*
DIRECT HELP				
Identification of Helper One**				
Respondent's Spouse	23	22.1	31	32.3
Respondent's Sister	30	28.8	21	21.9
Respondent's Brother	22	21.2	16	16.7
Relative's Spouse	6	5.8	5	5.2
Identification of Helper Two**				
Respondent's Spouse	3	6.3	5	7.5
Respondent's Sister	5	10.4	15	22.4
Respondent's Brother	12	25.0	8	11.9
Respondent's Sister-in-law	6	12.5	15	22.4
Identification of Helper Three**				
Respondent's Spouse	3	14.3	5	13.9
Respondent's Sister	3	14.3	3	8.3
Respondent's Brother	3	14.3	7	19.4
Respondent's Brother-in-law	2	9.5	5	13.9
ASSISTIVE HELP				
Identification of Helper				
Respondent's Spouse	41	30.4	39	33.9
Respondent's Daughters	19	14.1	10	8.7
Respondent's Sons	11	8.1	14	12.2
Respondent's Sister	26	19.3	25	21.7
Respondent's Brother	21	15.6	25	21.7
Other Family	26	19.3	26	22.6
Friends	21	15.6	13	11.3
Caregiver Support Group	10	7.4	9	7.8
Respite Care	3	2.2	3	2.6
Other	14	10.4	7	6.1

*Percentage refers to the number of individuals identified as helpers in each category, divided by the total number of helpers for that category. Note that the N for each cell varies.
**Top Two/Three Helpers in Each Category (Helper One, Helper Two, Helper Three) Listed.

Table 2.3 shows the differences between direct and assistive help for respondent and helpers. It is important to note prior to interpreting Table 2.3 that respondents reported on the identification and activities of each individual helper with respect to direct help (those helpers providing assistance directly to the older person) but could only

report in an aggregate manner on those individuals providing assistive help (help given to the respondent caregiver) (see Measures section for more detail).

Concerning direct help, primary caregivers most often reported sisters as being the number one helper. The number one helper was the person who the respondent listed first as providing help, the number two helper was the second person and the number three helper the third person (see Measures section for more detail). Number two helpers were most often brothers (25.0%) while number three helpers were with equal frequency spouse, sister and brother (14.5%). Helpers most often reported their spouse as the number one helper (32.3%) suggesting that the spouse helper is likely the primary caregiver.

In assistive help spouses are the most frequent helpers to both respondent primary caregivers and helpers. Brothers and sisters provide direct and assistive help with greater frequency than brothers-in-law and sisters-in-law while friends are frequently identified as assistive helpers for both primary caregivers (15.6%) and helpers (11.3%). The daughters and sons of the respondent caregiver also appear as assistive helpers (these are the grandchildren of the person receiving care). This group is not often recognized in the caregiving literature as providing care. It should be noted that respondents had the opportunity to list multiple assistive helpers.

How Do Helpers Help?

The second research question, 'how do helpers help?' is a multi-faceted research question. Like the first research question, in order to determine the ways in which 'helpers' help, it is essential to consider whether 'help' or tasks are provided directly (help to the older family member) or in an assistive manner (by way of help given to the

primary caregiver). For example, do helpers participate in providing instrumental support or in providing affective relations to the primary caregiver who then in turn performs the bulk of instrumental tasks? Abel & Nelson (1990:4) note that the character or nature of a caregiving exchange can encompass "instrumental tasks and/or affective relations".

Table 2.4: Assistive Help Provided to Respondent Caregivers by "Helpers"

Type of Assistive Help	Primary Caregiver (N=135)		Helper (N=114)		p[11]
	N	%	N	%	
Household Chores	37	44.6	34	48.6	ns
Childcare	1	1.2	3	4.3	ns
Financial Assistance	5	6.0	11	15.7	.043*
Home-Yard Maintenance	36	43.4	31	44.3	ns
Moral Support	62	74.7	52	74.3	ns
Other: e.g., transportation, running errands, meal preparation, socializing.	14	16.9	15	21.4	ns

* significant at the .05 level, ** at the .01 level, *** at the .001 level

Using a chi-square test, Table 2.4 highlights the responsibilities of helpers to those who are primary caregivers and those who are helpers[12]. Moral support (75%), household chores (45%) and home-yard maintenance (43%) are the types of help most often provided to primary caregivers. Similarly, moral support (74%), household chores (49%) and home-yard maintenance (44%) are the types of help most often provided to respondent helpers. Results shows that help to the respondent caregiver or helper is predominantly affective in nature. There are more similarities than differences with respect to assistive help, (help to the helper) between respondent caregivers and helpers.

[11] Chi-square tests assume equal probability of responses. Significant and non-significant results must therefore be interpreted cautiously.
[12] Helpers who are also respondents.

The only statistically significant difference between assistive help to primary caregivers versus helpers is in the provision of financial help ($p>.05$), with helpers providing financial assistance more frequently than primary caregivers.

Table 2.5: Direct Help Provided to Older Relative/Friend by "Helpers"

Type of Direct Help	Primary Caregiver (N=135)		Helper (N=114)		p
	N	%	N	%	
Household Care	34	25.2	28	24.6	ns
Personal Care	28	20.7	19	16.7	ns
Financial Support	18	13.3	12	10.5	ns
Emotional Support	49	36.3	47	41.2	ns
General Care*	37	27.4	45	39.5	ns

* General Care is defined as: transportation, shopping and/or errands.

Table 2.5 documents direct help given to the older adult as identified by primary caregivers and helpers. Emotional support followed by general care and household care, are the most frequent types of direct help as indicated by both groups of respondents. There are no significant differences between types of direct help provided to older relatives. Like results in Table 2.4 on assistive help, there are more similarities in direct help as identified by respondents than there are differences.

Table 2.6: Total Direct Help: A Comparison of Means

	Total Help Received	
	M	SD
One Helper	23.6	7.2
Two Helpers	48.7	12.5
Three Helpers	71.9	16.0

Table 2.6 shows the total mean score for direct help for those respondents who report having one, two and three direct helpers. The mean score was computed by

totaling the frequency of providing assistance with personal care, household care, financial support, emotional support and general care and then computing the mean for this total value. The total possible score for those respondents having one helper is 35 (this would mean providing daily help with each type of assistance), for those having two helpers the total possible score is 70, and for those who report having three helpers it is 105. The mean score for those having one helper is 23.6 (SD: 7.2), for those with two helpers 48.7 (SD: 12.5) and for those with three helpers 71.9 (SD: 16.0). Table 2.6 shows that there is an additive effect with the addition of each helper. This results in an increase in the mean score. There is a slightly greater jump in the score from one to two helpers than from two to three helpers. This additive increase suggests that with the addition of each helper the overall mean score almost equivalently increases. Simply, the more helpers you have the more help you get.

What Predicts Help?

Ordinary Least Squares (OLS) regression was conducted using SPSS to address the question of whether the help provided by direct helpers (general, household or emotional) can be predicted by the activities of the respondent caregiver when controlling for health, age and marital status of the older person. Ordinary Least Squares regression was selected as the analytical tool for this portion of the investigation as the dependent variables used were continuous with almost normal distribution of responses (see Measures section for more detail). Dependent variables included: help (general, household, emotional) provided by the helper. Personal care and financial support were not included in the regression analyses, as they did not satisfy assumptions of normal distribution. Independent variables included: help provided by respondent caregivers

(general, household, emotional). Health (overall and emotional) status of the older relative, and marital status and age of the older relative were entered in Step 1 of the regression. Table 2.7 shows the correlations, means and standard deviations of variables entered into the OLS regression equation.

Table 2.7: Correlation Matrix for Variables Included in OLS Regression

	1	2	3	4	5	6	7	8	9	10
1. Age Older Person (OP)	1.00									
2. Marital Status (OP)	.07	1.00								
3. Overall Physical Health (OP)	.11	-.04	1.00							
4. Overall Emotional Health (OP)	.03	.01	.50**	1.00						
5. Provided General Care	-.12	-.10	-.08	-.06	1.00					
6. Provided Household Care	.08	.08	-.16*	-.10	.56**	1.00				
7. Provided Emotional Support	-.02	-.03	-.27**	-.32**	.53**	.48**	1.00			
8. Helper Provided General Care	-.04	.04	-.06	.03	.17*	.05	.07	1.00		
9. Helper Provided Household Care	.06	.17*	-.14*	-.12	.08	.21**	.06	.43**	1.00	
10. Helper Provided Emotional Support	-.08	.18**	-.16*	-.26**	.00	.03	.27**	.36**	.40**	1.00
Mean	76.5	1.80	2.67	2.38	4.74	5.41	3.92	4.07	4.68	3.73
SD	8.16	.70	.82	.90	1.77	1.80	1.90	1.80	2.11	2.00
N	232	232	230	230	230	227	226	199	197	197

* significant at the .05 level, ** at the .01 level, *** at the .001 level

Table 2.7 shows the correlation matrix for those variables included in the regression analyses. There are a number of significant correlations that suggest that the type of help provided in caregiving is influenced by the activities of respondent caregiver and can be attributed to some characteristics of the older person.

The marital status of the older person is significantly related to the helper providing household care ($p<.05$) and the helper providing emotional support ($p<.01$). The overall physical health of the older person is significantly related to the respondent providing household care ($p<.05$) and is also significantly correlated to the provision of emotional support by respondent caregivers ($p<.01$). The overall physical health of the older person is also significantly correlated to the helper providing household care ($p<.05$) and it is also correlated with the provision of emotional support by helpers in caregiving ($p<.05$).

The overall emotional health of the older person is correlated with the respondent caregiver providing emotional support ($p<.01$) and the helper providing emotional support ($p<.01$).

The provision of general care by respondent caregivers is correlated with a number of variables. Provision of general care by respondent caregivers is significantly correlated to the provision of household by respondent caregivers ($p<.01$), it is also significantly correlated with the provision of emotional support by respondent caregivers ($p<.01$). By squaring the correlation in Table 2.7 and converting to a percentage, 25.0% of those providing general care also provided household care, similarly 25.0% of respondent who provide general care also provide emotional support.

The provision of household care by respondent caregivers is significantly correlated to the provision of emotional support by respondent caregivers ($p<.01$); 25.0% of those respondents providing household care also provide emotional support. The provision of household care by respondent caregivers is also significantly related to the provision of household help by helpers ($p<.01$). The provision of emotional support by

respondent caregivers is correlated with the provision of emotional support by helpers ($p<.01$).

The provision of general care by helpers is correlated with the provision of household care by helpers ($p<.01$) and the provision of general care by helpers is correlated with the provision of emotional support by helpers ($p<.01$). By squaring the correlation in Table 2.7, 18.0% of those helpers that provide general care also provide household care, similarly 73.0% of those helpers that provide general care also provide emotional support.

Table 2.8: Multivariate unstandardized (b) and standardized (beta) regression coefficients for factors associated with the provision of General Care by Helpers

Variable	B	SE B	β
Step 1			
Age of Older Person	-.01	.02	-.05
Marital Status of Older Person	.16	.20	.06
Overall Physical Health of Older Person	-.21	.18	-.10
Overall Emotional Health of Older Person	.14	.17	.07
Step 2			
Age of Older Person	-.005	.02	-.02
Marital Status of Older Person	.21	.10	.08
Overall Physical Health of Older Person	-.22	.18	-.10
Overall Emotional Health of Older Person	.16	.17	.08
Respondent Provided General Care	.25	.10	.24*
Respondent Provided Household Care	-.11	.10	-.10
Respondent Provided Emotional Support	-.01	.09	-.01
Step 3			
Respondent Provided General Care	.18	.07	.17*

Note: $R2 = .012$ for Step 1; $\Delta R2 = .028$ for Step 3; N=191
* significant at the .05 level, ** at the .01 level, *** at the .001 level

Table 2.8 shows results of the regression analysis with the provision of general care (general care is defined as: transportation, shopping and/or errands) by helpers as the dependent variable. In step one of the regression analysis, none of the control variables

significantly predict the provision of general care by helpers. In step two, the provision of general care by the respondent caregiver is the only significant predictor of helpers providing general care ($p<.05$). It should be noted that the β weight in step two for the provision of general care by the respondent is higher than its β weight in the correlation matrix (Table 2.7). When put alone into the regression equation its β weight is the same, indicating that there is a suppression effect by one of the other variables. Adding each individual, the provision of household care by the respondent, is the variable that changes the β weight of the provision of general care. Step three is the regression with only the provision of general care. Step three explains 2.8% of the variance in the provision of general care by helpers to the older person.

Table 2.9: Multivariate unstandardized (b) and standardized (beta) regression coefficients for factors associated with the provision of Household Care by Helpers

Variable	B	SE B	β
Step 1			
Age of Older Person	.01	.02	.06
Marital Status of Older Person	.51	.23	.16
Overall Physical Health of Older Person	-.23	.21	-.09
Overall Emotional Health of Older Person	-.14	.19	-.06
Step 2			
Age of Older Person	.01	.02	.04
Marital Status of Older Person	.49	.23	.16
Overall Physical Health of Older Person	-.16	.21	-.07
Overall Emotional Health of Older Person	-.18	.19	-.08
Respondent Provided General Care	.003	.12	.03
Respondent Provided Household Care	.24	.11	.20*
Respondent Provided Emotional Support	-.08	.10	-.07

Note: $R2 = .12$ for Step 1; $\Delta R2 = .05$ for Step 2; N=190
* significant at the .05 level, ** at the .01 level, *** at the .001 level

Table 2.9 shows the results of the regression analysis with the provision of household care by helpers as the dependent variable. In step one of the regression analysis none of the control variables significantly predict the provision of household care. In step two the provision of household care by the respondent caregiver is the only significant predictor of helpers providing general care ($p<.05$). Step two explains 5.0% of the variance in the provision of household care by helpers to the older person.

Table 2.10: Multivariate unstandardized (b) and standardized (beta) regression coefficients for factors associated with the provision of Emotional Support by Helpers

Variable	B	SE B	β
Step 1			
Age of Older Person	-.02	.02	-.09
Marital Status of Older Person	.58	.21	.19
Overall Physical Health of Older Person	-.07	.19	-.03
Overall Emotional Health of Older Person	-.55	.17	-.25
Step 2			
Age of Older Person	-.02	.02	-.10
Marital Status of Older Person	.57	.20	.19
Overall Physical Health of Older Person	-.01	.19	-.20
Overall Emotional Health of Older Person	-.44	.17	-.01*
Respondent Provided General Care	-.13	.10	-.11
Respondent Provided Household Care	-.05	.10	-.04
Respondent Provided Emotional Support	.29	.09	.26**

Note: $R2 = .12$ for Step 1; $\Delta R2 = .04$ for Step 2; N=190
* significant at the .05 level, ** at the .01 level, *** at the .001 level

Table 2.10 shows results of the regression analysis with the provision of emotional support by helpers as the dependent variable. In step one of the regression analysis none of the control variables significantly predict the provision of emotional support. In step two the provision of emotional support by the respondent caregiver is a significant predictor of helpers providing emotional support ($p<.01$), as is the overall emotional health of the older person ($p<.05$). Step two explains 4.0% of the variance in the provision of emotional support by helpers to the older person.

Discussion

This research explored the interplay of contributions and relationships in family caregiving, with attendant emphasis on the presence of 'helpers'. Based on the findings on who helps, how helpers help, and what predicts help, a picture of helping in caregiving emerges. This study disentangled some of the dimensions of helping and caregiving such as the distinction between direct and assistive help and between primary caregivers and helpers. It is also examined the nature of help to the respondent caregiver (assistive help) and help to the older person receiving care (direct help).

Results of this study show that caregivers do not act in isolation from their families in the context of providing care to an older person. Caregivers most often have help in their caregiving. As shown in Table 2.2, 82% of primary caregivers have help in caregiving and 92% of respondent helpers have help. Spouses, sisters, sisters-in-law, brothers and brothers-in-law are identified as direct helpers (Table 2.3). Spouses, sisters, daughters, sons, other family, and friends are among those identified as assistive helpers. Family caregiving is often comprised of multiple individuals providing assistance to one another in addition to care provided to an older relative(s)/friend(s).

In addition to the assistance given to one another, many caregivers and helpers provide simultaneous care to more than one older person (Table 2.2). In contrast to conceptions of caregiving, where there is one caregiver and one care recipient, Table 2.2 shows that many caregivers and helpers are providing assistance to more than one older person. This finding has research and policy implications. From a research perspective, particularly from a stress and burden perspective, the addition of care recipient(s) likely

influences the caregiving experience. From a policy perspective, provisions must be made for the caregivers simultaneously caring for multiple older adults.

Helpers have extensive help from a variety of sources not unlike primary caregivers (Table 2.3). With a focus on primary caregivers in most research, and with little known about the contributions of other individuals in the provision of care to an older relative/friend, it was anticipated that primary caregivers would have a range of help. The range of helpers identified by helpers was an unexpected finding of this study (Table 2.3). Both primary caregivers and helpers receive assistance that helps them in their caregiving contributions. Primary caregivers and helpers report spouses and siblings as providing direct assistance; however, helpers identify spouses with slightly greater frequency than primary caregivers (most likely because the spouse is de facto the primary caregiver). With respect to assistive help, there is reliance on spouses, sisters, sisters-in-law, brothers, brothers-in-law, daughters, sons and other family and friends for assistive help. The helping networks of helpers are as varied as primary caregivers.

This finding extends Kahn & Antonucci's (1981) work on convoys of social support and Cantor's (1991) social care model by showing that helpers and caregivers have networks of support, much like the older person receiving care. Kahn & Antonucci (1981) and Cantor (1991) highlight the range of assistance provided to an older person receiving care, but they do not highlight the networks of support that exist for primary caregivers and helpers. In this study, caregiving is shown to be comprised of individuals providing multiple and differential contributions to the older person receiving care and to one another. Caregiving is more than the support provided to one older person by one caregiver. These findings support the addition of arrow a. and arrow b. in Figure 2.2, and

extend Kahn & Antonucci's (1981) and Cantor's (1991) models of social support to a family level model. The revised model (including arrows a. and b.) better reflects the reality of family caregiving, where there are contributions to the older person, to the primary caregiver and between caregivers and helpers.

The predominance of kin is evident in the identification of helpers for both primary caregivers and helpers. Caregivers do not act in isolation from their families in the context of providing assistance to an older relative/friend. The predominance of kin highlights the potential for family dynamics when multiple members of the same family provide care to an older relative. The involvement of multiple family members in caregiving likely has both positive and negative implications. For example, the giving and receiving of contributions in the context of providing care can enhance family relationships and dynamics. However, relationships can also be stressed and strained by feelings of obligation, unspoken agendas, implicit and explicit negotiations and the individual and collective stress associated with caring for a sick and/or frail older relative. With each added individual in family caregiving, there is the possibility for the exponential addition of relationship dynamics – some good, some bad, some enhanced, some impeded. Examining contributions in caregiving, as in this study, begins to highlight the potential for these relationship dynamics when multiple individuals contribute to the care of an older relative.

To date, the distinction between direct and assistive help[13] has not been made in the family caregiving literature. This is in part due to a lack of acknowledgement of the participation of individuals beyond the primary caregiver. By expanding the research

[13] Direct help was operationalized as being help or care given directly to the older person receiving care. Assistive help was the help given to the respondent caregiver/helper.

focus from one primary caregiver to contributions from multiple individuals, a distinction can be made between direct and assistive help. This distinction helps to identify one of the salient issues in contemporary family caregiving research – there are different types of contributions within the context of care provision. This issue has been explored with respect to the nature of primary caregiver activities but has not been examined with respect to the differences in contributions to the older person and/or to other caregivers. In many caregiving circumstances particularly those where multiple family members are involved, different people will be making different types of contributions. Examining family caregiving as a series of contributions, with variations in those activities, creates a web-like picture. The distinction between direct and assistive helps illustrate the different ways in which family members contribute to the care of older kin.

As shown in the results section, direct and assistive help to the caregiver and help to the older adult are both similar and different (Table 2.4 & Table 2.5). Respondent caregivers most often receive assistance in the form of moral support and aid with household chores, while 'helpers' most often assist their older relative/friend with transportation, shopping and errands, followed by emotional support. Assistive help is most often affective (emotional) in nature while direct help tends to be instrumental. While some helpers provide instrumental support to the respondent caregiver it is much less frequent than the affective help. Helpers in caregiving emotionally support primary caregivers, offering encouragement and validation, which likely enables or supports the provision of care to the older relative. 'Help' therefore supplements care to the respondent caregiver and to the older relative.

Helpers in family caregiving provide affective and instrumental support to both the care recipient and the respondent caregiver. However, direct help is provided with greater frequency than assistive help. The reason for this finding may be due in part to the structure of the CARNET survey. More detailed information was gathered on direct help (see Measures section for more detail) than on assistive help. Respondents were able to comment individually on the type and frequency of direct help to the older person receiving care by each individual helper. However, in contrast, the information on assistive help was aggregated across helpers (i.e. respondents were asked to check as many applicable responses to the question 'who helps you?').

An expected finding of this study was that the addition of direct helpers raised the overall mean for total amount of help. Simply, the more helpers, the more help. However, the total mean did not go up equally. There is a larger jump with the addition of a second helper than a third helper. This suggests that helper three provides help less frequently and/or help with time-limited tasks. This points to the potential limits of help and supports Kahn & Antonucci's (1981) notion that as individuals become more distant from the older person, the help is less extensive (as depicted in the concentric rings moving away from a central care recipient in Figure 2.2). However, what is not known but can be speculated based on findings from this study, is that a similar situation exists with assistive help. As assistive helpers become more distant from the caregiver, the help they offer is likely less extensive (although qualitatively still important). In the Work and

Eldercare Study of CARNET respondents were able to order[14] helpers for direct help but not assistive helpers.

