

Care-Related Out-of-Pocket Costs

Final Report

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Abstract

The purpose of this project was to use existing Canadian data to examine the prevalence, correlates, and social and economic consequences of the care-related out-of-pocket expenses of caregivers. These expenses result from providing unpaid care to family members and friends with long term disabilities or health problems.

We conducted secondary analysis of cross-sectional data from two national surveys, the 2007 General Social Survey (Cycle 21) and the Hidden Costs/Invisible Contributions (HCIC) survey, also conducted in 2007. The GSS data yielded population estimates for Canadians age 45 and older; the HCIC data provided more detailed information on a subgroup of caregivers to care receivers with high needs.

We found that 35.1% of the respondents to the GSS, or over 1.2 million Canadians aged 45 years or older, reported incurring out-of-pocket expenses. These costs varied widely, and collectively amounted to almost \$12.6 million in 2007. Caregivers were more likely to incur out-of-pocket costs if they were retired, reported stress sometimes, always or often, were caring for a family member or friend who had a combination of physical and mental health conditions, and if they lived outside the same area as the care receiver. Financial support in the form of tax benefits for care expenses, gifts from the care receiver, or financial support from family or friends also increased the likelihood of having care-related expenditures.

Care-related out-of-pocket spending can play an important role in increasing the social inclusion of care receivers, but at the same time it can contribute to the social exclusion of caregivers. We find such spending is common among Canadian caregivers, it can be substantial, and that relatively few caregivers receive financial supports that can defray these costs.

Keywords

Care-related out-of-pocket expenses; family/friend caregiving; economic costs of care; economics of aging; social inclusion/exclusion.

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1. Executive Summary

The purpose of this project was to use existing Canadian data to examine the prevalence, correlates, and social and economic consequences of the care-related out-of-pocket expenses of caregivers. These expenses result from providing unpaid care to family members and friends with long term disabilities or health problems.

The study drew on social exclusion and family ecological theory. Variable selection was also guided by the Taxonomy of Economic Costs of Care to Family/Friend Caregivers, which was developed as part of a companion project to this one. Secondary analysis was conducted on cross-sectional data from two national surveys, the 2007 General Social Survey (Cycle 21) and the Hidden Costs/Invisible Contributions survey, also conducted in 2007. The GSS data yielded population estimates for Canadians age 45 and older; the HCIC data provided more detailed information on a subgroup of caregivers to care receivers with high needs. Bivariate and multivariate logistic regression analyses were used to:

- Estimate the proportion of family/friend caregivers who have incurred out-of-pocket expenses by providing care and to examine differences by characteristics of the caregiver and the care receiver;
- Estimate the average annual amount of out-of-pocket expenses due to care provision;
- Determine the factors that are associated with out-of-pocket expenses including characteristics of the caregiver, the care receiver and the caregiver-care receiver dyad, and the context in which they live;
- Explore sources of funding that could help off-set some of the out-of-pocket costs of caregiving (e.g., government benefits, tax credits, financial assistance from family/friends);
- Examine social and economic consequences associated with caregivers' out-of-pocket expenditures.

Key findings of the study are:

- 35.1% of the respondents to the GSS, or over 1.2 million Canadians aged 45 years or older, reported incurring care-related out-of-pocket expenses. These costs varied widely, and collectively amounted to almost \$12.6 million in 2006.
- Caregivers were more likely to incur out-of-pocket costs if they were retired, reported stress sometimes, always or often, were caring for a family member or friend who had a combination of physical and mental health conditions, and if they lived outside the same area as the care receiver.

- Although relatively few caregivers receive financial supports, these supports (tax benefits for care expenses, gifts from the care receiver, or financial support from family or friends), increased the likelihood of spending on care-related needs.
- Caregivers who incur out-of-pocket expenses are much more likely to experience consequences that include cutting back on social activities or holiday plans, postponing enrolment in an educational or training program, moving in with the care receiver, and turning down a job offer or promotion than caregivers who do not incur care-related expenses.

Care-related out-of-pocket spending can play an important role in increasing the social inclusion of the care receiver, but at the same time it can contribute to the social exclusion of the caregiver. We find such spending is common among Canadian caregivers, it can be substantial for some, and that relatively few caregivers receive financial supports that might defray these costs. More detailed care-related expenditure data at the national level are needed to more fully understand the range of care-related out-of-pocket expenses and the consequences of this spending for Canadians.

