## Health Policy Research Program Summary of Research Results

Title: Informal<sup>1</sup> Care Networks of Canadian

**Seniors with Long-Term Health Problems** 

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## **Executive Summary**

Throughout the past decade there has been a policy focus on the contributions of family/friend caregivers to the continuing care of frail seniors. Questions about the nature and caring capacity of the family/friend sector formed the basis for this project. There is considerable controversy over these questions. While some believe that there is unused capacity in this sector and that families and friends should pool their resources and do more, others have argued that family/friend caregivers often care alone and are expected to do work that exceeds their personal resources. Unfortunately, we have relatively little evidence to inform the debate. We know a great deal about individual caregivers. Yet knowledge of care *networks* is necessary to understand both the breadth of family/friend caring resources and their need for support.

Data on seniors' care networks were derived from the 1996 Canadian General Social Survey on social support. We utilized the subset of 1,107 respondents aged 65 years or older who received assistance with one or more care tasks<sup>2</sup> during the previous year from a family member, friend or neighbour because of their own long-term health or physical limitation(s). Networks were counts of all those who provided one or more care tasks to a target senior. Network characteristics were: network size, gender, relationship and age composition, and proximity. Descriptive statistics, multiple and logistic regression, and K-means cluster analyses to derive network typologies were utilized to achieve our

<sup>&</sup>lt;sup>1</sup> Since beginning this project, we have begun to use the term 'family/friend' caregiver in preference to 'informal' caregiver. 'Informal' has connotations of casual, intermittent or voluntary, which do not reflect the enormity of the job.

<sup>&</sup>lt;sup>2</sup> Care tasks include meal preparation or cleanup; housekeeping; shopping; transportation; home maintenance and repair; assistance with banking or bill-paying; personal care; and emotional support or checking-up to make sure the senior is all right.

objectives. All analyses were weighted to ensure that estimates are representative of the Canadian population.

Objective 1: To clarify conceptual differences among social, support and care networks. The purpose of this element of the project was to develop a common language for terms such as care and care network in order to better understand the needs and capacities of the family/friend care sector.

Fundamental to the question of the caring capacity of the family/friend care sector is an understanding of the ways in which social networks of older people might evolve into care networks when needed. We addressed this objective by undertaking a review and critique of current knowledge of social, support and care networks. Based on this review we argued that these types of networks are distinct. While *social networks* are sets of social ties to others (such as neighbours, friends and family members), *support networks* are subsets of these people who provide emotional and tangible assistance with everyday activities. However, in the face of long-term health problems of older adults, support network members may be called upon to increase the range, amount or intensity of assistance - exhausting the resources of the support network. The subset of support network members that provides this more intense help is the *care network*.

The work done for this objective provides a basis for our assessment of the caring capacity of the family/friend sector. While having kin and friends is a necessary prerequisite to receiving care, it is not sufficient. Care networks likely are a small core group of the larger social network.

Objective 2: To describe the characteristics of family/friend care networks of Canadian seniors with long-term health problems/disabilities. To address this objective, we studied the caregiving network rather than individuals. We described characteristics of care networks including size, proximity to the cared-for person, gender and kin relationship.

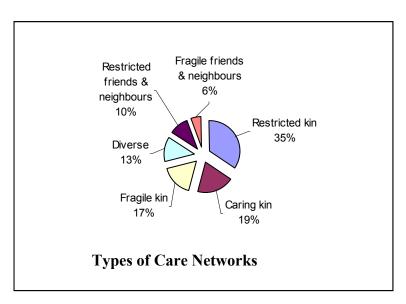
We found that frail seniors' care networks are predominantly small in size, female and kin dominated, mostly young to middle aged, and living in separate households from the care recipient. However, network characteristics also are notable in their variability. While more than 25% have three or more members, 40% have only one, suggesting that many care networks do not have sufficiently large membership to share caring responsibilities. Substantial minorities of networks are entirely men, non-kin, over age 65, and co-resident.