Correlation and regression analyses helped to indicate predictors of type of help. They were also instrumental in underscoring interconnectedness between direct help and the activities of the respondent caregiver. The type of care provided by helpers was significantly related to the contributions of the respondent caregiver for a number of different types of care (general, household, emotional) (Table 2.7, 2.8, 2.9 & 2.10). While this result seems somewhat intuitive, it speaks to the intricacy of family caregiving arrangements. The types of care and help within a family are not solely tied to health, marital status or age of the older person receiving care, but are also a function of what others are doing. For example, the provision of household care by helpers is significantly correlated to the provision of household care by respondent caregivers ($p<.01$) and the provision of general care by helpers is correlated to the provision of emotional support by helpers ($p<.01$) and the provision of household care ($p<.01$) (Table 2.7). The findings, as shown in Table 2.7 – 2.10, like the findings on total mean amount of help, point to the interconnectedness of family care. It is not enough to know what one caregiver is doing independently. Family caregiving, and the multiple contributions that exist within caregiving, are better understood by using a social care network model as suggested by Kahn & Antonucci (1981) and Cantor (1991). Like studies of marriage, where there is often a focus on his marriage, her marriage and their marriage, family caregiving has similar overlaps and combinations of contributions.

[14] Respondents were able to order direct helpers (i.e. helper one, helper two, helper three) but they were not asked to rank the helpers. However, in most cases, helper one was the individual providing the most help, helper two the second most, etc.

The following vignette describes the care situation of a participant caregiver in CARNET and was developed using descriptive and verbatim data from the CARNET Work and Eldercare Study. This vignette illustrates the contributions of multiple individuals, the balance of direct and assistive help, the nature of help provided (affective/instrumental) and the interconnection of helping and caregiving contributions.

Maria is an elementary school teacher, 40 years old, married and with two children ages six and three. Both her parents are still living. She has one brother and one sister. She provides help/care to her widowed mother-in-law, Gloria age 75, who lives in her own home/apartment. Her mother-in-law's physical health is described as excellent, but her emotional health as "fair". Instrumental activities performed by Maria include help with transportation and meal preparation (three years ago Maria was helping weekly with meal preparation, transportation, shopping and running errands, but now she helps two to three times a week with the same tasks as well as helping several times a week with emotional support). Although Maria provides more help than does anyone else to her mother-in-law, others also provide assistance to both Gloria and to Maria. Maria receives help with household chores and also moral support from her husband Willem and friends. This assistance helps Maria in that it "frees her up" to provide assistance/care to Gloria. Gloria receives help from Maria's husband Willem, and also from Maria's sister-in-law Carry. Gloria's friend Gertrude also provides help to Gloria. While Maria is the primary caregiver for her mother-in-law Gloria she is also concerned about the well-being and future of her own parents who are in their 80's and live outside Canada. Maria states: "I am just beginning to undertake arranging for my parents to come to Canada if and when necessary for health reasons. This has taken a fair bit of time already, and I've made a little headway. Having one "elder" in town takes time, but when your own parents are far away, it raises many issues and problems that are not easy to solve. I'm not sure what will happen if either of my parents becomes seriously ill or hospitalized. I think my sister and I will have to take time off work and leave our families to take care of them...work and family responsibilities obviously come into the picture when making the difficult decisions that lay ahead".

This vignette describes a family caregiving scenario with a relatively low level of caregiving need and responsibility. However, even within the context of this rather circumscribed family caregiving scenario, the variety of contributions and interconnectedness of direct and assistive care are illustrated. While balancing the needs of a young family, Maria helps to sustain her mother-in-law living alone with both direct and assistive help. The vignette, with attention to describing assistive/direct help and

affective/instrumental support, highlights the intertwining of family caregiving responsibilities.

An interesting component of this vignette, when considering who helps and how they help, is its reference to the passage of time. In this vignette, Maria has concerns regarding the balance of help, as articulated in her verbatim account of current and anticipated care roles. She is worried that her parent's probable changing needs will require ongoing adjustment and re-organization of work and family lives. This raises an additional perspective on the family, while research captures a current perspective on their caregiving, it is expected to, and likely will change. For example, as family caregiving extends through time, a number of possible and probable changes can occur that serve to increase the likelihood of helpers being involved. These include: changing health status of the older relative, changing work/family responsibilities of the respondent caregiver, and/or increased competency and delegation of family responsibilities by the respondent caregiver. The further broadening of caregiving research, from a primary caregiver focus to a network of interconnected relationships including attention to the passage of time (in terms anticipated future needs), serves to improve our understandings of family caregiving. This is a logical extension of current caregiving conceptual frameworks like Kahn & Antonucci's (1981) convoys of social support model and Cantor's (1991) model of social care where the 'interconnectness' of relationships across the life span are not currently considered.

There are two limitations that affect the ability to generalize the findings in this study. The first limitation was the cap on the number of direct helpers that could be included in the survey responses. The CARNET survey limited respondents to naming

up to three helpers. However, Porter, Ganong, Drew & Lanes (2004) contend that while most individuals in receipt of care have only one or two caregivers, they can have up to eight helpers, many of whom do not provide regular assistance but are 'standing by' to provide short term assistance. Future studies would benefit from including information on more than three helpers, as well as better characterizing the roles and functions of those helpers who provide irregular or intermittent assistance, including both direct and assistive assistance. This type of research could provide information on the different types of helpers by making a distinction between those who are regular helpers and those who assist in the context of a crisis in caregiving. For example, in the case of geographically dispersed families it may be that some family members 'fly in' during the occurrence of a crisis to provide help. This type of help would be different from the assistance that another more geographically proximate helper might provide on a regular basis. Results of this study show that there are different types of assistive help, an understanding of the different types of helpers would further extend understandings of variations in assistive help.

The second limitation was the restricted amount of information on caregiving and helping tasks. Information on 'caregiving' and 'help' was limited to ADL/IADL distinctions. Open-ended questions like "how do you assist your older relative?" or "what type of help does your older relative/friend receive?" would illuminate the breadth and variety in caregiving contributions beyond responses to predetermined lists of questions on provision of tasks. Similarly, more varied and/or specific response categories, like understanding the different types of emotional support (i.e. listening, reassuring, socializing, etc.) would contribute to a more detailed understanding of the

differences, similarities and points of overlap in helping, caregiving and family life/responsibility (Piercy, 1998).

Conclusions

When research on family caregiving is broadened to include information about multiple individuals, as in this study of 'helpers', the varied responsibilities for helpers and caregivers are demonstrated, and family caregiving emerges as a complex concept comprising a network of active individuals. This 'illumination of complexity' has two main effects. First, it allows one to describe and examine the intricacies of family life as well as the dynamics that cannot necessarily be summarized by looking at the interactions between two individuals. Second, it enables the asking and answering of new questions about family caregiving beyond caregiving dyads.

The identification of helpers is different depending on whether the respondent is a primary caregiver or helper. For primary caregivers, adult siblings are the most frequently identified direct helpers while spouses are the most frequent assistive sources of help. For helpers, spouses are the most frequent direct and assistive helpers, and in many cases are de facto the primary caregivers. For both caregivers and helpers the predominance of women as helpers in caregiving is evident. The majority of helpers are family and friends with only a small percentage being non-kin or paid helpers. Helpers make a variety of contributions both directly to the older person receiving care and by assisting the caregiver.

Examining direct and assistive help demonstrates the range of contributions and underscores the responsibilities undertaken when there is only one caregiver. Family caregiving is often comprised of multiple individuals. However, there are those individual caregivers who have no help. Future research on helping and caregiving that examines the potential limits of help could further extend understandings of those

circumstances when caregivers act alone or 'feel' like they are acting alone. Understandings of helping and caregiving could also be further extended by determining the transition from normative exchanges of aid to helping in the context of caregiving.

Caregiving is a family/group level concept. As shown, there is evidence that individuals are most often not acting alone in caring for their older relatives. Future research on helping and caregiving contributions would benefit from including the older person's contributions in analyses of the caregiving network.

Examining family caregiving as a group/family level concept also has important policy implications. Most policies/programs (i.e. Federal Government of Canada compassionate caregiver leave) only allow one (employed) caregiver at a time to access and obtain benefits. Knowing that there are likely multiple and equivalent caregivers in some caregiving situations raises questions for policy makers. How can resources be accessed and distributed among multiple caregivers simultaneously?

In addition to substantive conclusions regarding help and caregiving, this study raises suggestions for conceptual clarity. Kahn & Antonucci's (1981) convoys of social support model and Cantor's (1991) social care model, explain the different types of help given to an older adult receiving care; however, the models do not include an explicit means for understanding the contributions of helpers, and in particular, assistive help. As demonstrated in this study, individual models and frameworks, like Kahn & Antonucci's (1981) model and Cantor's (1991), benefit from including mechanisms to look at the multiple contributions both to the older person receiving care and among different caregivers and helpers.

References

Abel, E. K. & Nelson, M. K. (1990). Circle of care: An introductory essay. In Abel, E.K. & Nelson, M. K. (Eds.), Circles of Care: Work and Identity in Women's Lives, (434). New York: State University of New York Press.

Allen, K. R., Blieszner, R., Roberto, K. A. (2000). Families in the middle and later years: A review and critique of research in the 1990's. Journal of Marriage & the Family, 62(4), 911 – 927.

Allen, K. R. & Walker, A. J. (1992). Attentive love: A feminist perspective on the caregiving of adult daughters. Family Relations, 41(3), 284 – 290.

Antonucci, T. C. (1990). Social supports and social relationships. In R. H. Binstock & L. K. George (Eds.), Handbook of Aging and the Social Sciences, 3rd Edition, (205-227). San Diego: Academic Press.

Antonucci T. C., & Akiyama, H. (1995). Convoys of social relations: Family and friendships within a life span context. In Bleiszner, R. & Bedford, V. H. (Eds.), Handbook of Aging and the Family, (355-371). Greenwood Press.

Bengtson, V. L., & Allen, K. R. (1993). The life course perspective applied to families over time. In Boss, P. G., Doherty, W. J., LaRossa, R., Schumm, W. R., & Steinmetz, S. K. (Eds.). Sourcebook of Family Theories and Methods: A Contextual Approach, (469 - 499). New York: Plenum Press.

Boss, P. (2005). Forward. In Bengtson, V. L., Acock, A. C., Allen, K. R., Dilworth-Anderson, P. & Klein, D. M. (Eds.), Sourcebook of Family Theory & Research, (xv – xvi). Sage: Thousand Oaks.

Bubolz, M. M., & Sontag, S. M. (1993). Human ecology theory. In Boss, P. G., Doherty, W. J., LaRossa, R., Schumm, W. R., & Steinmetz, S. K. (Eds.). Sourcebook of Family Theories and Methods: A Contextual Approach, (419 – 448). New York: Plenum Press.

Cantor, M. H. (1979). Neighbors and friends: an overlooked resource in the informal support system. Research on Aging, 1(4), 434 – 463.

Cantor, M. H. (1991). Family and community: changing roles in an aging society. The Gerontologist, 31(3), 337 – 346.

Connidis, I. A. (2001). Family Ties & Aging. Thousand Oaks: Sage Publications.

Dupuis, S. L. & Norris, J. E. (1997). A multidimensional and contextual framework for understanding diverse family members' roles in long-term care facilities. Journal of Aging Studies, 11(4), 297 – 325.

Fast, J., Keating, N., Otfinowski, P. & Derksen, L. (2004). Characteristics of family/friend care networks of frail seniors. Canadian Journal on Aging, 23(1), 5 – 19.

George, L. K. (1993). Sociological perspectives on life transitions. Annual Review of Sociology, 19(1), 353 – 373.

Gignac, M., Kelloway, K. E., & Gottlieb, B. H. (1996). The impact of caregiving on employment: a mediational model of work-family conflict. Canadian Journal on Aging, 15(4), 525 – 542.

Globerman., J. (1996). Daughters- and sons-in-laws caring for relatives with Alzheimer's disease. Family Relations, 45(1), 37 - 45.

Gottlieb, B. H., Kelloway, K., & Fraboni, M. (1994). Aspects of eldercare that place employees at risk. The Gerontologist, 34(6), 815 - 821.

Haines, V. A. & Henderson, L. J. (2002). Targeting social support: A network assessment of the Convoy Model of Social Support. Canadian Journal on Aging, 21(2), 243 – 256.

Hareven, T. K. (1994). Aging and generational relations: A historical and life course perspective. Annual Review of Sociology, 20(1), 437 – 461.

Kahn, R. L. & Antonucci, T. C. (1981). Convoys of social support: a life-course approach. In March, J. G., Kiesler, S. B., Morgan, J. N., & Oppenheimer, V. K. (Eds.), Aging: Social Change, (383 – 405). New York: Academic Press.

Katz, S. (1996). Disciplining Old Age. Charlottesville: University of Virginia Press.

Keating, N. C., Fast, J. E., Frederick, J., Cranswick, K., & Perrier, C. (1999). Eldercare in Canada: Context, Content, and Consequences. Ottawa: Minister of Industry, Statistics Canada.

Marshall, V. W., Matthews, S. H., Rosenthal, C. J. (1993). Elusiveness of family life: a challenge for the sociology of aging. In Maddox G. L., & Powell Lawton M. (Eds.). Annual Review of Gerontology and Geriatrics: Focus on Kinship, Aging, and Social Change, (39 – 72). New York: Springer.

Martin-Matthews, A. (2000). Intergenerational caregiving: how apocalyptic and dominant demographies frame the questions and shape the answers. In Gee, E. & Guttman (Eds). The Overselling Population of Aging: Apocalyptic Demography, Intergenerational Challenges, and Social Policy, (64 – 79). Don Mills: Oxford University Press.

Martin-Matthews, A. (2004). Keynote address, at conference of the Annual Educational & Scientific Meeting of the Canadian Association of Gerontology, Victoria, B.C.

Matthews, S. (2002). Sisters and Brothers/Daughters and Sons: Meeting the Needs of Old Parents. Bloomington: Unlimited Publishing.

Matthews, S. & Rosner, T. T. (1988). Shared filial responsibility: the family as the primary caregiver. Journal of Marriage and the Family, 50(1), 185 – 195.

Milardo, R. M. (1988). Families and social networks: An overview of theory and methodology. In Milardo, R. M. (Ed.), Families and Social Networks, (13 – 47). California: Sage Publications.

Navaie-Waliser, M., Spriggs, A. & Feldman, P. H. (2002). Informal caregiving: differential experiences by gender. Medical Care, 40(12), 1249 – 1259.

Opie, A. (1994). The instability of the caring body: Gender and caregivers of confused older people. Qualitative Health Research, 4(1), 31 – 51.

Pearlin, L. I., & Skaff, M. M. (1996). Stress and the life course: A paradigmatic alliance. The Gerontologist, 36(2), 239-247.

Piercy, K. W. (1998). Theorizing about family caregiving: the role of responsibility. Journal of Marriage & Family, 60(1), 109 – 118.

Porter, E. J., Ganong, L. H., Drew, N. & Lanes, T. I. (2004). A new typology of home-care helpers. The Gerontologist, 44(6), 750 – 759.

Pyke, K. D. & Bengtson, V. L. (1996). Caring more or less: Individualistic and collectivist systems. Journal of Marriage & Family, 58(2), 379 – 383.

Sims-Gould, J. & Martin-Matthews, A. (in press, 2005). Caregivers, Helpers, and Family: Family Caregiving Research in a Canadian Context. In Paoletti, I. (Ed.), Family Caregiving to older disabled people: relational and institutional issues. Nova Science Publisher.

Sumsion, T. (1999). Client-Centred Practice in Occupational Therapy. London: Churchill Livingstone.

Walker, A. J. & Pratt, C. C. (1995). Informal caregiving to aging family members: A critical review. Family Relations, 44(4), 402 – 412.

Warren, C. A. B. (1998). Aging and identity in premodern times. Research on Aging, 20(1), 11 – 35.

Withers Osmond, M. & Thorne, B. (1993). Feminist theories: The social construction of gender in families and society. In Boss, P. G., Doherty, W. J., LaRossa, R., Schumm, W. R., & Steinmetz, S. K. (Eds.). Sourcebook of Family Theories and Methods: A Contextual Approach, (591 – 623). New York: Plenum Press.

CHAPTER THREE

Study Two: The Intersection of Gender and Kinship with Helping[15]

Care of older adults, also described in the literature as family caregiving, informal caregiving, informal support, eldercare, and simply "caregiving", is an increasingly salient component of supporting an aging population (Guberman & Maheu, 2002; Hequembourg & Brallier, 2005; Keating, Fast, Frederick, Cranswick & Perrier, 1999; Perry, 2004). Guberman & Maheu (2002: 28) state "homecare [of older adults], as it is conceptualized in current social policy, would be seriously compromised without the contribution of family caregivers". It is estimated that 75 - 90% of care to older adults living in the community is provided by unpaid/family caregivers, with the bulk (also estimated at 80%) of this care being provided by women (Abel & Nelson, 1990; Li, 2004; Guberman & Maheu, 2002; Hequembourg & Brallier, 2005; Keating, et al., 1999; Stone, 2001).

Although the topic of caregiving is central in the provision of care to an aging population, there are significant gaps in knowledge surrounding family caregiving (Boaz & Hu, 1997; Keating, Otfinowski, Wenger, Fast, & Derksen, 2003; Fast, Keating, Otfinowski & Derksen, 2004; Marshall, Matthews & Rosenthal, 1993; Peek & Zsembik, 1997). To date, family caregiving research has largely been focused on studies of the "primary" caregiver, and typically emphasizes the motivation and costs associated with caring for an older family member. This focus has generated a surplus of research on individual caregiver stress and burden but has done little to advance knowledge and understanding of the contributions and relationship dynamics when multiple family members contribute to the care of elderly kin. The intent of this research has been to

[15] A version of this chapter will be submitted to a peer-reviewed journal (journal yet to be determined).

"describe commonalities in the caregiving process...the result has been a homogeneous portrait of caregiving provided by highly committed female individuals who are motivated by attachment and norms of filial obligation" (Pyke & Bengtson, 1996: 380). With a focus on the primary caregiver, a paucity of research has been conducted on the contributions of other caregivers or "helpers" within family caregiving.

In addition to a dearth of material on the presence and contributions of multiple individuals in caregiving, very little is known about the intersection of gender and kinship when multiple individuals are involved in the provision of care to an older person. Gerontological research on family caregiving has highlighted many of the gender differences associated with the provision of care tasks (Keith, 1995; Hequembourg & Brallier, 2005; Walker, 2001), the balance of caregiving and paid employment (Gignac, Kelloway & Gottlieb, 1996; Sarkisian & Gerstel, 2004) and the differential experience of stress, burden and physical ailments associated with caregiving among men and women caregivers (Navaie-Waliser, Spriggs & Feldman, 2002). Research on the contributions of women in caregiving has been instrumental in establishing the prevalence and personal costs often experienced by women involved in the care of an older relative (Aronson, 1992; Stoller, 1994; Guberman, 1999; Hequembourg & Brallier, 2005; Sarkisian & Gerstel, 2004). Similarly, research on men's caregiving has helped to raise the profile of men involved in family caregiving (Campbell & Martin-Matthews, 2003; Crocker Houde, 2002; Hequembourg & Brallier, 2005; Sarkisian & Gerstel, 2004).

Research has shown that women, particularly wives and adult daughters, provide assistance with more household tasks than their male counterparts, and men when compared to women, seldom provide personal care. Researchers have also argued that

men's and women's caregiving contributions can not be equated or compared, that there are fundamental social structural differences in how, when and why men and women contribute (McMullin, 2005; Miller, 1996). Clearly, with respect to understanding how men and women differentially contribute within the context of family caregiving, there is a more diverse and complex picture than has generally been described in gerontological research (Romoren, 2003).

Caregiving and gender studies have been instrumental in creating an awareness of the extent of care provided by women, but there remains a dearth of knowledge around the different types of care and circumstances that both men and women experience (Hequembourg & Brallier, 2005; Opie, 1994). Similarly, researchers note that very little is known about the collaboration of adult kin, particularly sibling responsibilities, in the context of providing care to an aging parent (s) (Connidis, 2001; Ingersoll-Dayton, Neal, Ha & Hammer, 2003; Matthews & Rosner, 1988; Matthews, 2002). Matthews (2002: 5) contends "there is very little [research] that focuses on the ways in which the family labor of meeting parents' needs is divided". This assertion comes fourteen years after Matthews & Rosner (1988: 185) stated: "how adult children organize to provide adequate care, however, is largely unknown." With little known about how adult kin organize to meet the needs of older relatives/friends, there is a paucity of knowledge surrounding the support that these adult children extend to one another in the context of providing care.

The purpose of this study is to examine how gender and kinship intersect with the caregiving contributions from multiple family members involved in providing care to an older family member/friend. Specific attention is paid to contributions from "helpers",

those individuals who provide assistance ('help'), to female and male caregivers[16]. The gender composition of caregiving networks and the influence on the type of help provided is also examined.

Helpers and Caregivers: The Influence of Gender and Kinship

Finch and Mason (1993) provide a conceptual framework for advancing understandings of how variables such as gender and kinship influence individual contributions within the context of family life. Finch & Mason (1993) suggest that an individual may possess certain characteristics or attributes, called 'legitimate excuses', which render them 'unable' to provide care when compared with other members of the family. Finch (1989) describes legitimate excuses as being reasons or situations that make it more acceptable for some family members not to be involved in providing care. These excuses are not necessarily verbalized, but are 'known' to individuals within a family. Campbell & Martin-Matthews (2003: S351) describe the concept of legitimate excuses as the non-judgemental "range of accounts, explanations and justifications that get constructed when individuals negotiate family obligations and care relationships". Finch & Mason (1993) highlight employment, family commitments, competence and resources as possible legitimate excuses, with gender and genealogy (kinship) serving as cross-cutting variables in establishing the legitimacy of an 'excuse'.

Gender and genealogy help explain how individuals get locked into making commitments or can be 'excused' from participating in others (Finch & Mason, 1993). For example, in their study of male caregivers, Campbell and Martin-Matthews (2003)

[16] The terms help and helpers are used to those individuals who provide assistance in caregiving who are NOT the primary caregivers. Help can be given to the primary caregiver (referred to as 'assistive help' in Study One) or direct help to the older person receiving care.

use the concept of legitimate excuses to explain how men have traditionally been "excused" from participating in family caregiving. In a similar way, this study examines whether legitimate excuses as conceptualized by Finch & Mason (1993) help contribute to an understanding of who is a helper and who is a caregiver and the types of contributions or tasks undertaken by each. It may be that some family members have "reasons" (i.e. gender or kinship position) that make them more likely to be helpers than caregivers and vice versa. Examining the influence of gender and kinship on helping and caregiving contributions serves to contribute to an understanding of who helps whom in the context of caregiving, how they help and whether there are differences in the provision of help for/by men and women. This extends current conceptualizations of gender and caregiving beyond a focus on a single caregiver by including the presence and contributions of helpers.