2. Introduction

The confluence of a number of different factors, including population aging, reductions in the supports available through provincial health and home care services, the move towards community care for people with disabilities, and longer life spans for people with disabilities and health problems means, that more Canadians will take on the role of caregiver to a family member or friend who is disabled, ill, or aging (Lero, Keating, Fast, Joseph, & Cook, 2007). Even though there is considerable breadth and depth to the caregiving literature, a substantial knowledge gap remains concerning the care-related out-of-pocket expenses of family/friend caregivers in Canada (Lero et al., 2007).

Out-of-pocket expenses, along with employment restrictions and caregiving labour, constitute the three major categories of costs in the Taxonomy of Economic Costs to Family/Friend Caregivers developed by Keating, Lero, Fast, Lucas and Eales (2011) (Figure 1). Although some studies show that a substantial proportion of caregivers experience out-of-pocket expenses (Fast, Keating, & Yacyshyn, 2008; Keating, Fast, Frederick, Cranswick, & Perrier, 1999), very few provide estimates of the amount, and fewer still attempt to explain either the outcomes or the correlates. A rare exception is Evercare's (2007) careful and systematic documentation of out-of-pocket expenses in the U.S., but no similar evidence exists for Canada.

This project uses the most current existing Canadian data to examine out-of-pocket expenses for Canadian caregivers and identifies gaps for future research. Good information on the prevalence, average annual amount, and correlates and outcomes associated with out-of-pocket expenses are required to assess the kinds of supports needed for caregivers across different care situations.

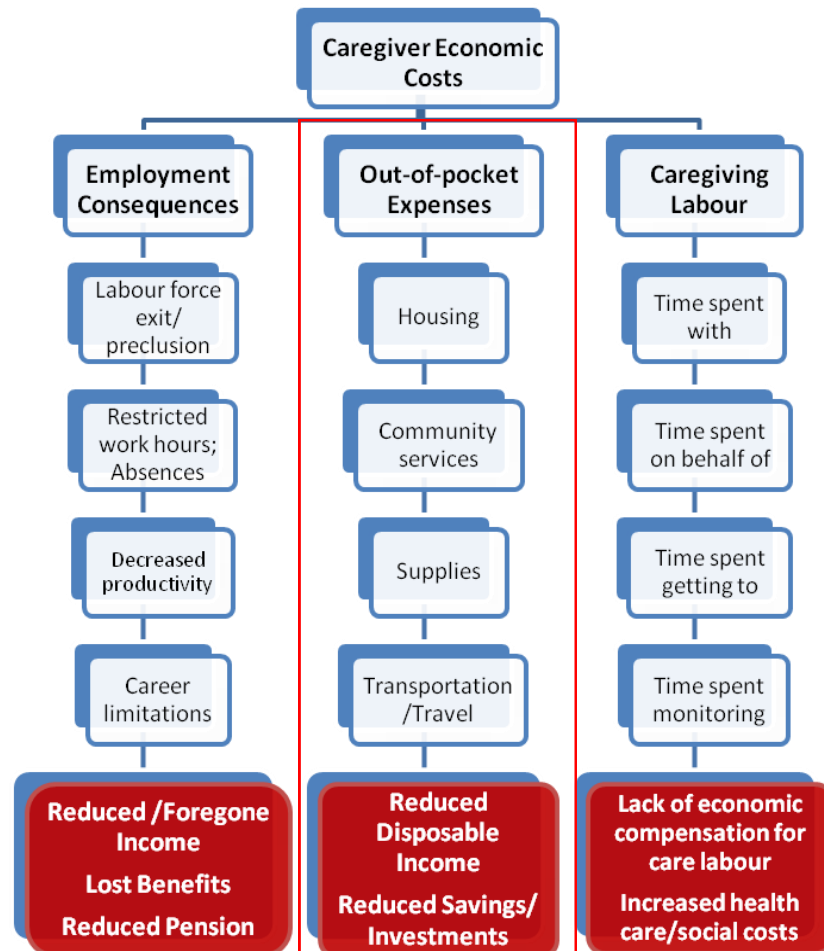
2.1. Project Objectives

The overall goal of this project is to use existing Canadian data, including nationally representative data, to better understand the prevalence, correlates, and social and economic consequences of out-of-pocket expenses that result from providing unpaid care to family members and friends with long term disabilities or health problems.