Findings on the relationship between network characteristics and receipt of care showed that size, gender composition and proximity are most important network characteristics. As network size increased, recipients received more hours of care, more care tasks, and had greater odds of receiving each care task. While networks comprising only women received about two hours more care per week than those whose networks were entirely men, mixed gender networks provided the widest range of tasks. Seniors whose entire care network lived in the same household received about 9 more hours of care per week

than those with no co-resident caregivers, while those with geographically proximate caregivers received a large number of care tasks.

Objective 3: To develop typologies of care networks of these seniors. The purpose of this objective was to develop evidence concerning the most common types of care networks represented by clusters of network characteristics.

We identified six types of care networks. Three are kin-based (Restricted, Caring, and Fragile), two are non-kin based (Restricted and Fragile) and one is Diverse. The three kin-based networks comprise 71% of all care networks, while 16% of networks are predominantly non-kin. The finding that there are two network types with predominantly non-kin and a third mixed network highlights the importance of friends and neighbours.



Network types differed in size. Most had one or two people, while Diverse networks had 3 to 8 carers. In all network types except Diverse and Restricted Friends & Neighbours, the majority of networks comprised only women. However, Diverse networks had a mix of women and men, while substantial minorities of Caring Kin and Fragile Kin networks (30% and 38% respectively) comprised only men. Proximity composition also was related to receipt of care. From the perspective of the care recipient, few network members lived more than ½ day away. Further research is needed to determine if there are more distant members who do care management and whose work is invisible to the care recipient because it is not done face-to-face.

Objective 4: To determine consequences to senior recipients of having different types of care networks. A key question in this project was how well frail seniors are served by their care networks. Thus we investigated a number of health and care outcomes for recipients of different types of care networks.

We found that all frail seniors who need care are at some risk of receiving inadequate care—not enough or of the wrong type. We also found that seniors' outcomes differ by network type, leading us to conclude that some network types are likely to be more fragile over the long-term than others. Seniors with Diverse, Fragile Kin, and Caring Kin networks received the most hours and types of care. Diverse networks may be robust since they are large, gender balanced, comprise kin and non-kin, and can share the care among more people than other networks. However, only 13% of seniors had this type of care network. Seniors with Fragile Kin networks had the poorest health and were the

least happy despite—or perhaps because of—receiving the most hours of care and widest range of tasks. Fragile Kin networks comprise mainly elderly spouses caring alone, who also are aging, and may themselves become (or be) frail. Their care responsibilities also may cause them to become isolated and lonely, making the care network even more fragile.

Seniors with Fragile Non-Kin and Restricted Non-Kin care networks received the least amount of care, and the fewest number of tasks. However, while all seniors in the study reported long-term health problems, seniors with these two network types were the healthiest. The two non-kin network types may also be extremely fragile because they lack the normative obligations to care usually associated with kinship. As seniors in these types of networks become increasingly frail, it is unlikely that the Fragile Non-Kin and the Restricted Non-Kin networks would persevere over the long-term.

<u>Policy implications</u>. The assumption made by policy makers that seniors are surrounded by large networks of family, friends, and neighbours who provide care if needed, is not supported by our research. Care network type is strongly related to outcomes such as type and amount of care received, health, and quality of life, suggesting the importance of providing different kinds of supports to seniors depending on their care network type. Policies to support this goal could include:

- targeting home care policies to enhance sustainability of the variety of care networks.
- broadening the conditions of the Caregiver Tax Credit to benefit members of care networks, across a wider set of residency/relationship criteria.
- providing financial support for a finite period or eldercare allowances within the Canada Pension Plan to the 83% of care networks that have employed caregivers if they take a temporary leave of absence from the labour force because of heavy eldercare responsibilities.

Finally, it is important to recognize that some care networks seem better positioned to meet the needs of frail seniors than do others. Networks that provide high levels of care need particular attention. Policies meant to support caregivers would benefit from an analysis of how public policies are supportive to different care network types.

## The views expressed herein do not necessarily represent the views of Health Canada

In addition to the above Summary, the full report can be accessed in the following ways:

• The print version of the full report can be obtained in the language of submission from the Health Canada Library through inter-library loan.

• An electronic version of the report in the language of submission is available upon request from Health Canada by e-mailing rmddinfo@hc-sc.gc.ca.

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