Another important dimension in understanding helping and caregiving contributions by multiple individuals within a family is whether certain helping relationships take primacy over others. Cantor (1979, 1991) and Penning (1990) describe a hierarchical compensatory model of social support whereby the care provided by some caregivers is preferred over others. Cantor (1979) suggests that certain relationships take primacy over others. For example, spouses and adult children (daughters) are more highly 'ranked' in terms of their position in the social support hierarchy and are more likely to be identified as active contributors to caregiving. This premise is similar to the work of Finch & Mason (1993) in that it suggests that certain attributes like gender or kinship status might influence who contributes. What is not known is whether a similar hierarchy exists for help to the caregiver and whether gender or kinship are significant

factors in the helping relationship hierarchy. In their work on social support, Kahn & Antonucci (1981) & Cantor (1991) describe the primacy of certain relationships over others and the link to care provision. Their models show that the most preferred individuals occupy the first concentric ring around the older person receiving care. More distant and less involved individuals occupy outer rings (see Figure 2.3 in Study One). This study uses this framework to determine whether a similar structure exists with respect to the contributions of helpers both to the primary caregiver and the older person receiving care.

Helping and Caregiving Networks: Gender and Kinship Composition

Hareven (2001: 151) argues that studies of gender and caregiving tend to focus on the study of task allocation. The majority of caregiving research has focused on tabulating the contributions of men in comparison with contributions of women. Little is known about how families (men and women) contribute together in caregiving and whether family composition influences or predicts types of help/care given. In their work on the gendered nature of men's filial care, Campbell & Martin-Matthews (2003) show that understanding differences (and similarities) in caregiving between men and women is more complex than tabulating the type and number of tasks performed by the caregiver. Matthews' (2002: 211) argues, "family structure ... including size and gender composition – and members' relative attributes affect who does what [in the provision of support to older relatives]".

To advance our current understanding of family caregiving, and the contributions of helpers and caregivers, this study examines how the gender and kinship composition of a family influence the provision of helping and caregiving. Included in this

understanding is an examination of whether the type of help provided by helpers is influenced by the composition of the family or the size of the network. Connidis, Rosenthal & McMullin (1996: 426) contend, "the relationships between family composition variables and helping behaviour are complex; future research that examines these relationships further will enhance our understanding of assistance patterns in older families." Moving beyond an individual level of analysis, to a family level of analysis, this study examines the influence of gender and kinship composition on helping and caregiving contributions.

Research Questions

To examine the organization of helping networks and the intersection of gender and kinship composition, several research questions are addressed:

- How do gender and kinship influence helping networks of caregivers? Who helps? How do helpers help?
- Does the gender and kinship composition of caregiving/helping networks influence or predict the help given to the caregiver or older person?

Methods

Design

The CARNET Work and Family Study conducted from 1991-1992 involved the distribution of surveys to 9,693 employees in eight Canadian organizations[17]. The organizations do not represent a random cross-section of Canadian employees, but efforts were made to select organizations representing different employment sectors, including government agencies, financial services, manufacturing, health services and educational institutions (Gottlieb, Kelloway & Fraboni, 1994; Gignac, Kelloway & Gottlieb, 1996).

Personal meetings (by individuals involved in the initial data collection of the Work and Family Study) were conducted with employers to describe and explain the purpose of the study. Once an organization agreed to participate, employees were mailed an information letter describing the study. They were also mailed a questionnaire comprised of standardized scales from previous research as well as items developed specifically for this study (Gottlieb, Kelloway & Fraboni, 1994). In six (of eight) of the organizations participants over the age of 35 were over-sampled to increase the likelihood of identifying people currently providing assistance to a relative aged 65 or older (Gottlieb, Kelloway & Fraboni, 1994; Gignac, Kelloway & Gottelieb, 1996).

A variety of methods were used to distribute and collect the survey in accordance with the preferences of participating organizations (Gottlieb, Kelloway & Fraboni, 1994). The questionnaire was self-administered and took approximately 35 to 45 minutes to complete. A reminder notice was mailed one week after the survey was distributed to each company to remind all respondents who had not returned a questionnaire to please do so. Across all participating organizations, a total of 5, 496 usable surveys were

[17]Most of the organizations were located or had headquarters in the province of Ontario; they were situated in both urban and rural environments.

returned, yielding an overall response rate of 57 per cent in the first wave of the study (1991-1992). At this stage, 878 respondents identified themselves as being available for further follow-up studies and provided follow-up contact information.

The second phase of the research, conducted in 1994, involved a follow-up with the respondents who had provided contact information in stage one. Of the 878 who provided follow-up contact information, 497 could be located. This second stage was conducted as a screening step to identify individuals for inclusion in stage three. Individuals were asked a variety of questions regarding the provision of care to an older adult, including: "Do you provide assistance with personal care (i.e. feeding, bathing, etc.)?", "Do you provide assistance with household chores/maintenance?", "Do you provide assistance with finances?", "Do you provide emotional support ?" In order to be included in the third phase of the study the respondent had to be providing care to at least one relative and assisting with one Activity of Daily Living (feeding, bathing, dressing, etc.) or two Instrumental Activities of Daily Living (home maintenance, transportation, shopping, etc.). As a result of this screening 328 of the 497 individuals surveyed were identified for inclusion in the third and final stage of CARNET, The Work and Eldercare Study.

Of the 328 individuals to whom the survey was sent, 250 individuals (108 men and 142 women) completed the survey questionnaire. The respondents reported on various aspects of care provision for up to three elderly family members; they also provided information on caregiving contributions for up to three 'helpers". The third stage of research was conducted in order to examine patterns of formal service use and the frequency, type and duration of help provided by caregivers and those who they

identified as providing 'help' in family caregiving in a sample of employed Canadians. These 250 respondent caregivers form the sample for the present secondary analysis.

It is important to note that in this third phase, respondents were asked to respond to the dichotomous (yes/no) question "Are you the only person providing care to your older relative/friend?" to determine whether the respondent caregiver was the person most responsible for providing care to their older relative (often referred to in literature as the primary caregiver). The data from this third phase therefore contain responses from those who identify as primary caregivers and those who do not.

Sample

Table 3.1: Sample Characteristics of Respondents

	Respondent Caregiver Is the Primary Caregiver N=135				Respondent Caregiver Is Not the Primary Caregiver N=114			
	Men N=51		Women N=84		Men N=56		Women N=58	
Average Age	43.3 SD: 7.64		43.6 SD: 6.86		43.9 SD: 7.29		42.1 SD: 6.86	
	N	**%**	**N**	**%**	**N**	**%**	**N**	**%**
Marital Status								
Married	40	78.4	67	80.7	51	91.1	46	79.3
Common-law	5	9.8	4	4.8	2	3.6	1	1.7
Separated	3	5.9	1	1.2	2	3.6	2	3.4
Divorced	1	2.0	7	8.4	0	0	3	5.2
Widowed	0	0	0	0	0	0	2	3.4
Single/Never Married	2	3.9	4	4.8	1	1.8	4	6.9
Only Person Providing Help								
No	39	83.0	64	81.0	50	100.0	53	100.0
Yes	8	17.0	15	19.0	0	0	0	0
Number of Helpers								
One	26	63.4	30	47.6	15	33.3	14	27.5
Two	7	17.1	20	31.8	14	31.1	17	33.3
Three	8	19.5	13	20.6	16	35.6	20	39.2
Older Person Receiving Care								
Spouse	-	-	3	2.3	-	-	-	-
Mother	28	20.2	55	41.7	20	29.4	31	24.2
Father	7	7.1	6	6.1	8	8.1	1	0.8
Mother-in-law	6	6.1	6	4.5	11	11.1	10	8.3
Father-in-law	1	1.0	0	0	2	3.0	1	0.8
Grandmother/Grandfather	2	2.0	3	2.3	2	2.0	3	2.3
Aunt/Uncle	4	3.0	5	3.0	-	-	4	3.0
Parents/Parents-in-law	-	-	-	-	-	-	1	0.8
Friend/Neighbour	2	2.0	1	0.8	3	3.9	-	-
Other Family	1	2.1	-	-	1	2.0	-	-

Table 3.1 shows select sample characteristics of respondents in the CARNET Work and Eldercare Study. Table 3.1 shows sample characteristics for those respondents who identify themselves as a primary caregiver and those who do not. As shown in Table 3.1, of the 250 individuals surveyed, 54% indicated being the primary caregiver. A higher percentage of primary caregivers were women while a higher percentage of

helpers were men. This points to the gendered nature of family caregiving where women are most often primary caregivers, and in this study if they are not the primary caregiver, they are often identified as being the number one helper. Marital status also differed between groups with respondent helpers (in particular men) reporting being married more frequently than primary caregivers.

The frequency distribution of reporting one helper, two helpers, or three helpers differed between primary caregivers and helpers for both men and women. Male primary caregivers reported with greater frequency (63.4%) having a helper than female primary caregivers (47.6%). Female primary caregivers more frequently reported having two or more helpers than male primary caregivers. For both men and women, mothers were identified as the person who most frequently is the recipient of caregiving.

Table 3.2: Sample Characteristics of Older Person

Older Person Characteristics	N	%	M	SD
			2.67	.82
Overall Physical Health	41	17.8		
Poor	84	36.5		
Fair	94	40.9		
Good	11	4.8		
Excellent				
Overall Emotional Health			2.38	.90
Poor	30	13.0		
Fair	63	27.4		
Good	101	43.9		
Excellent	36	15.7		
Age			76.5	8.16

As shown in Table 3.2 the majority of older individuals in the CARNET Work and Eldercare Study are identified by the respondent as being in fair (36.5%) or good

(40.9%) overall physical health and fair (27.4%) or good (43.9%) overall emotional health. The individuals receiving care in this study averaged 76.5 years (SD = 8.16).

Measures

Measures include dependent variables, independent variables, control variables and explanatory variables. The variables used in Study Two are the same variables used in Study One. The measures section in Study Two therefore contains repeated information from Study One. Several new variables appear in Study Two in the explanatory variable section (p. 87). As in Study One, Appendix 1 (p. 150) provides a copy of the survey instrument. Means and standards deviations for dependent and independent variables can be found in Table 3.9 (correlation matrix).

Dependent Variables.

Help Provided to Older Person by Helpers (Direct Help). To determine the type and frequency of help provided by helpers, respondents were asked five different questions. In a successive series of questions respondents were asked, "Within the past six months, how often *has this person* (helper one, helper two, helper three) helped your older relative/friend with feeding, bathing, dressing, toileting, or taking medication (personal care)?; second, by providing transportation, doing shopping and/or errands (general care)?; third, with laundry, household chores, meal preparation, home maintenance or yard work (household care)?; fourth, with moral or emotional support (emotional support)?; and fifth, with money management, or negotiating on behalf of their older relative (financial support)?". Respondents were asked to check the appropriate response category for each question, in relation to each helper, to indicate

frequency of helping with that particular type of activity (0=never, 1= once or twice in the last 6 months, 2= every 1 or 2 months, 3=2-3 times a month, 4=once, 5=once a week, 6= several times a week, and 7= daily). Items were reverse coded for this measure as the original coding was counter intuitive with, 1=daily, 2=several times a week, 3=once a week, 4=2-3 times a month, 5=once every 1 or 2 months, and 6=once or twice in the last 6 months, 7=never. Univariate analyses show the responses are almost normally distributed for general care (SK .12, SE .17; K -1.1, SE .34)[18], household care (SK -.44, SE .17; K -1.2, SE .35) and emotional support (SK .21, SE .17 ; K -1.2, SE .35). When the values for skew and kurtosis are divided by the standard error[19], general care is not skewed (.71) but slightly kurtotic (-3.2), household care is not skewed (-2.6) but slightly kurtotic (-3.4) and emotional support is not skewed (1.2) but slightly kurtotic (–3.4). Personal care (SK –1.1, SE .17; K -.43, SE .34) is skewed (-6.4) but not kurtotic (-1.3) and financial support (SK –1.2, SE .17; K 2.5, SE .35) is skewed (7.0) and kurtotic (7.1). In both instances this is due to low response rates to the questions, very few respondents indicated that their relatives were receiving direct help with personal care or financial support. The measures regarding general care, household care and emotional although not normally distributed are not skewed but are slightly kurtotic. The measures used in the questions regarding type and frequency of help use Katz's (1963) classification of ADLs (feeding, bathing, dressing, toileting, help with medication) and IADLs (transportation, shopping, doing errands, laundry, household chores, meal preparation, home maintenance and yard work) a well-known categorical distinction for caregiving tasks. Although there is academic debate on the classification of tasks in caregiving, the

[18] SK denotes skew, SE standard error and K for kurtosis.
[19] When skew and kurtosis values are divided by their standard error, if the coefficient is greater than 3.0 or less than –3.0 it is skewed and/or kurtotic.

ADL and IADL distinctions developed by Katz are currently the most well tested and widely used categories of tasks.

Help Provided to Respondent by Helpers (Assistive Help). To examine patterns of assistive help (the help provided to the respondent caregiver who then in turn provides help to the older relative) respondents answered the question: "In the last six months has anyone assisted *you* in helping your elderly relatives/friend in any of the following ways: household chores, childcare, financial assistance, home/yard maintenance or repair, moral/emotional support or other?" Responses were dichotomous with a check/no check response format; respondents were asked to check each item where they received help (household chores, childcare, financial assistance, home/yard maintenance or repair, moral/emotional support, other). If they selected 'other', respondents were asked to write down the nature of the help. Univariate analyses show that household support (SK .15, SE .20; K –2.0, SE .39) is not skewed (.75) but kurtotic (-5.1) and moral support (SK – 1.1, SE .20; K -.71, SE .39) is skewed (5.5) but not kurtotic (-1.8). Childcare (SK 5.9, SE .20; K 34.4, SE .39), financial support (SK 2.6, SE .20; K 4.8, SE .39) and home-yard maintenance (SK .25, SE .20; K -1.9, SE .39) have very skewed and kurtotic distributions most likely as a result of very low response rates to these questions.

Independent Variables.

Care Provided by Respondents. To determine the type and frequency of care provided, respondents were asked five different questions. These five questions form an index (not a scale) as items are not intended to be correlated. In a successive series of questions drawing Katz' distinction between ADLs and IADLs, respondents were asked, "Within the past six months, how often *have you* helped your older relative/friend with

feeding, bathing, dressing, toileting, or taking medication (personal care)?; second, by providing transportation, doing shopping and/or errands (general care)?; third, with laundry, household chores, meal preparation, home maintenance or yard work (household care)?; fourth, with moral or emotional support (emotional support)?; and fifth, with money management, or negotiating on behalf of their older relative (financial support)?". Respondents were asked to check the appropriate response category (0=never, 1=daily, 2=several times a week, 3=once a week, 4=2-3 times a month, 5=once every 1 or 2 months, and 6=once or twice in the last 6 months). Univariate analyses show that general care (SK -.36, SE .16; K -.93, SE .32) is not skewed (-2.25) or kurtotic (-2.9) and emotional support (SK .11, SE .16; K -1.2, SE .32) is not skewed (.68) but slightly kurtotic (3.7). The measures regarding general care and emotional support are reliable with the variance of responses almost normally distributed. Personal care (SK –2.8, SE .16; K 7.6, SE .32), household care (SK -.99, SE .16; K -.18, SE .32) and financial support (SK –1.4, SE .16; K 1.6, SE .32) are very skewed. The skews can be attributed to low response rates. Very few respondents indicated that they provide assistance to their relatives with personal care, household care or financial support. The measures with skewed distributions are therefore used only in descriptive statistics and not in the correlation or regression analyses.

Number of Hours of Care/Week Provided by Respondents. Respondents were asked to estimate the number of hours of help provided to their older relative in an average week or month by giving a numeric estimation (i.e. 4 hours per week or 12 hours per month) in response to the question "Overall, please estimate the number of hours of help you have provided to your older relative in an average week or month". The mean

hours per week of care provided was 30 with a standard deviation of 9.31. Respondents were able to report on the amount of care provided for each of three older people.

Control Variables.

Older Person Characteristics. Age of the older person receiving care was determined by the respondent who responded to the question "How old is your relative?" Age of the older relative was denoted by the respondent placing a numeral (i.e. 76, 84, etc.) in a blank space, followed by the word 'years'. Physical health status and emotional health status were each indicated by the respondent checking the appropriate category in response to the question "How would you rate your older relative's physical / emotional health status?" The checklist options included: 1=excellent, 2=good, 3=fair, 4=poor.

Explanatory Variables.

Respondent Characteristics. Respondent gender and marital status were identified by checking the appropriate response category (i.e. male/female, and married, common-law, separated, divorced, widowed, single/never married) in response to the questions "Are you (male / female)?" and "What is your present marital status?" Respondent age was denoted by a numeric (i.e. 42, 57, 33, etc.) in response to the question "What is your age in years?"

Primary Caregiver Identification. Respondents were asked to respond to the dichotomous (1=yes, 0=no) question "Are you the person who provides the most care to your older relative/friend?" to determine whether the respondent was the person most responsible for providing care to their older relative (often referred to in literature as the primary caregiver) or whether the respondent was a helper.

Helper Identification. The identification of direct helpers (those individuals whom the respondent caregiver identifies as providing help to the older person by the respondent caregiver) was determined by asking respondent caregivers, "Who else helps this relative?" Respondents were asked to identify the person providing help to the older relative/friend by noting their relationship to the older person receiving care. Examples of responses included: brother, son, relatives spouse, respondents spouse, respondents sister, home support worker, foot care provider, etc. Respondents were able to identify up to three helpers involved in providing help to the older relative/friend.

The identification of assistive helpers was determined by respondents who were asked "Who helps you?" Respondents were asked to check as many categories as applicable. Categories included: your spouse, your daughter(s), your son(s), your sister(s), your brother(s), other family members, friends, caregiver support group, respite care, other (specify). Respondents were able to identify assistive helpers for up to three relatives that they (the respondent) were providing care for.

Total Direct Help. Several summative indices were developed to measure the total amount of direct help provided by helpers to the older relative or friend receiving care. These indices were developed as there was no question regarding total amount of help received (for all types of help) by the older adult receiving care from the helper(s). The indices were developed to give an overall total score for help received in the absence of a direct measure of total help.

Respondents were asked five separate questions, "Within the past six months, how often *has this person* (helper one, helper two, helper three) helped your older relative/friend: first, with feeding, bathing, dressing, toileting, or taking medication

(personal care)?; second, by providing transportation, doing shopping and/or errands (general care)?; third, with laundry, household chores, meal preparation, home maintenance or yard work (household care)?; fourth, with moral or emotional support (emotional support)?; and fifth, with money management, or negotiating on behalf of their older relative (financial support)?". Respondents were asked to check the appropriate response category (0=never, 1= once or twice in the last 6 months, 2= every 1 or 2 months, 3=2-3 times a month, 4=once, 5=once a week, 6= several times a week, and 7= daily). Items were reverse coded for this measure as the original coding was counter intuitive with 7=never, 1=daily, 2=several times a week, 3=once a week, 4=2-3 times a month, 5=once every 1 or 2 months, and 6=once or twice in the last 6 months.

For each of the types of help (personal care, general care, household care, emotional support, financial support) there is a range of possible answers ranging from 0 (never) to 7 (daily) with a total maximum score of 35. A sum of the individual types of help creates an overall index for total amount of direct help provided by helpers. An alpha reliability was computed for the second and third index to ensure that respondents were answering the same question in each index for each of the two and three helpers. For example, that general care was interpreted similarly for helper one, helper two and helper three. An alpha reliability was not needed for the first index, as it was for one helper only.

The first index, One Helper, (N=197), was created by adding the 'help scores' for each type of care provided by helper one to create an overall score (maximum 35). The range for this index was 5.0 – 35.0 with a mean of 23.6 and a standard deviation of 7.2.

The second index, Two Helpers, (N=111), was created by adding the amount of care for each type of care provided by helper one and helper two (personal care, general care, household care, emotional care, financial care) to create an overall total score for two helpers (maximum 70). The range for this index was 22.0 – 70.0 with a mean of 48.7 and a standard deviation of 12.4 and a reliability alpha of .87.

The third index, Three Helpers, (N=55), was created by adding the amount of care for each type of care provided by helper one, helper two and helper three (personal care, general care, household care, emotional care, financial care) to create an overall total score for three helpers (maximum 105). The range for this index was 33.0 – 105.0 with a mean of 71.9 and a standard deviation of 16.1 and a reliability alpha of .92.

Network size. Network size was a measure created by summing the respondent caregiver with the number of other helpers to the older person receiving care (as indicated by the respondent caregiver) to generate a total number (up to 4) involved in the provision of care. The number of consaguinal kin in the network was determined in the same manner, with those individuals as being blood related to the respondent caregiver being counted as consaguinal kin (i.e. siblings, children, etc.)

Proportion Kin/Proportion Women. Proportion kin in the network and proportion women in the network were determined by dividing the number of kin/number of women in the network by the total number of individuals in the network.

Analysis

The quantitative data, as well as written responses to long answer questions, allowed for the development and analysis of descriptive vignettes. In addition, SPSS statistical software was used to generate frequency data on helpers in caregiving.

Correlations were used to determine the presence of significant relationships between variables.

Ordinary Least Squares (OLS) regression was conducted using SPSS to address the question of whether the type of help provided by direct helpers is related to the network composition. Ordinary Least Squares regression was selected as the analytical tool for this portion of the investigation, as the dependent variables used are continuous variables with almost normal distribution of responses (see Measures section for more detail). Dependent variables (continuous) included: help (general, household, emotional) provided by the helper. Independent variables included: network size and percentage kin in the network. Age, marital and health status of the older relative were entered as control variables. The analysis of direct help is restricted to direct help by helper one.