The specific research objectives are to:

- 2.1.1. Estimate the proportion of family/friend caregivers who have incurred out-of-pocket expenses when providing care and to examine differences by characteristics of the caregiver and the care receiver;

Figure 1. Taxonomy of the economic costs of care to family/friend caregivers



Source: Keating, Lero, Lucas, Fast, & Eales (2011).

- 2.1.2. Estimate the average annual amount of out-of-pocket expenses due to care provision;
- 2.1.3. Determine the factors that are associated with out-of-pocket expenses including characteristics of the caregiver, the care receiver, the caregiver-care receiver dyad, and the context in which they live;
- 2.1.4. Explore sources of funding that could help off-set some of the out-of-pocket costs of caregiving (e.g., government benefits, tax credits, assistance from other family/friends);
- 2.1.5. Examine social and economic consequences associated with caregivers' out-of-pocket expenditures.

3. Conceptual Framework and Background Literature

Unpaid caregiving can have a number of costs not only to caregivers, but also to care receivers, families of caregivers, employers, and society (MetLife Mature Market Institute [MMMI], National Alliance for Caregiving [NAC], & Centre for Long Term Care Research and Policy [CLTCRP], 2011; Fast, Williamson, & Keating, 1999; Feinberg, Reinhard, Houser & Choula, 2011; Habtu & Popovic, 2006; Lero et al., 2007). However, as caregivers experience the many economic and non-economic costs of care most directly (Lero et al., 2007), this paper will focus particularly on the out-of-pocket costs incurred by caregivers, as well as various factors that influence these costs. First, relevant theoretical perspectives are examined for guidance as to risk factors and outcomes of out-of-pocket spending. Second, background literature on out-of-pocket expenses is reviewed.

3.1. Theoretical Perspectives

Social exclusion. According to Levitas and colleagues (2007), social exclusion can be understood as “the lack or denial of resources, rights, goods and services, and the inability to participate in the normal relationships and activities available to the majority of people in a society” (p.25). Further, the degree to which an individual or group experiences social exclusion will vary, depending on the number of life domains from which exclusion is experienced. When older adults and other care receivers do not have the resources to meet their needs for material goods and services they may be at risk of social exclusion. Indeed, the level of access to such varied goods and services such as communication (e.g., telephone, internet) and health care (e.g., dentist, chiropractor) has been identified as an important social exclusion risk marker (Becker & Boreham, 2009). Out-of-pocket spending by caregivers essentially helps raise care receivers’ access to resources. However, caregivers do not necessarily have the funds to adequately support both the care receivers’ needs as well as their own. Therefore, caregivers’ out-of-pocket spending can decrease the risk of social exclusion for care receivers while increasing the risk of social exclusion for caregivers themselves.

While not enough research has been done to elucidate the causal factors associated with social exclusion, factors related to caregiving at both the individual level (micro) and the structural/environmental level (macro) are thought to impact the degree of social exclusion an individual may experience (Levitas et al., 2007). For example, friends or family members caring for someone who cannot afford to pay for goods or services may purchase them for the care receiver. Factors at the structural level may impact social exclusion through the availability of programs that cover the cost of health services for the care receiver, thereby reducing out-of-pocket costs to caregivers.

Scharf and colleagues (2001) have similarly discussed several theories related to social exclusion, and identified two dimensions of social exclusion which are particularly relevant for this research: exclusion from material resources and exclusion from social relations. These dimensions are related because inadequate material resources resulting from care-related out-of-pocket expenses can affect caregivers' ability to access social relationships and to participate more widely in society.

Family ecological theory. As noted by Lero and colleagues (2007), much of the literature on care-related out-of-pocket costs focuses primarily on caregiver and care receiver characteristics as influences without considering other contextual factors that can differentially impact the costs and consequences of caregiving. Therefore, a family ecological approach will be used to understand and interpret how the caregiving context relates to out-of-pocket expenses and social exclusion.

A family ecological approach explores human behavior and related outcomes from a holistic perspective, explicitly taking context into consideration. According to this theoretical perspective, the family unit is but one of the systems that are situated within the larger human ecosystem (Bubolz & Sontag, 1993). Due to the interdependent nature of the ecosystem, families are affected by changes in other components of the ecosystem and changes to families affect other levels of the human ecosystem.