Helping Networks of Men and Women

Table 3.3: Helper Identification for Male and Female Respondents

	Respondent Caregiver Is the Primary Caregiver N=135				Respondent Caregiver Is Not the Primary Caregiver N=114			
	Men N=51		Women N=84		Men N=56		Women N=58	
	N	%*	N	%*	N	%*	N	%*
DIRECT HELP								
Identification of Helper One**								
Respondent's Spouse	11	26.8	12	19.0	19	42.2	12	23.5
Respondent's Sister	11	26.8	19	30.2	6	13.3	15	29.4
Respondent's Brother	6	14.6	16	25.4	8	17.8	8	15.7
Identification of Helper Two**								
Respondent's Spouse	-	-	-	-	5	16.7	-	-
Respondent's Sister	-	-	4	12.1	3	10.0	12	32.4
Respondent's Brother	3	20.0	9	27.3	3	10.0	-	-
Respondent's Sister-in-law	3	20.0	3	9.1	-	-	8	21.6
Respondent's Brother-in-law	-	-	-	-	-	-	4	10.8
Respondent's Son	-	-	-	-	4	13.3	-	-
Identification of Helper Three**								
Respondent's Spouse	-	-	3	23.1	2	12.5	3	15.0
Respondent's Sister	-	-	2	15.4	2	12.5	-	-
Respondent's Brother	-	-	2	15.4	-	-	6	30.0
Respondent's Brother-in-law	2	25.0	-	-	3	18.8	2	10.0
Relative's Friend	2	25.0	-	-	-	-	-	-
ASSISTIVE HELP								
Identification of Helper								
Respondent's Spouse	10	55.6	25	61.0	21	47.7	24	45.3
Respondent's Daughters	2	11.1	10	24.4	4	9.1	13	24.5
Respondent's Sons	2	11.1	7	17.1	6	13.6	10	18.9
Respondent's Sister	3	16.7	9	22.0	14	31.8	25	47.2
Respondent's Brother	4	22.2	13	31.7	14	31.8	15	28.3
Other Family	5	27.8	9	22.0	17	38.6	21	39.6
Friends	4	22.2	12	29.3	6	13.6	12	22.6
Caregiver Support Group	3	16.7	5	12.2	5	11.4	6	11.3
Respite Care	-	-	1	2.4	1	2.3	4	7.5
Other	2	11.1	7	17.1	5	11.4	7	13.2

*Percentages refer to the number of individuals identified as helpers in each category, divided by the total number of helpers for that category. Note that the N for each cell is different.

**Top Two/Three Helpers in each category (Helper One, Helper Two, Helper Three) listed.

Table 3.3 shows the differences between direct and assistive help for female and male, primary caregivers and helpers. It is important to note prior to interpreting Table 3.3 that respondents were able to report on the identification and activities of each individual helper with respect to direct help (those helpers providing assistance directly to the older person) but could only report in an aggregate manner on those individuals providing assistive help (help given to the respondent caregiver) (see Measures section for more detail). It is also important to note that the number of responses in each category varies, changing the N from cell to cell in the Table.

The most striking difference between men and women in the identification of helpers was in the kin relationship of their helpers. Female primary caregivers (30.2%) and helpers (29.4%) reported that their sister was their number one direct helper. Male primary caregivers indicated that their spouse (26.8%) and sister (26.8%) were their number one direct helpers. Male helpers indicated (42.2%) that their spouse was their number one direct helper.

For female primary caregivers brothers (27.3%) were reported as their number two helper and spouses (23.1%) were reported as their number three direct helper. For female helpers sisters (32.4%) were reported as their number two helper and brothers (30.0%) were reported most frequently as their number three direct helper.

For male primary caregivers' brothers and sisters-in-law (20.0%) were reported as their number two helpers and brothers-in-law and friends (25.0%) were reported most frequently as their number three direct helper. For male helpers spouses (16.7%) were reported most frequently as their number two helper and brothers-in-law (18.8%) were reported most frequently as their number three direct helper.

Assistive help did not follow the same pattern. Spouses were most frequently identified as assistive helpers for women and men with one exception. Female helpers most frequently identified their sisters as being assistive helpers. Daughters, sons, sisters, brothers and other family were all listed as assistive helpers. Women (both primary caregivers and helpers) identified friends as assistive helpers more frequently than men.

As indicated, help can be provided both assistively (to the primary caregiver) and directly (to the older person). Table 3.4 and Table 3.5 illustrate assistive and direct helping contributions for male and female respondents.

Table 3.4: Assistive Help to Respondent Caregivers from Helpers

Type of Assistive Help	Men N=107		Women N=142		p
	N	%	N	%	
Childcare	3	4.8	1	1.1	ns
General Care*	11	20.5	18	26.2	ns
Household Chores	30	48.4	41	45.1	ns
Home-Yard Maintenance	29	46.8	38	41.8	ns
Moral Support	41	66.1	73	80.2	.03
Financial Assistance	8	12.9	8	8.8	ns

* General Care is defined as: transportation, shopping and/or errands.
** significant at the .05 level

Table 3.4 highlights the frequency of help received by male and female caregivers. Across all categories moral support is the type of support received most frequently by both male and female caregivers. Chi-square tests for significance indicate a significant difference at $p<.05$ between moral support received by male and female respondents. Female caregivers indicate receiving help most often with moral support followed by household chores/ home-yard maintenance. This is very similar to the type of help received by male caregivers who indicate receiving help most often with moral support and household chores.

Table 3.5: Direct Help to Older Person from Helpers

Type of Direct Help	Men N=107		Women N=142		p
	N	%	N	%	
Personal Care	35	32.7	45	31.7	ns
General Care*	73	68.2	101	71.1	ns
Household Care	67	62.6	76	53.5	ns
Emotional Support	73	68.2	99	69.7	ns
Financial Support	48	44.9	52	36.6	ns

* General Care is defined as: transportation, shopping and/or errands.

Table 3.5 documents direct help given to the older person as recorded by male and female caregivers. Female caregivers indicate the provision of general care and emotional support to the older person with greatest frequency. Male caregivers indicate the provision of emotional support and household care with greatest frequency. The provision of personal care by a helper is the least frequent type of care identified by both male and female respondents. There are no significant differences in the report of frequency of providing personal care, general care, household care, emotional support or financial support. There are similarities in the reporting of help between male and female respondents.

Composition of Helping and Caregiving Families

Table 3.6: Caregiving and Helping Network Composition

Composition Characteristics	N (N=250)	%
Network Size (# of individuals)		
1.00	50	20.0
2.00	87	34.8
3.00	56	22.4
4.00	57	22.8
Consaguinal Kin in Network (# of individuals)		
1.00	112	44.8
2.00	80	32.0
3.00	47	18.8
4.00	11	4.4
Proportion Kin (%)		
00	4	1.6
25	1	0.4
33	1	0.4
50	11	4.4
66	4	1.6
75	11	4.4
100	218	87.2
Proportion Women (%)		
00	35	14.0
25	7	2.8
33	22	8.8
50	79	31.6
66	25	10.0
75	22	8.8
100	60	24.0
Average Network Size*	**M**	**SD**
Men	2.4	1.05
Women	2.5	1.05

* Note maximum number in network is four individuals (one respondent plus a maximum of three helpers).

Table 3.6 illustrates the composition profile of caregiving and helping networks. In terms of size, most networks consist of two individuals (34.8%); however, there is almost an equal distribution of networks comprising, 1, 3 and 4 individuals. The vast majority of networks (87.2%) are comprised only of kin, and in most cases, one or two of these individuals are consaguinal kin (blood related, not through marriage). While

research would suggest that helping and caregiving networks are predominantly female, that is not entirely the case in this investigation. In 31.6% of the cases, the helping and caregiving networks are comprised equally of women and men , while 24% of networks are all female and 14% all male. Average size is relatively similar for both men (2.4) and women (2.5) – that is, one caregiver and one helper.

Table 3.7: Proportion of Women in Helping Network

	Proportion of Women (%)						
Size	00	25	33	50	66	75	100
1.0	26 (52.0%)						24 (48.0%)
2.0	8 (9.2%)		1 (1.1%)	55 (63.2%)	1 (1.1%)		22 (25.3%)
3.0	1 (1.8%)	1 (1.8%)	20 (35.7%)		24 (42.9%)		10 (17.9%)
4.0		6 (10.5%)	1 (1.8%)	24 (42.1%)		22 (38.6%)	4 (7.0%)
TOTAL	35 (14.0%)	7 (2.8%)	22 (8.8%)	79 (31.6%)	25 (10.0%)	22 (8.8%)	60 (24.0%)

Table 3.7 shows the size of helping/caregiving units cross-tabulated with the proportion of women in the network. The most common configuration of helping/caregiving networks is two individuals with one woman and one man (63.2%). Of the networks consisting of four individuals there are no all male networks, 42.1% have two men and two women, 38.6% have three women and one man and 10.5% have three men and one women. The most common all male network contains one individual (52.0%) followed by two male individuals (9.2%). Similarly, the most common all female network has one individual (42.9%) followed by two female individuals (25.3%). While most networks are small (Table 3.6) the larger the network the more likely it is to be mixed gender.

Table 3.8: Total Help* Provided By Helpers to Older Relative/Friend

Total Direct Help Provided By:	Men N=107		Women N=142		p
	M	SD	M	SD	
One Helper	22.3	7.6	24.6	6.8	ns
Two Helpers	47.2	13.1	49.6	12.0	ns
Three Helpers	69.3	18.3	73.8	14.2	ns

* Only those respondents who indicated having at least one helper are included in this table.

Table 3.8 helps to illustrate how the contributions by multiple helpers in caregiving compound. While it is important to understand what each helper contributes individually to caregiving, it is also essential to understand how having one helper, two helpers or three helpers influences overall caregiving contributions to the older person. Table 3.8 shows the means for the total amount of help contributed by helpers for male and female respondents. Total help is a score based on frequency of the provision of five types of tasks (see Measures section for details). As shown in Table 3.8 with the addition of each helper the mean value for total direct help increases. Female caregivers with three helpers have the highest mean value (73.8) for total direct care, while male caregivers with three helpers report a slightly lower mean value (69.3). There is a similar pattern for one helper and two helpers with the mean score being slightly higher for women, although the difference in scores between men and women is not statistically significant. Both male and female respondents show a similar pattern in the calculation of the mean score. There is an additive and almost equivalent increase in the mean score with the addition of each helper. This suggests that each helper is providing similar help with similar frequency.

Table 3.9: Correlation Matrix for Variables Included in OLS Regression

	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Age Older Person (OP)	1.00												
2. Marital Status (OP)	.08	1.00											
3. Overall Physical Health (OP)	.11	-.04	1.00										
4. Overall Emotional Health (OP)	.03	.01	.50**	1.00									
5. Provided General Care	-.12	-.10	-.08	-.06	1.00								
6. Provided Household Care	.08	.08	-.15*	-.10	.56**	1.00							
7. Provided Emotional Support	-.02	-.03	-.27**	-.32**	.53**	.47**	1.00						
8. Helper Provided General Care	-.04	.05	-.06	.03	.17*	.05	.07	1.00					
9. Helper Provided Household Care	.06	.17*	-.14*	-.12	.08	.21**	.06	.43**	1.00				
10. Helper Provided Emotional Support	-.08	.18**	-.16*	-.26**	.00	.03	.27**	.36**	.40**	1.00			
11. Network Size	-.01	-.09	.07	-.02	.04	-.00	-.05	-.01	-.02	-.16*	1.00		
12. Proportion Kin in Network	-.10	-.06	-.04	.02	-.01	-.11	.03	.05	-.05	-.09	-.14*	1.00	
13. Proportion Women in Network	.04	.06	.01	.05	-.16*	-.03	-.18**	.04	.16	-.07	.11	-.15*	1.00
Mean	76.5	1.80	2.67	2.38	4.74	5.41	3.92	4.07	4.68	3.73	2.48	.94	.57
SD	8.16	.70	.82	.90	1.77	1.80	1.90	1.80	2.11	2.00	1.05	.18	.32
N	232	232	230	230	230	227	226	199	197	197	250	250	250

* significant at the .05 level, ** at the .01 level, *** at the .001 level

Of particular interest in Table 3.9 is whether any significant correlations exist between network size, proportion kin in the network or proportion women in the network. The focus of these analyses is to determine whether the group size or composition influences the type of help provided by caregivers and/or helpers.

Table 3.9 shows a significant correlation between network size and the provision of emotional help by helpers ($p<.05$). The proportion of kin in the network is significantly correlated with network size ($p<.05$). The proportion of women in the network is significantly correlated with the provision of general care by the respondent caregiver ($p<.05$) and with the provision of emotional support by the respondent caregiver ($p<.01$). Proportion women in the network is also significantly correlated with the proportion of kin in the network ($p<.05$).

Table 3.9 shows the correlation matrix for those variables included in the regression analyses. Network size is significantly correlated with the provision of emotional support by helpers ($p<.05$). Results point to a connection between the type of help given, the type of care provided by respondent caregivers and overall network size, composition kin and proportion women in the network.

Ordinary Least Squares (OLS) regression analysis was used to answer the third research question, 'Is the help given by helpers predicted by gender or kinship composition?' Based on the correlation matrix, the only dependent variable tested was the provision of emotional support by helpers. Results are shown in Table 3.10

Table 3.10: Multivariate unstandardized (b) and standardized (beta) regression coefficients for factors associated with the provision of Emotional Support by Helpers

Variable	B	SE B	β
Step 1			
Age of Older Person	-2.08	.02	-.09
Marital Status of Older Person	.53	.20	.18
Overall Physical Health of Older Person	-3.47	.19	-.01
Overall Emotional Health of Older Person	-.55	.17	-.24
Step 2			
Age of Older Person	-2.47	.02	-.10
Marital Status of Older Person	.48	.20	.16*
Overall Physical Health of Older Person	-3.33	.18	-.01
Overall Emotional Health of Older Person	-.56	.17	-.24**
Network Size	-.36	.16	-.15*
Step 3			
Marital Status of Older Person	.47	.20	.16*
Overall Emotional Health of Older Person	-.58	.16	-.26***
Network Size	-.34	.15	-.15*

Note: R2= .32 for Step 1; ΔR2 = .11 for Step 3; N=196
* significant at the .05 level, ** at the .01 level, *** at the .001 level

Table 3.10 shows the results of the regression analysis with the provision of emotional support by helpers as the dependent variable. In step two, network size is a significant predictor of helpers providing emotional support ($p<.05$), as is the overall emotional health of the older person ($p<.01$) and the marital status of the older person ($p<.05$). In step three marital status is significant ($p<.05$), network size ($p<.05$) and overall emotional health of the older person ($p<.001$). Step three explains 11.0% of the variance in the provision of emotional support by helpers to the older person.

Discussion

This study contributes to an overall picture of helpers in caregiving and the intersection of gender, kinship and family composition. Findings show that helping networks are relatively small, kin-centered and female dominated. A critical approach to the interpretation of findings reveals features that raise questions about helping and suggest directions for future analysis of helpers.

Consistent with research on caregiving that stresses gender differences in the provision of care to older relatives and friends (Abel & Nelson, 1990; Cicerelli, 2003; Globerman, 1994; Miller, 1996; Perry, 2004; Phillips, 2000), findings from this study highlight that there are also gender differences in helping. The most significant difference in helping for men and women is in the identification of assistive and direct helpers. Women who identify themselves as the person providing the most care to their older relative or friend (primary caregiver) most frequently indicate their number one helper as being a sister, while men in the same situation identify their spouse. This finding extends the idea of the gendered division of work in caring one step further than previous research in that it implicates groups of women in the provision of care. Not only do women form the bulk of caregivers, even when a spouse is present, the bulk of their support comes from their sisters. Women also report that their daughters and sisters-in-law are assistive helpers more frequently than men. Women tend to rely more on other women for assistance while men rely on their spouses for help.

The results on direct help corroborate and extend Cantor's (1979) theory of hierarchical compensatory support. Cantor's (1979) theory postulates that there is a hierarchy in terms of who is identified as a primary caregiver, helper one, helper two, etc.

and that family takes primacy over paid care. Results of this study (Table 3.3) show a similar pattern in the identification of helpers, with one additional component. The identification of helpers has a gendered dimension. Women identify their sisters as direct helpers while men most often identify their spouse as helpers. While, gender plays a role in the selection of helpers, it is not known if there are other factors, such as those identified by Finch & Mason (1993) (geographical proximity, employment commitments and/or family life stage) that also influence the identification of helpers. The CARNET Work and Eldercare Study did not ask about the geographical proximity, the employment status or family life stage of helpers. Questions in the CARNET study focused on the identification and contributions of helpers, not on the characteristics of those helpers. The inclusion variables outlined by Finch & Mason (1993) would further advance understandings of helpers in caregiving and the application of Cantor's hierarchical compensatory theory.

As stated, women identify sisters as their number one helper with greater frequency than male CARNET respondents; however, common to both women and men is the identification of adult siblings as helpers. Both male and female respondent caregivers indicate receiving substantial help from siblings and/or siblings-in-law. This finding highlights the importance of adult sibling ties in later life (Connidis, 2001; Eriksen & Gerstel, 2002; Ingersoll-Dayton et al.; 2003; Matthews, 2002) and also begins to underscore some of the similarities in the provision of help for men and women. Although research on the sibling tie has predominantly focused on the socio-emotional aspects of adult relationships, adult sibling ties clearly have an instrumental component. Both male and female caregivers receive instrumental help such as household help and

home maintenance from siblings in the context of caregiving for an older relative/friend. The sibling relationship, within the present examination of helpers, is clearly more complex than has been depicted in gerontological research literature. According to Ingersoll-Dayton et al. (2003:52) "most research on sibling caregiving to date has emphasized the conflict that occurs among siblings...considerably less attention has been devoted to sibling cooperation". In this study, siblings play an important role in helping in the context of family caregiving through their contributions to one another and to the older person receiving care. What is not known about the provision of help is how these contributions are negotiated or divided among multiple members within the same family.

While there are differences in the helping networks of women and men there are also similarities. Both men and women receive help from helpers for a variety of tasks (Table 3.4 & Table 3.5). Similarly, male and female respondent caregivers report comparable patterns in the frequency and type of direct help to their older relative/friend. Acknowledging similarities between women and men, as in this study of helpers, is important as it helps to avoid the flattening of women and men "into a single dimension, ... seeing them as of significance only in contrast to the other gender" (Lopata, 1995: 116). There are similarities in both assistive and direct help reported by women and men.

Although there are similar response patterns regarding help and more similarities than differences in the help received by women and men, these findings must be interpreted cautiously. In her work on gender differences in caregiving, Miller (1996: 195) found that women and men ascribe different meanings to their caregiving contributions related to the gender role stereotypes individuals ascribe to their contributions; this is likely true of help. Women and men may define help differently and

as such, identify helpers and helping using these differential meanings. For example, household help or general care may mean something very different to women than men. Research has shown that women are often bound by strong norms of nurturing while men have more of a managerial approach (Miller, 1996; Raschick & Ingersoll-Dayton, 2004). According to Raschick & Ingersoll-Dayton (2004: 321) women operate from "an internalized model of caregiving" where as men, according to Russell (2001: 355) have "greater perceived control...the ability to choose to act or not act".

Consistent with research on the size of caregiving networks (Aartsen, van Tilburg, Smits, Knipscheer, 2004; Fast et al., 2004; Piercy, 1998) the average helping network in this study is small, 2.4 for men and 2.5 for women (Table 3.6). However, while the average size is small, some 45 % of the helping networks include three or four individuals. In this case averages mask an important finding with almost half of helping networks consisting of three-four individuals who are making contributions (either to the respondent caregiver or the older person). As shown in the results, 24% of the networks are all female, while 14% are all male (Table 3.7). All male only networks contain one, two or three individuals while all female only networks contain one, two, three and four. This finding emphasizes the involvement of men in helping and contrasts conceptions of female dominated care. While men may not be primary caregivers as often as their female counterparts, they are identified as helpers. Men's identification as helpers also shows that groups of men organize together to provide help and care, an activity more often attributed to groups of women. This finding underscores the presence of men and women in helping.

The correlation and regression analysis in this study show that network size, proportion kin and proportion women in the network have predictive capacity in determining the provision of emotional support by helpers (Table 3.9). While proportion of kin in the network and proportion of women in the network did not predict other types of help this is not an unexpected finding given the complexity of helping and caregiving. What individuals contribute in family caregiving/helping or even in the context of day-to-day family life is influenced by both the number of individuals in a family and also the interconnection and relationships between individual personalities in response to a particular circumstance. An important component of who helps and how helpers help is based on what Gubrium (1988: 202) defines as being "issue-contingent". Help is predicted by a variety of factors, proportion kin in the network, proportion women in the network, network size, and also, as identified by Gubrium (1988) what needs to be done.

While seemingly simple, this underscores an extremely important finding particularly when making policy considerations. The number of individuals involved in helping/caregiving is important, but you cannot solely look at the numbers of individuals available to determine available support. Caregiving is a concept that includes helping and is situated within a relational and social milieu.

In conclusion, the following vignette, taken from verbatim and survey data from the three phases of the CARNET study, reflects the social structure of family caregiving, the nature of help provided, the balance of both direct and assistive help by and the intersection of gender and kinship.

Rita is a married bank clerk with one child (aged 21 years) and one grandchild. Rita provides approximately five hours of care per week to her 71-year-old sister-in-law Aggie. Aggie is in fair physical and poor mental health and lives in her own home. Rita provides personal care, general care, and household care every one to two months in

addition to emotional support once a week and financial support two to three times a week. In addition to the care provided to Aggie, Rita also provides two hours of care a week to her 76-year-old mother Edith. Edith although in good physical health and poor emotional- mental health, also resides in her own home. Rita helps Edith with financial support every six months. Rita receives help with household chores, home yard maintenance, moral support and transportation in the care of Edith from her sister Andrea, her husband Mike and Edith's good friend Betty. Andrea provides daily personal assistance to Edith as does Mike. Andrea also provides help several times a week with general care, and household care as well as daily help with emotional support. Mike helps Edith with general care every one to two months as well as household care two or three times a week. Betty assists with daily emotional support and weekly financial support.

This vignette reflects the perspective of a primary caregiver reporting on the activities of other family members in the care of two older relatives. The vignette illustrates the nature of caregiving and helping, and shows the distribution of helping and caregiving across the family, both to the primary caregiver and to the older person receiving care. The intricacies of care work among adult sisters as well as the gendered nature of care work are evident in this vignette. There are more women involved in this helping/caregiving network, and the women are providing help with greater frequency. This is consistent with findings on the total mean score for direct help (Table 3.8) where women report having more hours of direct help than men.

This vignette depicts the predominance of emotional/moral support in helping and caregiving as found in this study (Table 3.4 and Table 3.5). MacRae (1998) argues that caregiving is emotion work and can require the management of complex feelings. Results show that helping also involves emotion work. Individuals help the caregiver by providing emotional support while many also simultaneously provide emotional support to the older person receiving care.

The present study advances our understanding of caregiving through an examination of helping. As illustrated in the vignette of Rita, Aggie and Edith, helping is a significant component of family caregiving. Helping, like caregiving, intersects with gender, kinship and network composition.

There are two data limitations that may have affected the results of this study. The first limitation was the way in which helping tasks were grouped. Tasks were grouped into categories, for example, general care included: transportation, shopping and errands. The category 'general care' has multiple constituent parts and the groupings were broad and not necessarily exhaustive of all the kinds of help caregivers were receiving. This may have had implications in terms of capturing differences and similarities between women and men. For instance, women and men may be receiving help with different aspects of general care but the structure of the question did not allow respondents to identify the individual aspects of general care with which they received help. Future studies would benefit from including more and/or different groupings as well as the inclusion of open-ended questions on the contributions of helpers. The inclusion of open-ended questions on help would be useful to further identify the range of helper contributions and also allow for the development of differential meanings of help for women and men (Miller, 1996).

The second limitation of this study was the lack of information on the personal characteristics of helpers. For example, the CARNET data did not include any questions on the age, employment status, or geographical proximity of the helpers. This made it impossible to determine how help is negotiated based on personal, employment or other related characteristics as described by Finch & Mason (1993). Future research that

examines how help is negotiated using helper characteristics in addition to gender and kinship would further extend our understanding of helping networks.

Conclusions

Based on the findings from this study, it can be concluded that there are multiple individuals who help each other and provide help to an older person within the context of family caregiving. Gender and kinship are important factors in understanding who helps who, how they help and the composition of helping/caregiving families. Adult siblings actively assist one another in caring for aging parents and are identified as helpers by both men and women. Although helping networks are relatively small, composed predominantly of kin and are female dominated, they have variability. Helping is an important component of caregiving, which is best conceptualized at a familial level of analysis.

References

Aronson, J. (1992). Are we really listening? Beyond the official discourse on needs of old people. Canadian Social Work Review, 9(1), 73 – 87.

Aartsen, M. J., van Tilburg, T., Smits, C. H. M. & Knipscheer, K. C. P. M. (2004). A longitudinal study of the impact of physical and cognitive decline on the personal network in old age. Journal of Social and Personal Relationships, 21(2), 249 – 266.

Abel, E. K. & Nelson, M. K. (1990). Circle of care: An introductory essay. In Abel, E. K. & Nelson, M. K. (Eds.), Circles of Care: Work and Identity in Women's Lives, (4 – 34). New York: State University of New York Press.

Boaz, R. F. & Hu, J. (1997). Determining the amount of help used by disabled elderly persons at home: The role of coping resources. Journal of Gerontology: Social Sciences, 52B(6), S317 – S324.

Campbell, L. D. & Martin-Matthews, A. (2003). The gendered nature of men's filial care. Journal of Gerontology: Social Sciences, 58B(6), S350-S358.

Cantor, M. H. (1979). Neighbors and friends: an overlooked resource in the informal support system. Research on Aging, 1(4), 434 – 463.

Cantor, M. H. (1991). Family and community: changing roles in an aging society. The Gerontologist, 31(3), 337 – 346.

Cicerelli, V. G. (2003). Mothers' and daughters' paternalism beliefs and caregiving decision making. Research on Aging, 25(1), 3-21.

Connidis, I. A. (2001). Family Ties & Aging. Thousand Oaks: Sage Publications.

Connidis, I. A., Rosenthal, C. J. & McMullin, J. A. (1996). The impact of family composition on providing help to older parents. Research on Aging, 18(4), 402 - 429.

Crocker Houde, S. (2002). Methodological issues in male caregiver research: an integrative review of the literature. Journal of Advanced Nursing, 40(6), 626 – 640.

Eriksen, S. & Gerstel, N. (2002). A labor of love or labor itself: care work among adult brothers and sisters. Journal of Family Issues, 23(7), 836 – 856.

Fast, J., Keating, N., Otfinowski, P. & Derksen, L. (2004). Characteristics of family/friend care networks of frail seniors. Canadian Journal on Aging, 23(1), 5 – 19.

Finch, J. (1989). Family Obligations and Social Change. Southhampton: Camelot Press Ltd.

Finch, J. & Mason, J. (1993). Negotiating Family Responsibilities. London: Tavistock/Routledge.

Gignac, M., Kelloway, K. E., & Gottlieb, B. H. (1996). The impact of caregiving on employment: a mediational model of work-family conflict. Canadian Journal on Aging, 15(4), 525 – 542.

Globerman, J. (1994). Balancing tensions in families with Alzheimer's disease: the self and the family. Journal of Aging Studies, 8(2), 211 – 232.

Gottlieb, B. H., Kelloway, K., & Fraboni, M. (1994). Aspects of eldercare that place employees at risk. The Gerontologist, 34(6), 815 - 821.

Guberman, N. (1999). Daughters-in-law as caregivers: how and why do the come to care? Journal of Women & Aging, 11(1), 85 – 102.

Guberman, N. & Maheu, P. (2002). Conceptions of family caregivers: Implications for professional practice. Canadian Journal on Aging, 21(1), 27 – 37.

Gubrium, J. F. (1988). Family responsibility and caregiving in the qualitative analysis of the Alzheimer's disease experience. Journal of Marriage and the Family, 50(1), 197 – 207.

Hareven, T. K. (2001). Historical perspectives on aging and family relations. In Binstock, R. H. & George, L. (Eds.). Handbook of Aging and the Social Sciences, 5th Edition, (141 – 155). San Diego: Academic Press.

Hequembourg, A. & Brallier, S. (2005). Gendered stories of parental caregiving among siblings. Journal of Aging Studies, 19(2), 53 – 71.

Ingersoll-Dayton, B., Neal, M. B., Ha, J. & Hammer, L. B. (2003). Collaboration among siblings providing care for older parents. Journal of Gerontological Social Work, 40(3), 51 – 66.

Kahn, R. L. & Antonucci, T. C. (1981). Convoys of social support: a life-course approach. In March, J. G., Kiesler, S. B., Morgan, J. N., & Oppenheimer, V. K. (Eds.), Aging: Social Change, (383 – 405). New York: Academic Press.

Katz, S., Ford, A. B., Moskowtiz, R. W., Jackson, B. A. & Jaffee, M. W. (1963). Studies of illness in the aged. The index of ADL: a standardized measure of biological and psychological function. Journal of the American Medical Association, 185, 914 – 919.

Keating, N. C., Fast, J. E., Frederick, J., Cranswick, K., & Perrier, C. (1999). Eldercare in Canada: Context, Content, and Consequences. Ottawa: Minister of Industry, Statistics Canada.

Keating, N. C., Otfinowski, P., Wenger, C., Fast, J. E. & Derksen, L. (2003). Understanding the caring capacity of informal networks of frail seniors: A case for care networks. Ageing & Society, 23(1), 115-127.

Keith, C. (1995). Family caregiving systems: models, resources, and values. Journal of Marriage and the Family. 57(1), 179 – 189.

Li, L. W. (2004). Caregiving network compositions and use of supportive services by community-dwelling dependent elders. Journal of Gerontological Social Work, 43(2/3), 147 – 164.

Lopata, H. Z. (1995). Feminist perspectives on social gerontology. In Blieszner, R. & Bedford, V. H. (Eds). Handbook of Aging and the Family. Westport: Greenwood Press.

MacRae, H. (1998). Managing feelings: caregiving as emotion work. Research on Aging, 20(1), 137- 160.

Marshall, V. W., Matthews, S. H., Rosenthal, C. J. (1993). Elusiveness of family life: a challenge for the sociology of aging. In Maddox G. L., & Powell Lawton M. (Eds.). Annual Review of Gerontology and Geriatrics: Focus on Kinship, Aging, and Social Change, (39 – 72). New York: Springer.

Matthews, S. (2002). Sisters and Brothers/Daughters and Sons: Meeting the Needs of Old Parents. Bloomington: Unlimited Publishing.

Matthews, S. & Rosner, T. T. (1988). Shared filial responsibility: the family as the primary caregiver. Journal of Marriage and the Family, 50(1), 185 – 195.

McMullin, J. (2005). Patterns of paid and unpaid work: the influence of power, social context, and family background. Canadian Journal on Aging, 24(3), 225 – 236.

Miller, B. (1996). Beyond gender stereotypes: spouse caregivers of persons with dementia. Journal of Aging Studies, 10(3), 189 – 205.

Navaie-Waliser, M., Spriggs, A. & Feldman, P. H. (2002). Informal caregiving: differential experiences by gender. Medical Care, 40(12), 1249 – 1259.

Opie, A. (1994). The instability of the caring body: Gender and caregivers of confused older people. Qualitative Health Research, 4(1), 31 – 51.

Peek, C. W. & Zsembik, B.A. (1997). The changing caregiving networks of older adults. Research on Aging, 19(3), 333 – 362.

Piercy, K. W. (1998). Theorizing about family caregiving: the role of responsibility. Journal of Marriage & Family, 60(1), 109 – 118.

Penning, M. J. (1990). Receipt of assistance by elderly people: hierarchical selection and task specificity. The Gerontologist, 30(2), 220 – 228.

Perry, J. (2004). Daughters giving care to mothers who have dementia: mastering the 3 R's of (Re)calling, (Re)learning, and (Re)adjusting. Journal of Family Nursing, 10(1), 50-70.

Phillips, J. (2000). Working carers: caring workers. In Bernard, M., Phillips, J., Machin, L. & Harding Davies, V. (Eds.), Women Ageing: Changing Identities, Challenging Myths, (40-57). Routledge: London.

Pyke, K. D. & Bengtson, V. L. (1996). Caring more or less: Individualistic and collectivist systems. Journal of Marriage & Family, 58(2), 379 – 383.

Raschick, M. & Ingersoll-Dayton, B. (2004). The costs and rewards of caregiving among spouses and adult children. Family Relations, 53(3), 317 – 325.

Romoren, T. I. (2003). The carer careers of son and daughter primary carers of their very old parents in Norway. Ageing & Society, 23(4), 471 – 485.

Russell, R. (2001). In sickness and in health: a qualitative study of elderly men who care for wives with dementia. Journal of Aging Studies, 15(4), 351 – 367.

Sarkisian, N. & Gerstel, N. (2004). Explaining the gap in help to parents: the importance of employment. Journal of Marriage and Family, 66(2), 431 – 451.

Stoller, E. P. (1994). Teaching about gender: the experience of family care of frail elderly relatives. Educational Gerontology, 20(7), 679 – 697.

Stone, R. I. (2001). Home and community based care: Toward a caring paradigm. In Cluff, L. E. & Binstock, R. H. (Eds.). The Lost Art of Caring: A Challenge for Health Professionals, Families, Communities, and Society, (155 - 176). Baltimore: John Hopkins University Press.

Walker, A. (2001). Conceptual perspectives on gender and family caregiving. In J. W. Dwyer & R. T. Coward (Eds.), Gender, Families and Elder Care (pp. 34 – 48). Thousand Oaks, CA: Sage.

CHAPTER FOUR

Study Three: Helpers in Family Caregiving: Three Case Vignettes[20]

Caregiving is a complex concept that often involves multiple members of a single family. Armstrong & Kits (2004: 45) argue, "caregiving is not a simple act but rather a complex social relationship – one embedded in personal histories and located within specific conditions". The key to understanding helping and caregiving is therefore to distinguish and organize the multiple meanings, relationships and responsibilities within a specific social context or family.

Very little work has been done on understanding caregiving when multiple individuals are involved in the provision of care to an older person. In his work on family caregiving, Gubrium (1988:197) contends that researchers must be careful not to homogenize the experience of caregivers. However, this is precisely what has happened in much of the research on caregiving. Researchers have tended to develop understandings of caregiving by focusing on issues that are "most" pressing or most evident (Martin-Matthews, 1999). These have typically included the stress, burden and health impacts on primary caregivers. This focus in caregiving research has created an awareness of the deleterious health impacts on primary caregivers. It has, however, not extended our understanding of how multiple individuals contribute in the context of family caregiving to primary caregivers and to the older person receiving care.

Gubrium (1988: 206) argues that the "interpretation of the caregiving experience by any one caregiver or family member is tied to others, suggesting a limitation of individual measurement". Responding to this comment and consistent with findings from Study One and Study Two in this dissertation, family caregiving research must extend

[20] A version of this chapter will be submitted to a peer-reviewed journal (journal yet to be determined).

analyses to include the contributions of multiple individuals. Research that focuses on the contributions of multiple individuals serves to improve understandings of how care is organized and negotiated while also raising the profile of those 'lone' caregivers. As shown in Study One and Study Two of this dissertation, the experience of primary caregivers in the context of a family with multiple individuals contributing is different than a primary caregiver providing care without assistance. The present research extends previous research on primary caregivers by focusing on the experience when multiple individuals are involved in the provision of care.

In addition to a focus on family caregiving that has relied extensively on the primary caregivers, the bulk of caregiving research has been focused methodologically on analyses of statistical averages and deviations in mean scores. Blumstein & Swartz (1983: 23) contend that a reliance on statistical averages is problematic as it often "obscures the amount of variation that really exists". Similarly, Aronson (1992) argues that there is a tendency among researchers to be reductionist when defining the needs of older people. Very few studies take a reflexive approach to determine what is lost or at least less considered by adopting a particular strategy or approach (Martin-Matthews, 1999). This study, using a case vignette methodology, examines commonalities across several cases and also highlights variations. In an attempt to further the reflexivity of this study, findings are compared with Study One and Study Two.

If the social phenomenon of caregiving is to become better understood, new directions and explanatory paradigms must be developed (Fast, Keating, Otfinowski & Derksen, 2004; Keating, Fast, Connidis, Penning & Keefe, 1997; Miller, 1998). Explanations of caregiving must move beyond statistical averages and task-centered

descriptions (Miller, 1998) and focus on alternative approaches to dominant conceptions of caregiving and caregivers (Aronson, 1992; Martin-Matthews, 1999; Perry, 2004; O'Connor, 1999). Gubrium (1988) and Hequembourg & Brailler (2005) suggest that research on caregiving must include the perspectives of multiple family members.

The primary purpose of this study is to provide insight into the multiple relationships and contributions involved in the context of providing care to an aging family member. With little research focusing on family relationships in caregiving, and an emphasis on the "work" of providing care (Perry, 2004:51), family caregiving has been cast as an individual responsibility and not a family level experience. This study advances understandings of caregiving through a focus on caregiving as a group/family level concept. This is accomplished through the adoption of a case vignette methodology using verbatim and survey data from the Canadian Aging Research Network (CARNET) study of employed Canadians.

The second purpose of this study is to compare case vignette findings with findings from quantitative research on caregiving using the same CARNET data set as reported in Study One and Study Two. This study, through the use of vignettes, explores in detail three families providing care to an older relative. It focuses on the complexity of family relationships and multiple contributions within the context of caring for an older relative by comparing the three families to each other, as well as to previous work on family caregiving. In their work on married couples, Blumstein & Swartz (1983: 23) adopt a similar methodological strategy using case vignettes to illustrate "majority patterns and important exceptions" in marriage. This approach will extend previous analyses on caregiving by highlighting commonalities among three caregiving families

and also by emphasizing their differences, both to the other families and to previous caregiving research using the same CARNET data set.

This research adopts a case vignette approach and is guided by several research questions.

- What are the commonalities and differences of family helping/caregiving evident in the three case vignettes used in this study?
- How does helping and caregiving as conceptualized in case vignettes compare with findings from those in quantitative findings on caregiving using the same CARNET data set (i.e. Study One and Study Two)?
- Do case vignettes serve as a useful methodological tool?

The Study

Design

The CARNET Work and Family Study, was conducted in 1991-1992 and involved the distribution of surveys to 9,693 employees in eight Canadian organizations[21]. The organizations do not represent a random cross-section of Canadian employees, but efforts were made to select organizations representing different employment sectors, including government agencies, financial services, manufacturing, health services and educational institutions (Gottlieb, Kelloway & Fraboni, 1994; Gignac, Kelloway & Gottlieb, 1996).

During initial data collection stages, personal meetings were conducted with employers to describe and explain the purpose of the study. Once an organization agreed to participate, employees were mailed an information letter describing the study and a questionnaire comprised of standardized scales from previous research. The questionnaire also included items developed specifically for this study (Gottlieb, Kelloway & Fraboni, 1994). In six of eight of the organizations, participants over the age of 35 were over-sampled to increase the likelihood of identifying people currently providing assistance to a relative aged 65 or older (Gottlieb, Kelloway & Fraboni, 1994; Gignac, Kelloway & Gottelieb, 1996).

A variety of methods were used to distribute and collect surveys in accordance with preferences of participating organizations (Gottlieb, Kelloway & Fraboni, 1994). The questionnaire was self-administered and took approximately 35 to 45 minutes to complete. A reminder notice was mailed to each company one week after the survey was

[21]Most of the organizations were located in the province of Ontario and were situated in urban and rural environments.

distributed to remind all respondents to return questionnaires. Across all participating organizations, a total of 5, 496 usable surveys were returned, yielding an overall response rate of 57 per cent in the first phase of the study (1991-1992). At this stage, 878 respondents identified themselves with contact information so that they could be reached in follow-up studies.

The second phase of the research conducted in 1994 involved a follow-up with the 878 respondents who had provided contact information in stage one. This second stage was conducted as a screening stage to identify individuals for inclusion in stage three. Of the 878 individuals who provided information for further follow-up 497 were reached. Individuals were asked a variety of questions regarding the provision of care to an older adult, some of which included: "Do you provide assistance with personal care (i.e. feeding, bathing, etc.)?", "Do you provide assistance with household chores/maintenance?", "Do you provide assistance with finances?", "Do you provide emotional support ?" In order to be included in the third phase of the study the respondent had to be providing care to at least one relative and assisting with one Activity of Daily Living (feeding, bathing, dressing, etc.) or two Instrumental Activities of Daily Living (home maintenance, transportation, shopping, etc.). As a result of this screening process 328 individuals were identified for inclusion in the third and final stage of CARNET, The Work and Eldercare Study.

Of the 328 individuals surveyed, 250 individuals (108 men and 142 women) completed the survey questionnaire. The respondents reported on various aspects of care provision for up to three elderly family members; they also provided information on caregiving contributions for up to three 'helpers". The third stage of the research was

conducted to examine the patterns of formal service use and the frequency, type and duration of help provided by caregivers and those who they identified as providing 'help' in family caregiving in a sample of employed Canadians. In this third stage, 55 respondents provided written verbatims in response to several open-ended questions regarding helping and caregiving. These 55 individuals comprise the sample for the present analysis.

Case Vignettes

Marshall (1999: 377) argues that case studies, which emphasize the meanings of social behaviour, are an ideal approach to generate in-depth and contextualized data. Cases can examine individuals or any social or organizational unit such as a family or a firm (Marshall, 1999). Yin (1994: 13) suggests that the case itself is the unit of analysis, and Walton (1992: 122) explains the cases utility to "demonstrate a casual argument about how general social forces take shape and produce results in specific settings". Stake (1995) suggests a case study that is instrumental to the accomplishment of goals such as answering specific questions or hypotheses can be called "an instrumental case study".

In this investigation, cases are not used to answer a specific question or hypothesis but rather to underscore particular elements in caregiving potentially not captured in the other analyses. This study uses descriptive cases or vignettes as a research lens for examining caregiving, the similarities and differences across cases and compared to previous findings on caregiving using the same data set. While some of the ideas that drive case study analysis have been used in this paper, the methodology is not a case study analysis as described by Marshall (1999), Yin (1994) or Stake (1995) but

rather an examination of several purposively chosen cases to illustrate particular elements of the family caregiving experience. This methodological approach is similar to that used in Blumstein & Swartz's (1983) study of married couples where case vignettes are used to demonstrate majority patterns and unique exceptions in the relationship dynamics of married couples.

Developing Cases

In order to develop each family caregiving case vignette, descriptive data from the CARNET study were utilized. The descriptive data were used in conjunction with written verbatim responses to open ended questions from the 55 respondents who provided verbatim data in phase three of the CARNET study. Respondents provided written responses to questions such as: "what has helped you to balance your work and family responsibilities?" and "what would make a difference for you?" as well as providing written responses in the "free comment" section of the CARNET Work and Eldercare Questionnaire. This section invited respondents to "make any further comments about combining work and family responsibilities".

In addition to verbatim responses to open ended questions on caregiving, respondents provided demographic information on gender, age, occupation, living arrangements and parental status by answering questions such as "What is your marital status?", "What is your age in years" etc. To explore the provision of care to an older person, respondents were asked: "Are you the person most responsible for providing care to your older relative?"; "If no, then who is?"; and, "Who else has helped this relative?". These questions allowed for a determination as to whether the respondent caregiver was

the primary caregiver or not. It also identified who helped the respondent caregiver and who helped their relative (the helpers).

Development of the three cases required analysis of responses to such questions as: "In the last six months has anyone assisted *you* in helping your elderly relatives/friend in any of the following ways: household chores, childcare, financial assistance, home/yard maintenance or repair, moral/emotional support or other?", "Within the past six months, how often *has this person* (helper one, helper two, helper three) helped your older relative/friend with bathing, dressing, feeding, toileting or taking medication?".