For example, when a family member requires care, other family members may respond by making decisions about how to meet those care needs. Culture affects which family member(s) are given the most responsibility for providing care. Those providing care make the necessary changes to meet their caregiving goals, such as altering their daily routines, work schedules, or spending habits, and the changes made are based on the resources available to them at an individual, community, or economic level. Various components of the ecosystem influence human behavior by either constraining or enabling individuals and families as they strive to reach a goal or outcome (Bubolz & Sontag, 1993). However, not everyone has the same amount of control or freedom to interact with various systems. In the case of caregiving, caregivers and care receivers who do not have access to formal care services choose other means of meeting care needs, such as making home modifications or having the caregiver reduce hours spent in paid employment.

Finally, a family ecological perspective is particularly useful for studying inequity or deprivation and its relationship to access to resources or power (Bubolz & Sontag, 1993). Within the context of caregiving we are interested in learning how social structures and ideology may be related to social exclusion for caregivers with varying access to resources or power. Research has shown that women caregivers, for example, may be particularly

vulnerable to social exclusion, and a family ecological approach can help to uncover the ways in which social structures and ideologies may constrain access to resources for women caregivers. Most importantly, a family ecological approach can help inform us about the ways in which other aspects of the ecosystem, such as political and economic systems, can be organized so that services and resources will be more equally accessible.

3.2. Extent of Out-of-Pocket Costs of Care

It is estimated that four to five million Canadians provide unpaid care to family or friends who are living with a chronic condition or long-term disability, equaling over 80% of the care required by those individuals (Torjman, 2010). Many of these caregivers incur out-of-pocket costs, although few studies have been conducted to estimate the proportion of caregivers who incur these costs, the average amount of expenditures, the correlates of this spending, or the outcomes associated with it. Moreover, we lack national estimates of the prevalence and magnitude of such spending.

Some studies have shown that a substantial proportion of caregivers may experience economic costs of care, some of which include out-of-pocket expenses. Keating and colleagues (1999) estimated that over 40% of Canadian caregivers reported making care-related out-of-pocket expenditures in 1996. More recently, Fast and colleagues (2008) found some caregivers to care receivers with high needs – adults living with spinal cord injuries, cerebral palsy, schizophrenia, or military service-related disabilities –reported spending more than \$5,000 during the past year.

Out-of-pocket spending falls into four main categories of expenditures: residential care, community services, supplies, and transportation and travel (Keating et al., 2012). Residential care includes not just the costs of nursing homes, assisted living facilities and acute care, but also the additional costs to the household when the care receiver lives with the caregiver. Expenditures for home care, respite, day support, household help, and the services of specialized health care professionals constitute the community services category. The category supplies comprises spending on a wide range of items for the care receiver: food, personal care, clothing, household goods, medication, equipment, health supplies, and adaptations to the residence (e.g., ramps and grab bars). Transportation and travel includes both the costs of travel with the care receiver and travel by the caregiver to provide care to the care receiver (e.g., parking, gas, taxis, airfare, meals and accommodation).

Caregivers may find themselves spending out-of-pocket in one or more of these categories of expenses, particularly when care needs are high. Research with breast cancer patients and their caregivers from Montreal, Quebec, and Baie-Comeau has revealed that families

help to cover a wide range of out-of-pocket expenses: travel costs and accommodations for getting to appointments for treatments, meals, medication, parking, wigs and hats, or new clothing as the result of weight changes after treatments (Lauzier, Maunsell, De Koninck, Drolet, Hébert-Croteau, & Robert, 2005). Travel costs related to radiotherapy treatments can be especially high because this treatment continues daily for several weeks. Out-of-pocket travel costs were higher when patients lived farther away from the treatment centre, averaging \$54 per week of treatment for those living 25 kilometres away compared to \$240 per week of treatment for those living over 50 kilometres away (Lauzier, Maunsell, Drolet, Coyle, & Hébert-Croteau, 2010). Average monthly out-of-pocket costs incurred by 279 patients receiving treatments for cancer in Ontario was \$213 per month plus \$372 per month in travel costs (Longo, Fitch, Deber, & Williams, 2006).