Responses to these questions allowed for the examination of patterns of assistive help to the older relative/friend (the help provided to the respondent caregiver who then in turn provided help to the older relative) as well as measurement of direct help (help from the respondent caregiver to the older relative and help from the helper to the older relative).

Case vignettes were developed by using the descriptive data and verbatim data noted above. Pseudonyms were assigned to caregivers, helpers and older individuals receiving care, to create a caregiving 'story'.

Selecting Cases

The first step in selecting which cases to develop into case vignettes involved the development of case profiles for respondents who gave verbatim responses in the "free comments" section of the CARNET Work and Eldercare Study. The 'free comments section' was where respondents provided any additional information on caregiving outside of the survey questionnaire. In many cases respondents used this section to summarize their experiences and to provide comments on what would have helped them,

what impeded their work as a caregiver and to make suggestions for research and policy development. This section, while limited, gave a narrative account of respondents experience as caregivers. There were 23 respondents who used the 'free comments section'. This reduced the potential number of profiles from 55 individuals who provided verbatim responses to 23. Each of these 23 respondents provided verbatim data and provided written responses in the 'free comments section'.

Several spreadsheets of responses were created with each row representing one of the 23 respondents. This created a statistical profile for each of the 23 respondents. The rows contained statistical demographic data and patterns of helping, and also identified key themes emerging from verbatim data. The key themes were identified through repeated reading of the responses.

The next step in selecting cases separated male from female caregivers and then separated those who identified having multiple helpers from those who identified one or no helpers. These groupings separated profiles into several distinct groups: male respondent/female respondent and have help/no help. Based on these groupings three profiles were selected for development into a case vignette. The three profiles for development into a case vignette included, a male respondent caregiver, a female respondent for whom little or no help was identified and a female respondent reporting the provision of help from multiple individuals. The selection of these case vignettes was not meant to fully represent all caregiving families, but rather to illustrate a spectrum of experiences within the CARNET data set.

Analysis

As stated above, the CARNET data includes written responses to closed and open-ended questions. The combination of frequency and verbatim responses allowed for the development and analysis of three cases. Once cases were developed, they were read and re-read to identify common themes across all three cases and to identify variations, called unique themes. Using findings from previous studies on caregiving using CARNET data (i.e. Study One and Study Two in this dissertation) common themes and unique characteristics, as identified within the case vignettes, were compared and contrasted. In this manner one might describe the technique as an "audit" of results (Lincoln & Guba, 1985: 317). The themes from the three case vignettes are corroborated with findings from the previous studies; this process is described by Lincoln & Guba (1985) as "authenticating findings" or by Blumstein & Swartz (1983) as identifying majority patterns and important exceptions.

This study presents each case vignette, its unique themes/qualities and then in a separate section, common themes across case vignettes are presented and discussed.

Three Cases: Unique and Common Themes

Case One: Julie Walsh

Julie is a 51-year old teacher who provides regular care to her 84-year old mother Mary. Julie is married and has two children Blaine and Jennifer, ages 27 and 25. Julie indicates that she is a caregiver for her mother Mary. Mary lives in her own home and is in good physical and emotional health. Julie emotionally supports Mary once a week. She also helps her once or twice every six months with general care, household care, and personal care. Julie has two brothers and one sister whom she reports as non- participants in the care of Mary. When asked if Julie receives help in caring for Mary she indicated no, but when asked if Mary receives help from other individuals directly, Julie indicated yes. Mary receives assistance from a Homecare worker, a foot care helper and a hired helper. They are all non-kin and paid helpers. The Homecare worker assists with personal care 2-3 times a week and household help once or twice every six months. The foot care helper assists with personal care every 1-2 months, and the hired helpers assist every 1-2 months with personal care and general care, and with household care once or twice every six months.

Unique Theme: 'Un'Helper or Absent Caregivers.

The case of Julie and Mary illustrates an important theme that recurs in written responses in the CARNET data, and is not captured in statistical analyses of this data; the identification of an absent caregiver(s) and the tension created by that absence. This is a sensitive area for Julie who, when asked what would make a difference in helping care for her mother, responded:

More interest on part of my 2 brothers – one not as far from her as I am. I have a sister in Nova Scotia with a husband. When she visits she won't stay more than 1 night, I have been the main person. I did all packing on several moves, and I drive her to all her appointments.

This comment reflects the situation or circumstances of 17 of 55 (31%) respondents in the CARNET study who responded to the same question in a very similar manner. For example, other study participants similarly noted the impact of family members absent from caregiver activities:

More help and support from rest of family members.

My brother and sister do not provide any assistance or support. I have to work so I can't give enough care. The Dr. says Mom can live on her own with support services yet the Long Term care assessor says she should not be left alone. Family sharing responsibilities would help.

Regular contact by all family members. One sister does not consistently telephone/write except when she needs something. More filial care and altruism is required.

I provide excellent care. I get NO help from my brothers or sister, financial or otherwise. My sister never visits, my brother visits once a year. More family assistance.

Other family members could have more involvement and provide for needs from relative's perspective versus what they (other family members) define as being required.

More help and understanding from other family members.

In his work on meaning making Rubinstein (1989) found that caregivers often implicate others who are not actively involved in caregiving. Rubinstein (1989: 135) states, "the narrative account – the story of the caregiving, or of the parent's illness, or of the caregiver's life – cannot be told without reference to this other person or persons". Similarly, Finch & Mason (1993: 81) highlight "the importance of looking at what is not discussed openly [in the context of negotiating family responsibilities], and who is not

included". In this case, Julie is openly critical of the lack of participation of her brothers and the limited involvement of her sister. She highlights this within her written responses, and also within her identification of helpers. She does not include her siblings as helpers to her or to her mother Mary. When asked if she had any closing comments on combining work and family responsibilities, Julie's statement reflects her displeasure with her brothers and sisters (lack of) involvement in providing care for Mary:

> *I visited every 2 weeks when my Dad was dying and I was working full time. My brother and his large family, living in the same town and rarely bothered. He [father] was in hospital with bone cancer for 6 months.*

Rubinstein (1989: 136) suggests the existence of those who 'do less' or who according to Finch & Mason (1993) are perceived as 'unwilling' to participate, frame the narrative of the caregiver's experience. The caregiver's work is described in direct reference to the lack of 'work' or contributions of another. The inclusion of 'non-participants' in family caregiving is an important component of continuing to understand the experiences of caregivers and helpers. In this way, previous models for understanding family caregiving such as the convoys of social support (Kahn & Antonucci, 1981) and hierarchical compensatory (Cantor, 1979, 1991), are limited. These models focus on who is doing what and the relative proximity to the older person, but exclude considerations of who is available and whether they are providing care or not.

A limitation of the data on caregiving networks in the CARNET study is that it is restricted to those who are identified as providing help to either the respondent caregiver or to the older person receiving care. As a result, it is not possible to determine the profile of those who are 'available' to help but not participating. Analysis of written

responses and the 'free comments' sections, provided a place for many of the respondents to discuss the availability of other family members and also to articulate their lack of participation.

Case Two: Libby Jones

Libby is a 40-year old divorced nursing attendant who lives with her 14 year-old son. Prior to her mother's death one year ago, Libby provided approximately ten hours a week of care to her 74-year-old mother Elsa. At the time of the survey Elsa was in good physical and mental/emotional health. Libby assisted Elsa several times a week with dressing, medication, bathing/washing, using the toilet, transportation, shopping, and household chores. In addition to caring for Elsa, Libby also provided approximately three hours of care per week to her 85-year-old Aunt Rose who also lives alone in her own home. Libby has two brothers and four sisters. She received help in providing care for her mother Elsa, but received no support in caring for Aunt Rose. Libby received help with home yard maintenance and moral support in caring for Elsa. Her sister Linda and her niece Fanny also helped provide care for Elsa. Linda provided assistance to Elsa every one to two months with general care, as well as daily emotional support. Once a week, Fanny helped Elsa with personal care, general care, household care and emotional care.

When asked to comment on the balance of work and family responsibilities, Libby wrote:

> *While providing for my Mother before she died a year ago the assistance we received from Homecare and VON nurses was exceptional. But until after Mom died I didn't realize how continually stressed I was nor how it had affected my son and my brothers' and sisters' families. I believe caregivers need both emotional and in some cases financial assistance. I was asked to leave my new job as a*

secretary because of stress and lost time when Mom was dying...it's amazing how well you think you're coping until the pressure is over and you realize you were just "making it".

Libby concluded by stating:

If we had someone stay with Mother so we could work full time and be subsidized it would have helped.

Unique Theme: Multiple Care Receivers.

This case captures the organizational complexity of helping and caregiving for multiple individuals. Though this is typically not emphasized in studies of caregiving, the prevalence of caring for multiple older family members is significant. In the final phase of CARNET 44 % of respondents were caring for two older relatives, and 12 % of respondents were simultaneously caring for three older relatives.

Case Two illustrates helping and caregiving within a family. This case captures the intricacies involved in providing care to two aging relatives, and the breadth and depth of family involvement. Help is provided directly to the older adult(s) and assistively by providing support to the respondent caregiver (Libby). Studies of caregiving have focused predominantly on care provided directly to one older person, while this case demonstrates that the lived reality is often much more multi-faceted. Including responses concerning the provision of care to more than one care recipient could deepen understandings of the intricacies of family caregiving.

Another element highlighted in Libby's case is the retrospective nature of experiences. Libby reflects on the experiences of caregiving in a different way than those respondents who were still communicating in the present. Libby is able to offer another perspective on her experiences of balancing work and caregiving. Studies that continue

beyond the death of the care recipient, can provide insight into the overall caregiving experience.

Case Three: Jack Fraser

Jack is a married 55 year-old foreman/engineer with four grown children (ages 26-32 years). Jack, who indicated that he is the person most responsible for providing care, provides approximately ten hours of care per week to his mother-in-law Flora. Flora, who is in poor physical health and fair mental health, resides in her own home. Jack assists Flora with a variety of tasks on a weekly basis. Tasks include: general care, household care, emotional support, as well as monthly financial support. Jack receives help from his wife Betty in caring for mother-in-law Flora. Betty helps Flora several times a week with personal care, general care, household care, emotional and financial support. Betty helps Jack with moral support and household chores. When asked who else helps your relative, Jack also indicated that a worker from Homecare helps to provide care and assist in maintaining Flora in her own home. The Homecare worker provides help several times a week with personal care, household care and emotional support.

When asked to provide comment freely about his caregiving experience, Jack indicated:

> *Homecare is vital to helping us combine work & family responsibilities and keeping [our] relative out of nursing home. Recent Government cutbacks have caused Homecare to request the family to take over all shopping, thereby eliminating time allowed to relative for this duty. What really helps was knowing someone was there to check that [our] relative was o.k., it [Homecare] relieved pressure of visiting each day, knowing a meal was offered.*

Unique Theme: Men Are Caregivers.

Case Three, Jack and Flora, provides an example of men and women contributing together in the context of family caregiving. Jack, who identifies himself as the primary caregiver to his mother-in-law Flora, provides assistance with a range of activities. The experiences presented in this case study provide an important reminder; while men's caregiving may not be statistically significant because of the lower frequency of male caregivers, their experiences provide insight into how individuals, both male and female, organize to provide care to aging family members. It is not always the differential contributions that are useful to examine, but the combined, coordinated and relational contributions of men and women together.

An interesting component of this vignette is in the identification of who is the primary caregiver. Jack defines himself as the person most responsible for providing care, but upon reviewing the case vignette, clearly, Betty, meets the usual definition for primary caregiver (i.e. the person who is providing personal care is usually defined as the primary caregiver). This illustration corroborates research on the differential experiences of women and men in caregiving (Miller, 1996; Raschick & Ingersoll-Dayton, 2004; Ingersoll-Dayton, Neal, Ha & Hammer, 2003) and raises questions about the intersection of gender and the identification of being a caregiver/helper (see Study Two).

Common Themes

As identified within the three cases, there are unique characteristics within each vignette which help represent the experiences of helping and caregiving networks within the CARNET study (N=250). In addition to unique characteristics, there are also several common themes presented across all three cases that help illuminate critical aspects of

caregiving. These themes include: the balance of both direct and assistive help, and the inclusion of paid helpers in helping and caregiving networks.

Balance of Direct and Assistive Help.

Neysmith & MacAdam (1999: 12) contend, "a person does not operate outside of relationships; nor does she or he exercise rational choice based on a calculation of self-interest...decisions are made within a web of social relations". The 'web of social relations' present in family caregiving are particularly evident within case vignettes through an examination of the balance of direct and assistive help. As demonstrated in the case vignettes, families juggle responsibilities by providing assistance to one another and through the provision of support directly to the older person. In the verbatim data 19 of 55 respondents (35%) make reference to receiving help with caregiving and/or the involvement of more than one person in the provision of care. This is consistent with findings from other CARNET caregiving research (Study One and Study Two in this dissertation) where 199 of 250 respondents indicate having help in their caregiving from at least one other person; Study One and Study Two show that 23% of respondents indicate receiving help from at least three other individuals.

This picture of caregiving is in contrast to many previous conceptualizations of family caregiving where there is one caregiver acting alone in her caregiving. Emerging research suggests that a focus on individual roles and stresses is too simplistic (Phillips, 2000). Clearly this is the case with respect to caregiving research. In many cases there are multiple individuals beyond the primary caregiver involved in caregiving.

Understanding the balance of direct and assistive help advances understandings of the different types of assistance in the context of family caregiving and also the demands

placed on multiple individuals within a family. Examining assistive and direct help also contributes to knowledge about the coordination and juggling involved in the provision of care to an aging family member.

Networks with Paid Helpers.

The inclusion of non-kin in the helping and caregiving networks is an interesting component of the CARNET study. Without being prompted to include individuals 'outside' the family, 17 of 55 of the respondents (30%) included paid helpers[22] as being essential to their caregiving experience. This is a unique finding, as only very recently has the idea of caregiving as a partnership between family and paid caregivers emerged in gerontological research on caregiving (Martin-Matthews & Sims-Gould, 2004; Piercy, 2000; Porter, Ganong, Drew & Lanes, 2004; Ward-Griffin & Marshall, 2003). According to Ward-Griffin & Marshall (2003: 203) "a methodological and conceptual limitation of past research has been a heavy reliance on studying the vantage point of either the formal care providers or the informal family caregivers". In Study One and Study Two using the same CARNET data set, the presence of paid helpers is barely visible with paid help comprising only 3% of all helpers. However, verbatim data shows that paid helpers, also referred to in gerontological research as formal caregivers, are important contributors in family caregiving. Paid caregivers provide assistance to the older person (client) and they are also identified as 'helpers' by caregivers.

Research on family caregiving with a focus on understanding individual tasks and stress has failed not only to include the perspectives of multiple family members but also those individuals who transcend the paid caregiver role to become 'family-like'. Kahana

[22] Paid helpers included both those available through the publicly funded Home Care system and those privately employed by individual families.

& Young (1990: 93) contend, "caregiving arrangements are far more complex, generally involving entire family systems, on the one hand, and a network of formal caregivers on the other". In a study on family caregiving, Martin-Matthews & Sims-Gould (2004) (using the same CARNET data set as in this dissertation) found that family members often identify paid or formal caregivers as significant helpers, sometimes considered 'like family', in the context of providing care to an older relative. Similarly, in her study of homecare workers, Karner (1998) found that paid workers often provide "help" with duties that are not professionally assigned. The performance of these unassigned duties has been shown to create a set of "familial like" expectations and bonds that extend beyond the role of a paid employee. Karner (1998: 79) suggests, "workers become involved in a social interaction that reconstructs the relationship as one of fictive kin with all the attendant responsibilities and obligations of blood relations". This type of research, exploring the role of formal (paid) caregivers in helping and caregiving, has the potential to shift caregiving research into a new domain that seeks to define caregiving based on an understanding of multiple relationships; relationships outside of the domain of what is known to be 'family'.

Conclusions

The findings from this study illustrate several specific elements of helping and caregiving. These include, the importance of the 'un' helper or absent caregivers in caregiving, the acknowledgement that caregivers often provide simultaneous care to multiple care recipients and the participation of men in caregiving. This study also provides additional support for key findings identified in Study One and Study Two. These include, the balance of direct and assistive help and the presence of paid helpers in caregiving networks.

Extending the conclusion from Study One and Study Two that family caregiving consists of multiple family members with multiple and differential contributions, this study demonstrates that family caregiving networks also include absent or 'inactive' individuals. The absent or inactive individuals in family caregiving provide a touchstone for those actively contributing. The absent caregivers provide a comparison or baseline from which caregivers often compare and articulate their own contributions. The absent caregivers also provide a mechanism for caregivers to discuss their frustrations and the observed inequities that occur (for caregivers and helpers) within the context of family caregiving. These frustrations, in a more traditional dyadic study, without the touchstone of the absent caregiver, are more difficult for caregivers and helpers to articulate. Using the absent caregiver as a comparison, caregivers can position their experience against that of the absent individual(s). As demonstrated in the verbatim responses, caregivers use the absent caregiver as a vehicle for discussing stresses and anxieties associated with caring for an older relative.

Another important component of caregiving highlighted in this study is the reality that many caregivers provide simultaneous assistance to more than one older person. Caregiving is often conceptualized in research as one person providing care to one older individual (see Figure 2.1). However, like the findings from Study One and Study Two where there are often multiple individuals making caregiving and helping contributions, this study shows that caregivers often provide assistance to multiple care recipients.

Evident in the case vignettes in this study are the contributions of men in caregiving. Although statistically not as frequent as women's caregiving contributions, men also provide care to their older relatives as well as help to other caregivers. What is not known is the differential meaning that men and women ascribe to their caregiving and helping contributions and experiences. As identified in Study Two and highlighted in the present investigation, future research that examines the definition and meanings of caregiving and helping for men and women would contribute to a greater depth of understanding of their differences and similarities.

In addition to highlighting unique elements in caregiving, this study corroborates findings from Study One and Study Two regarding the relational nature of caregiving and helping. The case vignettes illustrate the relational nature of caregiving and helping while depicting the balance of direct and assistive help. The three case vignettes show that individuals contribute both directly to the older person requiring care and also in an assistive manner to other helpers and caregivers. Caregiving is an arrangement that involves caregiving, caring and helping in a number of different ways. Research with a focus on the different types of support within a family caregiving system, with particular attention to the influence of various family configurations, has implications for how

caregiving is conceptualized, as well as for the development of appropriate programs and services designed to support caregiving families.

A final contribution of this study, which challenges current conceptualizations of 'family' caregiving, is the inclusion of paid helpers in caregiving networks. Family caregiving, once thought of as in the domain of 'the family', for many individuals now includes paid helpers. This finding underscores the need to include questions about paid help in studies of family caregiving. It also raises questions regarding the appropriateness of the term family caregiving and/or what it means to be 'family'. Examining the contributions of paid helpers in the context of caregiving will serve to deepen understandings of caregiving and also of what it means to be 'like family'.

Based on the findings from this study, it can be concluded that men and women, kin and non-kin, consaguinal and affinal, and paid workers organize in concert to provide care to an older person in the context of family caregiving. An examination of the three cases in this study extends our understanding of caregiving beyond the primary caregiver by showing that there are contributions and relationships between multiple individuals. The next step in caregiving research will be to begin to define these relationships and contributions outside of the primary caregiver distinction. For example, in some families, the notion of a primary caregiver or helper may prove to be an inaccurate and unnatural distinction. Hequembourg & Brallier (2005) favour the distinctions caregiver, helper and co-provider. Another possibility for conceptualizing different types of caregivers and caregiver responsibilities could include distinctions such as 'daughter's caregiving', 'sister's caregiving' or 'spousal caregiving'. A number of researchers (O'Connor, 1995, 1999; Perry, 2004) have identified the latter as being an appropriate way of naming and

understanding the different types of caregiving and the associated caregiving responsibilities unique to spouses, daughters, sons etc. This nomenclature also captures the relational nature of caregiving contributions.

The analyses in this study were methodologically enhanced and extended through the use of case vignettes extracted from verbatim and quantitative data derived from the CARNET study. Using case vignettes helps to penetrate some of the intricacies of the sample and reveal those elements 'buried' within other forms of analyses (Blumstein & Swartz, 1983; Groger & Straker, 2001). These findings supplement the findings from previous chapters, confirming common themes identified in the analyses of Study One and Study Two as well as allowing for the development of case specific themes (unique themes).

References

Armstrong, P. & Kits, O. (2004). One hundred years of caregiving. In Grant, K. R., Amaratunga, C., Armstrong, P., Boscoe, M., Pederson, A. & Willson, K. (Eds.), Caring For/Caring About: Women, Home Care and Unpaid Caregiving, (43 - 73). Aurora, Ontario: Garamond Press.

Aronson, J. (1992). Are we really listening? Beyond the official discourse on needs of old people. Canadian Social Work Review, 9(1), 73 – 87.

Blumstein, P. & Swartz, P. (1983). American Couples: Money, Work, Sex. New York: William Morrow and Company Inc.

Cantor, M. H. (1979). Neighbors and friends: an overlooked resource in the informal support system. Research on Aging, 1(4), 434 – 463.

Cantor, M. H. (1991). Family and community: changing roles in an aging society. The Gerontologist, 31(3), 337 – 346.

Fast, J., Keating, N., Otfinowski, P. & Derksen, L. (2004). Characteristics of family/friend care networks of frail seniors. Canadian Journal on Aging, 23(1), 5 – 19.

Finch, J. & Mason, J. (1993). Negotiating Family Responsibilities. London: Tavistock/Routledge.

Gignac, M., Kelloway, K. E., & Gottlieb, B. H. (1996). The impact of caregiving on employment: a mediational model of work-family conflict. Canadian Journal on Aging, 15(4), 525 – 542.

Gottlieb, B. H., Kelloway, K., & Fraboni, M. (1994). Aspects of eldercare that place employees at risk. The Gerontologist, 34(6), 815 - 821.

Groger, L. & Straker, J. K. (2001). Counting and recounting: approaches to combining quantitative and qualitative data and methods. In Rowles, G. D. & Schoenberg, N. E. (Eds.), Qualitative Gerontology: A Contemporary Perspective (2nd Edition). New York: Springer Publishing Co.

Gubrium, J. F. (1988). Family responsibility and caregiving in the qualitative analysis of the Alzheimer's disease experience. Journal of Marriage and the Family, 50(1), 197 – 207.

Hequembourg, A. & Brallier, S. (2005). Gendered stories of parental caregiving among siblings. Journal of Aging Studies, 19(1), 53 – 71.

Ingersoll-Dayton, B., Neal, M. B., Ha, J. & Hammer, L. B. (2003). Collaboration among siblings providing care for older parents. Journal of Gerontological Social Work, 40(3), 51 – 66.

Kahana, E. & Young, R. (1990). Clarifying the caregiving paradigm: Challenges for the future. In Biegel, D. E. & Blum, A. (Eds.). Aging and Caregiving: Theory, Research and Policy, (76 – 97). Newbury Park: Sage Publications.

Kahn, R. L. & Antonucci, T. C. (1981). Convoys of social support: a life-course approach. In March, J. G., Kiesler, S. B., Morgan, J. N., & Oppenheimer, V. K. (Eds.), Aging: Social Change, (383 – 405). New York: Academic Press.

Karner, T. X. (1998). Professional caring: Homecare workers as fictive kin. Journal of Aging Studies, 12(1), 69 – 83.

Keating, N. C., Fast, J. E., Connidis, I. A., Penning, M., & Keefe, J. (1997). Bridging policy and research in eldercare. Canadian Journal on Aging/Canadian Public Policy, Supplement, 22 – 41.

Lincoln, Y. S. & Guba, E. G. (1985). Naturalistic Inquiry. Newbury Park, CA: Sage Publications Inc.

Marshall, V. W. (1999). Reasoning with case studies: Issues of an aging workforce. Journal of Aging Studies, 13(4), 377 – 389.

Martin-Matthews, A. (1999). Widowhood: dominant renditions, changing demography and variable meaning. In Neysmith, S. M. (Ed.). Critical Issues in Social Work with the Elderly. New York: Columbia University Press.

Martin-Matthews, A. & Sims-Gould, J. (2004). Who's family and whose work: Social dynamics in the provision of care to elders in Canada, presentation at conference of the Research Committee on Aging, International Sociological Association, Surrey, U.K.

Miller, B. (1996). Beyond gender stereotypes: spouse caregivers of persons with dementia. Journal of Aging Studies, 10(3), 189 – 205.

Miller, B. (1998). Family caregiving: telling it like it is. The Gerontologist, 38(4), 510 – 513.

Neysmith, S. M. & MacAdam, M. (1999). Controversial concepts. In Neysmith, S. M. (Ed.), Critical Issues for Future Social Work Practice with Aging Persons, (1 – 26). New York: Columbia University Press.

O'Connor, D. (1995). Supporting spousal caregivers: exploring the meaning of service use. Families in Society: The Journal of Contemporary Human Services, 76(5), 296 - 305.

O'Connor, D. (1999). Constructing community care: (re)storying support. In Neysmith, S. M. (Ed.), Critical Issues for Future Social Work Practice with Aging Persons, (71 – 96). New York: Columbia University Press.

Perry, J. (2004). Daughters giving care to mothers who have dementia: mastering the 3 R's of (Re)calling, (Re)learning, and (Re)adjusting. Journal of Family Nursing, 10(1), 50-70.

Phillips, J. (2000). Working carers: caring workers. In Bernard, M., Phillips, J., Machin, L. & Harding Davies, V. (Eds.), Women Ageing: Changing Identities, Challenging Myths, (40-57). Routledge: London.

Piercy, K. W. (2000). When it is more than a job: Close relationships between home health aides and older clients. Journal of Aging and Health, 12(3), 362 - 387.

Porter, E. J., Ganong, L. H., Drew, N. & Lanes, T. I. (2004). A new typology of home-care helpers. The Gerontologist, 44(6), 750 – 759.

Raschick, M. & Ingersoll-Dayton, B. (2004). The costs and rewards of caregiving among spouses and adult children. Family Relations, 53(3), 317 – 325.

Rubenstein, R. L. (1989). Themes in the meaning of caregiving. Journal of Aging Studies, 3(2), 119 - 138.

Stake, R. E. (1995). The Art of Case Study Research. Thousand Oaks: Sage Publications.

Walton, J. (1992). Making the theoretical case. In Ragin, C. C. & Becker, H. S. (Eds.). What is a Case? Exploring the Foundations of Social Inquiry. (121- 138), Cambridge: Cambridge University Press.

Ward-Griffin, C. & Marshall, V. W. (2003). Reconceptualizing the relationship between "public" and "private" eldercare. Journal of Aging Studies, 17(2), 189 - 208.

Yin, R. K. (1994). Case Study Research: Design and Methods. Thousand Oaks: Sage.

CHAPTER FIVE

Conclusion

Moving beyond a problem-centered micro focus (Hagestad & Dannefer, 2001), this dissertation extends understandings of family caregiving through an examination of helpers in caregiving. Study One highlights the contributions of multiple individuals in the context of family caregiving and underscores the relational nature of caregiving contributions. Study Two shows how gender and kinship intersect with helping and caregiving and examines characteristics of helping networks. Study Three identifies themes in helping and caregiving using a case vignette methodology.

While most caregiving/helping networks are relatively small, kin-centred and female dominated, family caregiving has complexity beyond the dyadic relationship between primary caregiver and older care recipient. Caregiving is a concept that involves multiple individuals within the same family and it often includes multiple care recipients. In addition to involving multiple individuals, caregiving consists of different types of helping and caregiving, such as assistive and direct help. Findings also show that helpers, like primary caregivers, have networks of support and within these networks adult siblings and paid helpers play important roles.

In addition to improving our understanding of family caregiving beyond the dyadic relationship between a single caregiver and a care recipient, findings from this dissertation advance the development and application of Kahn & Antonucci's (1981) convoys of social support model and Cantor's (1991) social care model in several ways. First, the study demonstrates that care recipients, caregivers and helpers each have networks of support by illustrating the multiple contributions to both care recipient(s) and

to caregivers (and helpers) within the context of providing care to an older relative. The research findings confirm the appropriateness of the addition of arrows a. and b. to the model (Figure 2.2). These arrows, which depict help given to the primary caregiver by helpers, and the help between helpers, extend the model and reflect the inclusion of multiple contributions in family caregiving. Second, the distinction between direct and assistive help, as made in Figure 2.3, further improves Kahn & Antonucci's (1981) convoys of social support model and Cantor's (1991) social care model by showing that there are different types of contributions within a caregiving network that directly and/or indirectly enable the provision of support to an older relative.

Third, findings show that gender and kinship are important factors in influencing who helps whom and how. For example, the gender of a primary caregiver influences who is identified as a helper for both direct and assistive types of help; women most frequently identify sisters as helpers and men identify spouses.

Implications for Professional Practice, Policy and Research

The next step in applying improvements in our understanding of family caregiving is in the development of suitable frameworks for practice, policy and research. Guberman & Maheu (2002: 35) argue that "professional practice requires a theoretical framework which directs a practitioner to the kinds of knowledge necessary to understand what is observed and which suggest principles to guide intervention".

Practice.

A focus on caregiving as an individual responsibility is implicit in current frameworks for understanding caregiving, where the only means to improving one's

situation is through the reduction of stress, anxiety, burdens and/or managing one's emotions (Guberman & Maheu, 2002). A focus on individual caregiving has largely ignored the social magnitude or responsibility of an aging society and shifting health care structures and has placed the onus of responsibility on the individual caregiver, in particular on the bulk of caregivers who are middle-aged to older women. Guberman & Maheu (2002: 31) argue:

> ...it [a focus on caregiving as an individual level phenomena] obscures the socio-political context in which families are expected by the State to take responsibility for caring for dependent adults, thus leaving caregivers with few alternatives for modifying their situation. By focusing on changes within caregivers themselves (raising self-esteem, reducing guilt, learning communication skills), this approach runs the risk of conveying to caregivers that they are the source of their own problem and if they would only modify their feelings or their skills the situation would improve.

A widened focus in examining family caregiving, like understanding the relationships and responsibilities of helpers, shifts the domain of caregiving research from individual caregiving to that of family contributions, relationships and dynamics; further shifts would include attention to the socio-political context of care. A focus on relationships and contributions allows for the development of an understanding of caregiving where individual behaviors are the products of interactions and not as autonomous beings engaged in an activity (Matthews, 2002). This shift supports the ideology of interdependence as opposed to autonomy and independence. With this shift, the implications for practice, at the individual and family level, are numerous and could include changes in approaches to assessment, treatment, and advocacy. For example, with a focus on understanding interactions of multiple family members, assessments could be directed at understanding how to best augment a family's ability to provide and sustain care to an older relative and not on making changes in one individual caregiver's

behaviour. This shift places interactions and interdependence above individual behaviour.

A movement to understand the complexity and interdependence of caregiving families moves the conceptualization of caregiving into a domain where caregiving is a social and political issue and not just one person's (woman's) responsibility. Ultimately, this extension has the potential to promote a broader sense of social responsibility in caring for an aging population.

Policy.

In Canada, there is very little public policy designed specifically to support the needs of family caregivers. Where there are policies to support caregivers, they are designed for the benefit of one primary caregiver and not a network of 'carers', as is the case with the federal tax credit and the compassionate care leave program. In addition to limited and narrow caregiver policy, recent policy reforms and health care restructuring expect that family and friends have and will continue to provide the majority of care for older persons requiring care. In their work on care networks Fast, Keating, Otfinowski, & Derksen (2004: 17) contend that policy "reflects an expectation that family and friends should and will assume an even greater share of the care burden in the future". Finch & Mason (1993: 10) argue, "assumptions are being made, and incorporated into social policies, which do not align with they ways in which kin relationships operate in practice".

Fast and colleagues (2004:17) suggest:

> "Large, mixed relationship, and mixed-gender networks would best facilitate this ['ideal' family caregiving]. But existing programs generally fail to support such a network structure, focusing as they do on one close family member".

There have been a number of suggestions as to why government policy currently does not reflect a family level focus. The first postulation is based on the notion that if government creates policy to support families and caregivers this will incite a resource issue. However, the idea of overuse of services or programs has been dispelled by a number of researchers. Several studies have shown that family members do not engage in service use at all (O'Connor, 1999), until they absolutely have to, or are engaged by the formal system as a result of a medical emergency. Another myth with respect to invoking a resource issue is that if suitable caregiver programs existed, families would 'abandon' their duties to older kin. Guberman (2004: 79) succinctly states:

> "there seems to be much concern that the provision of services will lead to family abdication, despite the reality that caregivers are difficult to recruit for most programs which are aimed at them and that families tend to delay their requests for service until the situation has become overwhelming".

Another suggestion includes the idea that family care has been romanticized (Guberman, 2004). This is the notion that families know best how to care for their older kin, or that family care is the preference of older people and that governments should not interfere within the domain of family.

While each of these postulations provide insight into the lack of appropriate caregiver policy and the delay in firm government commitments to family caregivers , the most deleterious and insidious effect on caregiver policy has come from a research focus on 'the primary caregiver'. The focus on a single-family member providing care structurally perpetuates the notion that caregiving is one person's (usually one woman's) responsibility and not a much broader social issue. In her research on spousal caregivers, O'Connor (1999) found that once a woman identified with the 'caregiver' label, she felt

less isolated. Further, she then felt less like her individual difficulties were failures, but rather could be accepted as situational and shared by many others.

In this same way, it can be argued that expanding the conceptualization of caregiving to include multiple individuals, like the present study of helpers, implicates more than a primary caregiver in the caregiving experience. It also highlights those exceptional circumstances where there is only one caregiver.

Once the experience of caregiving is extended to multiple individuals, a wider societal net is cast and in turn unconsciously raises the profile of caregiving. This has a ripple effect in terms of influencing policy. The more individuals who can identify as being touched by caregiving, the more societal support for developing appropriate policies and programs to support caregivers. The clarification of multiple caregiver roles needs to be addressed and acknowledged urgently, so that proper government policy can ensue. Furthermore, with the increasing numbers of older Canadians, there is a need to "get it right" prior to the increase of older Canadians potentially involved in family caregiving.

It can therefore be concluded that if family caregiving is to have more government support through the development of appropriate policy, the mechanism to do this is to raise the profile and 'net' of family caregiving beyond the individual and beyond the notion that this is normal or 'just what families do'. To do this, research needs to look at the entire care network as the unit of analysis while focusing on both structural and relationship elements. Research that seeks to uncover family diversity in experience and meaning, and not to simply homogenize the experience of families who provide care, will move the political caregiving agenda forward.

Research.

Understanding the tasks and commitment involved in family caregiving is essential to supporting caregivers in their roles (Keating, Fast, Fredrick, Cranswick & Perrier, 1999). However, as demonstrated, it is not just a focus on tasks and commitments that will generate adequate understanding and support for families. As argued, 'adequately supporting' caregivers through practice and policy requires an understanding and acknowledgement of the diversity and complexity of family dynamics and relationships, as well as the socio-political context of caring.

To facilitate the transition from understanding the behaviour of an individual caregiver to developing an awareness of family caregiving as a complex and heterogeneous social issue, research and education can begin by including the integration of frameworks that incorporate multiple levels of analysis, like the modified version of Kahn & Antonucci's (1981) convoy model and Cantor's (1991) social care model used in this dissertation..

In conclusion, the findings from Study One, Study Two and Study Three advance understandings of caregiving and helping and extend our knowledge of family dynamics in the provision of care to an older person. These advancements in understandings of family caregiving provide the foundation for improvements in academic gerontological caregiving research, in professional practice, and in policy. Gottlieb (1992: 307) contends that a better understanding of family caregiving serves to contribute to the "ways in which we conceive and measure social support". In the end, these refinements have the potential to lead to improvements in service, program, policy and research for caregivers, care recipients and their families.

References

Cantor, M. H. (1991). Family and community: changing roles in an aging society. The Gerontologist, 31(3), 337 – 346.

Fast, J., Keating, N., Otfinowski, P. & Derksen, L. (2004). Characteristics of family/friend care networks of frail seniors. Canadian Journal on Aging, 23(1), 5 – 19.

Finch, J. & Mason, J. (1993). Negotiating Family Responsibilities. London: Tavistock/Routledge.

Gottlieb, B. H. (1992). Social support: A relationship process, not a commodity. Canadian Journal on Aging, 11(4), 306 – 310.

Guberman, N. (2004). Designing home and community care for the future: who needs to care? In Grant, K. R., Amaratunga, C., Armstrong, P., Boscoe, M., Pederson, A. & Willson, K. (Eds.), Caring For/Caring About: Women, Home Care and Unpaid Caregiving, (75 - 90). Aurora, Ontario: Garamond Press.

Guberman, N. & Maheu, P. (2002). Conceptions of family caregivers: Implications for professional practice. Canadian Journal on Aging, 21(1), 27 – 37.

Hagestad, G. O. & Dannefer, D. (2001). Concepts and theories of aging: beyond microfication in social science approaches. In Binstock, R. H. & George, L. (Eds.). Handbook of Aging and the Social Sciences, 5th Edition, (3 - 21). San Diego: Academic Press.

Kahn, R. L. & Antonucci, T. C. (1981). Convoys of social support: a life-course approach. In March, J. G., Kiesler, S. B., Morgan, J. N., & Oppenheimer, V. K. (Eds.), Aging: Social Change, (383 – 405). New York: Academic Press.

Keating, N. C., Fast, J. E., Frederick, J., Cranswick, K., & Perrier, C. (1999). Eldercare in Canada: Context, Content, and Consequences. Ottawa: Minister of Industry, Statistics Canada.

Matthews, S. (2002). Sisters and Brothers/Daughters and Sons: Meeting the Needs of Old Parents. Bloomington: Unlimited Publishing.

O'Connor, D. (1999). Constructing community care: (re)storying support. In Neysmith, S. M. (Ed.), Critical Issues for Future Social Work Practice with Aging Persons, (71 – 96). New York: Columbia University Press.

APPENDICES

Appendix One

CARNET Work and Eldercare Survey Instrument

Work and Eldercare Questionnaire

This Study is conducted by:
CARNET:
THE CANADIAN AGING RESEARCH NETWORK
LE RESEAU CANADIEN RECHERCHE SUR LE VIELLISSEMENT

This questionnaire is part of a national study of how Canadians combine work and their responsibilities for assisting older relatives. Your participation will help make it successful. All the information you provide will be held in strictest confidence.

SECTION I: ASSISTANCE TO OLDER RELATIVES

When we last spoke with you, you indicated that you were providing assistance to:

Rel. 1 _____
Rel. 2 _____
Rel. 3 _____

1. Since we last spoke to you, have you continued to provide assistance to these relatives or assisted other elderly relatives?

☐ YES
☐ NO **[Go to Q.2]**

Please tell us who they are (e.g., mother, father, aunt, etc.,) even if it means repeating relatives from the first part of the question.

Rel. 1 _____ Go to Section II
Rel. 2 _____ Go to Section II
Rel. 3 _____ Go to Section II

2. If you no longer provide assistance to ANY relative and have not done so during the last 6 months, could we call you sometime in the future to respond to a questionnaire geared to assistance that you have provided in the past three years?

☐ Yes, you may contact me in the future.
☐ No, I would be unwilling to participate further.

Thank you for your interest in helping us. If you are able to assist with a questionnaire that is more applicable to your experiences, we look forward to talking with you in the future.

If you are now providing and/or have provided assistance to older relatives in the last 6 months, please continue with SECTION II: YOUR JOB.

SECTION II: YOUR JOB

We would like to ask a few questions about your work.

3. When we last spoke with you, you indicated that you were working for _____ **as a** _____.

Is this still the case?

☐ YES
☐ NO. What has changed?

_____
_____
_____

4. On average per week, do you work for pay:

☐ 35 hours or more
☐ less than 35 hours

5. How long does it usually take you to travel (one way) from your home to your work place?

_____ minutes

☐ **Not applicable (work at home)**

6. In the last three years have you participated in continuing education courses or retraining programs?

☐ Yes
☐ No **[Go to Q. 8]**

7. What sort of courses or retraining programs did you take? (Please check as many categories as are applicable).

- ☐ academic
- ☐ related to work (improve existing or learn new skills)
- ☐ computer
- ☐ leisure/interest
- ☐ Other. Please explain:

_____

_____

_____ **[Go to Q.9]**

8. If you have not taken continuing education courses or retraining in the last 3 years, what factors may have prevented you from doing so? (Please check as many reasons as are applicable).

- ☐ eldercare responsibilities
- ☐ other family responsibilities
- ☐ work schedule
- ☐ lack of money
- ☐ lack of education
- ☐ lack of interest
- ☐ Other. Please explain

_____

_____

_____

9. Which if any of the following factors might encourage you to take continuing education courses or retraining in the future? (Please check as many reasons as are aplicable).

- ☐ help with eldercare
- ☐ help with family responsibilities
- ☐ changes in work schedule
- ☐ having someone else pay for the course
- ☐ knowing the course would be useful
- ☐ Other. Please explain

_____

_____

_____

SECTION III: FAMILY CHARACTERISTICS

10. What is your present marital status?

- ☐ Married
- ☐ Common-Law
- ☐ Separated
- ☐ Divorced
- ☐ Widowed
- ☐ Single/Never Married

11. If you are married or in a common-law relationship, does your spouse/partner work for pay ?

- ☐ Yes, Full-time
- ☐ Yes, Part-time
- ☐ No **[Go to Q.13]**

12. How long does it usually take your spouse/ partner to travel (one way) from your home to his/her place of work?

_____ minutes

☐ Not applicable (work at home)

13. How many children do you have age 18 or younger living at home?

_____ child(ren)

b. What are their ages?

i) _____ ii) _____

iii) _____ iv) _____

14. Would you say that over the last three years your level of household income has:

- ☐ increased
- ☐ stayed the same
- ☐ decreased

SECTION IV: CHARACTERISTICS OF OLDER RELATIVES

Now we will ask some details about the older relatives to whom you provide assistance. Please state their relationship to you (e.g., Relative 1 is my mother; Relative 2 is my father etc.).Please keep this consistent throughout the questions.

	Relative 1 is my _____	**Relative 2 is my** _____	**Relative 3 is my** _____
15. How old is your relative?	_____ years	_____ years	_____ years
16. What is your older relative's current marital status?	☐ Married or Common-Law ☐ Widowed ☐ Separated ☐ Divorced ☐ Never Married	☐ Married or Common-Law ☐ Widowed ☐ Separated ☐ Divorced ☐ Never Married	☐ Married or Common-Law ☐ Widowed ☐ Separated ☐ Divorced ☐ Never Married
17. How would you describe your older relative's financial situation?	☐ Very Good ☐ Good ☐ Fair ☐ Difficult ☐ Do not know	☐ Very Good ☐ Good ☐ Fair ☐ Difficult ☐ Do not know	☐ Very Good ☐ Good ☐ Fair ☐ Difficult ☐ Do not know
18. What are your older relative's living arrangements?	☐ Lives with me ☐ Lives in their own home or apt. ☐ Lives in retirement home or nursing home ☐ Other. Please specify: _____ _____ _____	☐ Lives with me ☐ Lives in their own home or apt. ☐ Lives in retirement home or nursing home ☐ Other. Please specify: _____ _____ _____	☐ Lives with me ☐ Lives in their own home or apt. ☐ Lives in retirement home or nursing home ☐ Other. Please specify: _____ _____ _____

	Relative 1	Relative 2	Relative 3
19. For those relatives who do <u>not</u> live with you or in a retirement/ nursing home, do they live alone?	☐ Yes ☐ No. With whom do they live? ☐ their spouse ☐ my brother or sister ☐ another relative ☐ other _____	☐ Yes ☐ No. With whom do they live? ☐ their spouse ☐ my brother or sister ☐ another relative ☐ other _____	☐ Yes ☐ No. With whom do they live? ☐ their spouse ☐ my brother or sister ☐ another relative ☐ other _____
20. Does your older relative have the same living arrangements year round?	☐ Yes ☐ No. Please explain: _____ _____ _____	☐ Yes ☐ No. Please explain: _____ _____ _____	☐ Yes ☐ No. Please explain: _____ _____ _____
21. Where does your older relative live?	Name of community and province (or country if international) _____ _____	Name of community and province (or country if international) _____ _____	Name of community and province (or country if international) _____ _____
22. How long has your older relative lived there?	Length of Residence: _____ years	Length of Residence: _____ years	Length of Residence: _____ years
23. How do you usually get to your older relative's home?	☐ Walk ☐ Bus ☐ Taxi ☐ Car ☐ Train ☐ Plane ☐ Not applicable (older relative lives with me)	☐ Walk ☐ Bus ☐ Taxi ☐ Car ☐ Train ☐ Plane ☐ Not applicable (older relative lives with me)	☐ Walk ☐ Bus ☐ Taxi ☐ Car ☐ Train ☐ Plane ☐ Not applicable (older relative lives with me)

	Relative 1	Relative 2	Relative 3
24. How long does it usually take to travel (one-way) from your home to your older relative's home?	For a one way trip: ____ hours____minutes ☐ Not applicable (older relative lives with me)	For a one way trip: ____ hours____minutes ☐ Not applicable (older relative lives with me)	For a one way trip: ____ hours____ minutes ☐ Not applicable (older relative lives with me)
25. How many times has your older relative moved in the last 3 years?	☐ None [Go to Q.28] Older relative moved_____ times.	☐ None [Go to Q.28] Older relative moved_____ times.	☐ None [Go to Q.28] Older relative moved_____ times.
26. Thinking in terms of the <u>most recent</u> move, did your older relative move for any of the following reasons? **Please check as many as are applicable.**	☐ To be closer to you (but not into your home) ☐ To live with you ☐ To live in a retirement home or nursing home ☐ To live in a home or apt. of their own that was 'easier' for them ☐ To be closer to services they need ☐ To be closer to, or live with, another relative ☐ Other __________________	☐ To be closer to you (but not into your home) ☐ To live with you ☐ To live in a retirement home or nursing home ☐ To live in a home or apt. of their own that was 'easier' for them ☐ To be closer to services they need ☐ To be closer to, or live with, another relative ☐ Other __________________	☐ To be closer to you (but not into your home) ☐ To live with you ☐ To live in a retirement home or nursing home ☐ To live in a home or apt. of their own that was 'easier' for them ☐ To be closer to services they need ☐ To be closer to, or live with, another relative ☐ Other __________________

	Relative 1	Relative 2	Relative 3
27. Did these moves affect the assistance you provide to your relative?	☐ No ☐ Yes. Please explain __________ __________ __________ __________ __________	☐ No ☐ Yes. Please explain. __________ __________ __________ __________ __________	☐ No ☐ Yes. Please explain. __________ __________ __________ __________ __________
28. In the past <u>6 months</u> have you done any of the following to meet or prepare for any of your older relative(s) needs for care? **Please check as many as are applicable to your situation**	☐ urged an older relative to move closer to where I live ☐ made arrangements for an older relative to move closer to me ☐ urged an older relative to move into my home ☐ made arrangements for an older relative to move into my home ☐ looked into moving closer to an older relative ☐ made arrangements to move closer to an older relative	☐ urged an older relative to move closer to where I live ☐ made arrangements for an older relative to move closer to me ☐ urged an older relative to move into my home ☐ made arrangements for an older relative to move into my home ☐ looked into moving closer to an older relative ☐ made arrangements to move closer to an older relative	☐ urged an older relative to move closer to where I live ☐ made arrangements for an older relative to move closer to me ☐ urged an older relative to move into my home ☐ made arrangements for an older relative to move into my home ☐ looked into moving closer to an older relative ☐ made arrangements to move closer to an older relative
29. Does your older relative drive?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No

	Relative 1	Relative 2	Relative 3
30. Was your older relative born in Canada or in another country?	☐ Born in Canada ☐ Born in another country	☐ Born in Canada ☐ Born in another country	☐ Born in Canada ☐ Born in another country
31. Does your older relative have difficulty communicating in either of the official languages (English or French)?	English ☐ Yes ☐ No French ☐ Yes ☐ No	English ☐ Yes ☐ No French ☐ Yes ☐ No	English ☐ Yes ☐ No French ☐ Yes ☐ No

SECTION V: HEALTH STATUS OF OLDER RELATIVES

	Relative 1	Relative 2	Relative 3
32. How would you rate your older relative's general physical health?	☐ Excellent ☐ Good ☐ Fair ☐ Poor	☐ Excellent ☐ Good ☐ Fair ☐ Poor	☐ Excellent ☐ Good ☐ Fair ☐ Poor
33. How would you rate your older relative's emotional or mental health?	☐ Excellent ☐ Good ☐ Fair ☐ Poor	☐ Excellent ☐ Good ☐ Fair ☐ Poor	☐ Excellent ☐ Good ☐ Fair ☐ Poor
34. Has your older relative been hospitalized in the past year?	☐ No ☐ Yes Number of times in hospital: _____ Total number of days: _____	☐ No ☐ Yes Number of times in hospital: _____ Total number of days: _____	☐ No ☐ Yes Number of times in hospital: _____ Total number of days: _____

35. How well do you think your older relative can manage to do the following?

	Relative 1 My older relative can do this task:	Relative 2 My older relative can do this task:	Relative 3 My older relative can do this task:
i. Get up and down stairs and steps	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all
ii. Get around the house (except for stairs)	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all
iii. Get in and out of bed	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all
iv. Cut their toenails	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all
v. Bath, shower, or wash all over	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all
vi. Go out and walk down the road	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all	☐ on their own ☐ on their own, but with difficulty ☐ only with help, or not at all

Now we will ask you about some types of help which you may have provided to your older relatives in <u>the past 6 months.</u>

	Relative 1	**Relative 2**	**Relative 3**
36. How often have you helped your older relative with bathing, dressing, feeding, toileting, or taking medication?	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never. **Do they need any of these types of assistance?** ☐ Yes ☐ No	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never. **Do they need any of these types of assistance?** ☐ Yes ☐ No	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never. **Do they need any of these types of assistance?** ☐ Yes ☐ No
37. How often have you helped your older relative by providing transportation, doing shopping and/or errands?	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never. **Do they need any of these types of assistance?** ☐ Yes ☐ No	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never. **Do they need any of these types of assistance?** ☐ Yes ☐ No	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never. **Do they need any of these types of assistance?** ☐ Yes ☐ No

	Relative 1	Relative 2	Relative 3
38. In the last 6 months, how often have you helped your older relative with laundry, household chores, meal preparation, home maintenance or yard work?	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never. **Do they need any of these types of** assistance? ☐ Yes ☐ No	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never. **Do they need any of these types of** assistance? ☐ Yes ☐ No	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never. **Do they need any of these types of** assistance? ☐ Yes ☐ No
39. How often have you helped your older relative by providing them with moral or emotional support?	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never. **Do they need any of these types of** assistance? ☐ Yes ☐ No	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never. **Do they need any of these types of** assistance? ☐ Yes ☐ No	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never. **Do they need any of these types of** assistance? ☐ Yes ☐ No

	Relative 1	Relative 2	Relative 3
40. In the last 6 months, how often have you helped your older relative with money management or provided them with money, or negotiated on their behalf (e.g., with other family members or health service providers)?	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never. Do they need any of these types of assistance? ☐ Yes ☐ No	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never. Do they need any of these types of assistance? ☐ Yes ☐ No	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never. Do they need any of these types of assistance? ☐ Yes ☐ No
41. Overall, please estimate the number of hours of help you have provided to your older relative in an average week or month	Number of hours/week ______ OR Number of hours/month ______	Number of hours/week ______ OR Number of hours/month ______	Number of hours/week ______ OR Number of hours/month ______
42. In the last 6 months has anyone assisted you in helping your elderly relatives in any of the following ways? ☐ No [Go to Q.44, page 13] ☐ Yes Please check as many as are applicable to your situation.	☐ Household Chores ☐ Childcare ☐ Financial Assistance ☐ Home/Yard Maintenance or Repair ☐ Moral/emotional support ☐ Other. Please specify: ______ ______ ______ ______	☐ Household Chores ☐ Childcare ☐ Financial Assistance ☐ Home/Yard Maintenance or Repair ☐ Moral/emotional support ☐ Other. Please specify: ______ ______ ______ ______	☐ Household Chores ☐ Childcare ☐ Financial Assistance ☐ Home/Yard Maintenance or Repair ☐ Moral/emotional support ☐ Other. Please specify: ______ ______ ______ ______

	Relative 1	Relative 2	Relative 3
43. Who helps you? **Please check as many as are applicable to your situation for each relative.**	☐ your spouse ☐ your daughter(s) ☐ your son(s) ☐ your sister(s) ☐ your brother(s) ☐ other family members ☐ friends ☐ caregiver support group ☐ respite care ☐ Other. Please specify: __________ __________ __________	☐ your spouse ☐ your daughter(s) ☐ your son(s) ☐ your sister(s) ☐ your brother(s) ☐ other family members ☐ friends ☐ caregiver support group ☐ respite care ☐ Other. Please specify: __________ __________ __________	☐ your spouse ☐ your daughter(s) ☐ your son(s) ☐ your sister(s) ☐ your brother(s) ☐ other family members ☐ friends ☐ caregiver support group ☐ respite care ☐ Other. Please specify: __________ __________ __________

SECTION VI: CRISIS SITUATIONS

We would now like to ask you about any crisis situations that your older relatives may have experienced such as illness, accident, personal tragedy, or family crisis.

	Relative 1	Relative 2	Relative 3
44. Has there been an episode in the past 6 months when your older relative(s) experienced a crisis?	☐ Yes ☐ No. **[Go to Q.53, pg. 15]**	☐ Yes ☐ No **[Go to Q.53, pg. 15]**	☐ Yes ☐ No **[Go to Q.53, pg. 15]**
45. How many separate crises have there been in the past 6 months?	______ Crises	______ Crises	______ Crises

Please answer Questions 46-52 thinking about the crisis in which you were <u>most</u> involved.

46. What kind of crisis was it?

_____

_____

_____

_____

_____

47. How long did it last?

_____

_____

_____

_____

48. How were you involved?

_____

_____

_____

_____

_____

_____

_____

49. If you help more than one older relative, which one did this crisis involve?

_____

_____

_____

50. Did this crisis in any way interfere with your work or home life?

☐ No
☐ Yes. Did this require:

☐ travel
☐ lengthy or frequent telephone conversations
☐ time off work
☐ altered work schedules
☐ Other. Please explain:

_____

_____

_____

_____

_____

_____

51. Were there factors at work that helped you to deal with this crisis?

☐ No.
☐ Yes. Please check as many as are applicable:

☐ Supportive Supervisor
☐ Supportive Coworker
☐ Could take leave from work
☐ Could rearrange work schedule
☐ Could renegotiate work responsibilities
☐ Could take paid leave
☐ Other. Please specify:

_____

_____

_____

_____

52. Were there factors at work that made it difficult for you to deal with this crisis?

☐ No
☐ Yes. Please check as many as are applicable.

☐ Unsupportive Supervisor
☐ Unsupportive Coworker
☐ Could not take leave
☐ Could not rearrange work schedule
☐ Could not renegotiate work responsibilities
☐ Could not take paid leave
☐ Other. Please specify:

_____

_____

We would now like to ask you how you feel about combining work responsibilities with the responsibilities you have to your older relatives.

53. Please CHECK how much you agree or disagree with the following statements

	Strongly Disagree	Disagree	Agree	Strongly Agree
a. My job prevents me from spending as much time as I would like with my older relatives.	☐	☐	☐	☐
b. After work, I am too tired to do some of the things I'd like to do with my older relatives.	☐	☐	☐	☐
c. When I am at home I am distracted by thoughts about my job responsibilities.	☐	☐	☐	☐
d. My job prevents me from giving the kind of attention I would like to give to my older relatives.	☐	☐	☐	☐
My responsibilities to my older relatives take up time that I'd like to spend working on my job.	☐	☐	☐	☐
f. I'm often too tired at work because of the things I have to do for my older relatives.	☐	☐	☐	☐
g. When I am at work I am distracted by thoughts about my responsibilities to older relatives.	☐	☐	☐	☐
h. The quality of my work suffers because of the demands of my older relatives.	☐	☐	☐	☐

54. Now, considering life in general, how often in the last month have you:

	Never	Rarely	Sometimes	Often	Very Often
a. Been upset because of something that happened unexpectedly?	☐	☐	☐	☐	☐
b. Felt that you were unable to control the important things in your life?	☐	☐	☐	☐	☐

	Never	Rarely	Sometimes	Often	Very Often
c. Felt nervous & "stressed"?	☐	☐	☐	☐	☐
d. Felt confident about your ability to handle your personal life?	☐	☐	☐	☐	☐
e. Felt that things were going your way?	☐	☐	☐	☐	☐
f. Found that you could not cope with all of the things that you had to do?	☐	☐	☐	☐	☐
g. Been able to control irritations in your life?	☐	☐	☐	☐	☐
h. Felt that you were on top of things?	☐	☐	☐	☐	☐
i. Been angered because of things that happened that were outside of your control?	☐	☐	☐	☐	☐
j. Found yourself thinking about things that you have to accomplish?	☐	☐	☐	☐	☐

55. Have any of the following job-related situations happened to you in the past 6 months because of your responsibilities to your older relatives?

a. I had to take sick days when I was not sick.

☐ Yes
☐ No

If "yes", please estimate how many days this happened in the past 6 months _____Days

b. I had to stay away from work for a period of time.

☐ Yes
☐ No

If "yes", how many days were involved?
_____Days

What were these days?

☐ paid days
☐ unpaid days
☐ combination of paid and unpaid days

c. I had to lose time from work because of arriving late, leaving early, or extending lunch hours or breaks by 20 minutes or more.

☐ Yes
☐ No

d. I had to use vacation days to take care of responsibilities to my elderly relatives.

☐ Yes
☐ No

If "yes", on how many days did this happen in the past 6 months? _____Days

e. I was unable to go on business trips.

☐ Yes
☐ No
☐ Not Applicable

f. I was unable to attend meetings or training sessions.

☐ Yes
☐ No
☐ Not Applicable

g. I was unable to take on extra projects or responsibilities at work.

☐ Yes
☐ No
☐ Not Applicable

h. I was unable to seek or accept a promotion or job transfer

☐ Yes
☐ No
☐ Not Applicable

i. I was unable to attend social events related to my job that took place outside regular work hours.

☐ Yes
☐ No
☐ Not Applicable

j. Thinking only about the last month, did your responsibilities to older relatives interrupt your work day for at least 20 minutes?

☐ Not during this month
☐ One day this month
☐ 2 to 4 days this month
☐ More than 4 days this month

56. Have your responsibilities to your older relatives caused you to reduce the amount of time you give to:

	No	Yes: In the Last 6 Months	Yes: More Than 6 Months Ago
a. Volunteer Work	☐	☐	☐
b. Leisure Activities	☐	☐	☐
c. Socializing with friends	☐	☐	☐
d. Sleeping/Resting	☐	☐	☐
e. Other:	☐	☐	☐

_____

_____

_____

_____

_____

SECTION VII: OTHER HELPERS AVAILABLE TO OLDER RELATIVES

Now we would like to ask you a number of questions concerning the involvement of others in the family in providing assistance to your older relatives.

We would like you to focus on the relative to whom you provide the most assistance.

57. Who is this relative?

_____

58. Are you the only person who helps this older relative?

☐ Yes **[Go to Q.65, page 20]**
☐ No

	Helper 1	Helper 2	Helper 3
59. Who else has helped this relative? **Please indicate whether this is <u>your</u> spouse or <u>your relative's</u> spouse, <u>your</u> sister, or <u>your relative's</u> sister, <u>your</u> friend, or <u>your relative's</u> friend etc.**	**Helper 1 is** _____	**Helper 2 is** _____	**Helper 3 is** _____
60. Within the past 6 months, how often has this person helped your older relative with bathing, dressing, feeding, toileting, or taking medication?	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never
61. How often has this person helped your older relative by providing transportation, shopping and/or errands?	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never

	Helper 1	Helper 2	Helper 3
62. How often has this person helped your older relative with laundry, household chores, meal preparation, home maintenance or yard work?	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never
63. How often has this person helped your older relative with emotional support?	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never
64. How often has this person helped your older relative(s) with money management, or providing money, or negotiating on their behalf (e.g., with other family members or health service providers)?	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ Every 1 or 2 months ☐ Once or twice in the last 6 months ☐ Never

SECTION VIII: COMMUNITY SERVICES

We would now like to ask you a series of questions about services your older relative(s) receive, either within or outside of their home, which assist or support them in some way. This help could be provided by a government program (for example, Homecare), by a voluntary group in the community (for example, a church or social club), or by paid help.

65. Please tell us if <u>any</u> of your older relatives have used (in the last 6 months) or are currently using community services.

- ☐ Not now, or in the last 6 months.
- ☐ In the past 6 months, but <u>not</u> now **[Go to Q.67]**.
- ☐ Yes, services are being used currently **[Go Q.68]**.

66. Why didn't any of your older relatives use community services? (Please check as many responses as applicable).

- ☐ My older relatives' needs were/are not sufficiently serious
- ☐ I or other relatives provide any needed assistance
- ☐ Suitable services were/are not available
- ☐ Services were/are too expensive
- ☐ Other (Please specify)

Go to Q.80

_____

_____

67. Why did your older relatives stop using community services? (Please check as many responses as applicable).

- ☐ My older relative(s) no longer required the service
- ☐ My older relative(s) was (were) no longer eligible for the service
- ☐ I or other relatives took on the responsibility for providing needed assistance
- ☐ My older relative(s) no longer wanted the service
- ☐ The cost of services became a problem
- ☐ Other (Please specify)

Go to Q.80

_____

_____

_____

_____

_____

Thinking in terms of the relative to whom you provide the most assistance, please tell us as much as you can about each community service he or she receives now or in the last 6 months. If your older relative receives more than 3 services, please tell us about the 3 services that are most important to their well-being.

68. Before you begin, please remind us which relative you are thinking about:
☐ Relative 1, ☐ Relative 2, ☐ Relative 3

	Service 1 is _____	Service 2 is _____	Service 3 is _____
69. What type of assistance does the service provide?			
70. Did you arrange for the service?	☐ Yes ☐ No. Who did? _____	☐ Yes ☐ No. Who did? _____	☐ Yes ☐ No. Who did? _____
71. How frequently is the service used?	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ About once a month ☐ Less than once a month	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ About once a month ☐ Less than once a month	☐ Daily ☐ Several times a week ☐ Once a week ☐ 2-3 times a month ☐ About once a month ☐ Less than once a month
72. Has your relative received services on a weekend?	☐ Yes ☐ No	☐ Yes ☐ No	☐ Yes ☐ No
73. Is a fee paid for any of the services?	☐ No ☐ Yes. Who pays? _____	☐ No ☐ Yes. Who pays? _____	☐ No ☐ Yes. Who pays? _____
74. Still thinking in terms of the relative to whom you provide the most assistance, did you or your older relative experience problems obtaining community services?	☐ Yes ☐ No **[Go to Q.76]**	☐ Yes ☐ No **[Go to Q.76]**	☐ Yes ☐ No **[Go to Q.76]**

	Service 1	Service 2	Service 3
75. What sorts of problems were experienced in <u>obtaining</u> services? **Please check as many responses as are applicable.** **Please match Service 1, 2, and 3 to the order of services as answered in question 69, previously.**	☐ Suitable service not available ☐ Service not available at suitable times ☐ Older relative was not eligible for the service ☐ Appropriate person not available ☐ Other. Please specify: ____________ ____________	☐ Suitable service not available ☐ Service not available at suitable times ☐ Older relative was not eligible for the service ☐ Appropriate person not available ☐ Other. Please specify: ____________ ____________	☐ Suitable service not available ☐ Service not available at suitable times ☐ Older relative was not eligible for the service ☐ Appropriate person not available ☐ Other. Please specify: ____________ ____________
76. Have you or your older relative experienced problems while <u>using</u> community services?	☐ Yes ☐ No [Go to Q.78]	☐ Yes ☐ No [Go to Q.78]	☐ Yes ☐ No [Go to Q.78]
77. What sorts of problems were experienced in using services? **Please check as many responses as are applicable.**	☐ Service was not of high quality ☐ Service was not reliable ☐ Times and schedules were unsuitable ☐ Service was expensive ☐ Transportation ☐ Older relative did not like service provider ☐ Other. Please specify: ____________ ____________ ____________	☐ Service was not of high quality ☐ Service was not reliable ☐ Times and schedules were unsuitable ☐ Service was expensive ☐ Transportation ☐ Older relative did not like service provider ☐ Other. Please specify: ____________ ____________ ____________	☐ Service was not of high quality ☐ Service was not reliable ☐ Times and schedules were unsuitable ☐ Service was expensive ☐ Transportation ☐ Older relative did not like service provider ☐ Other. Please specify: ____________ ____________ ____________

78. To what extent has the use of community services by <u>any</u> of your older relatives helped you balance your work and your responsibilities to them?

- ☐ Not at all [Go to Q.80]
- ☐ Somewhat
- ☐ Quite a bit
- ☐ Very much

79. Please tell us <u>how</u> community services helped you to balance your work and family responsibilities.

80. How might existing community services be improved to help you meet your needs as an employed caregiver?

81. What sorts of new community services or programs might be started to help you meet your needs as an employed caregiver?

82. Overall, how satisfied are you with the assistance that your older relative receives from family members (including yourself), friends, community services and/or paid help?

- ☐ Satisfied
- ☐ Somewhat satisfied
- ☐ Neither satisfied nor dissatisfied — Go To Q.83
- ☐ Somewhat dissatisfied
- ☐ Dissatisfied

83. What would make a difference?

Thank you for assisting us with this survey. Upon receipt of your questionnaire, we will be pleased to forward to you a cheque for $10 in acknowledgement of your time and effort . Your support of this project is most appreciated.

Thank you very much for taking the time to complete this questionnaire.

We are very interested in any further comments you may wish to make about combining work and family responsibilities. Please feel free to use the space below for your comments.