Other Canadian research has used diaries completed over a two-week period to capture out-of-pocket expenses of either the caregiver or the care receiver (Chappell, Havens, Hollander, Miller, & McWilliam, 2004; Miller, Hollander, Corbett, & van der Valk, 2008; Miller, Hollander, & MacAdam, 2008). For veterans in and around Toronto, estimated annual out-of-pocket expenses averaged \$5,372 for those in community care, \$3,654 for those in supportive housing, and \$14,340 for those in a care facility, the latter included facility co-payments (Miller, Hollander, & MacAdam, 2008). A similar study found veterans in Halifax, Ottawa and Victoria averaged \$2,144 annually in out-of-pocket expenses if they were in community care and \$12,495 if they were in a care facility (Miller, Hollander, Corbett et al., 2008). In comparison of the costs associated with location of care in Winnipeg and Victoria, out-of-pocket spending was higher in home care settings, estimated at \$1,674-\$6,783 annually, depending on the care needs of the care receiver, compared to \$309-\$2,357 in care facilities (Chappell et al., 2004).

Although there is evidence of the extent of out-of-pocket spending by Canadian caregivers in the studies noted above, we lack solid national estimates of the prevalence and magnitude of such spending. Evidence from the United States indicates that out-of-pocket spending is common, variable, and the reported amount of spending varies with the data collection method (Evercare, 2007; Metropolitan Life Insurance Company [MetLife], 1999). However, the health care policy context is different in the two countries, so comparisons should be made with caution. Out-of-pocket expenses may be higher in the US if respondents lack health insurance; on the other hand, some private policies may cover more expenses than are covered in Canada.

Perhaps the most comprehensive research on out-of-pocket expenses was Evercare's (2007) telephone survey of 1,000 family caregivers who were providing unpaid care to someone over the age of 50 for five or more hours per week. As well, 41 of the participants

kept diaries of their care-related expenditures for a one-month period. Based on survey results, caregivers spent an average of \$5,531 per year on out-of-pocket costs. However, based on the diary reports, caregivers spent an average of \$12,348 per year, indicating that caregivers may seriously underestimate the actual amount they are spending on care-related out-of-pocket expenses.

When averaged across all 1,000 survey respondents, the largest expenditure share was for medical expenses (21%), followed by food and household goods (15.7%), travel costs (10%), services (day and home care) (9.9%), nursing home or assisted living facility care (9.0%), and home maintenance (8.1%). Caregivers also reported paying out-of-pocket for housing costs, caregiving services, home modifications, clothing, medical equipment, and legal fees. Based on the diary reports, caregivers frequently paid for medical expenses, groceries, household expenses, transportation, and personal expenses on behalf of the care receiver. The highest average monthly expenditures were for care attendants (\$572 per month) followed by medical expenses (\$424 per month) and household expenses (\$412 per month). An earlier study revealed that caregivers paid out-of-pocket for one or more items for their care receivers, and that food, medication, and transportation costs were frequently cited (MetLife, 1999).

Caregivers who paid costs related to housing such as rent or utilities also had high costs, averaging \$466 to \$485 per month (Evercare, 2007). MetLife (1999) found that the caregivers who incurred the highest average monthly out-of-pocket costs were paying for rent or mortgages (at \$364 per month) and for home care services (\$322 per month) for the care receivers.

The diary reports from the Evercare (2007) study show a wide range of expenses in some categories. Specific medical expenses listed in the diary reports were prescription and non-prescription drugs, insurance costs, medical equipment, and personal expenses including incontinence supplies and bath items. The diary reports also revealed information about unique or unexpected costs, such as pet-related expenses, cigarettes, or alcohol.

Lukemeyer, Meyers, and Smeeding (2004) calculated out-of-pocket spending among low income families of children living with a disability in the United States, noting that children in low-income families are more likely to be living with a disability. A total of 2,214 mothers were surveyed twice, several months apart. The most expensive type of out-of-pocket cost reported for the month preceding the survey was special expenses related to child care, which was reported by 18.9% of the mothers and averaged \$119. Out-of-pocket spending unrelated to childcare was reported by 37.9% of the mothers and averaged \$105 for the previous month. Major expenses (over \$100) on medical care and specialized equipment

were reported by 12.5% of the mothers. Some of the factors that were found to be associated with out-of-pocket spending among this sample were severity of the child's condition, and lacking insurance coverage, either private or Medicaid. In a US household survey on perceived family economic burden resulting from caring for children living with chronic illnesses and disabilities, nearly half of the households spent at least \$500 over the previous 12 months on care-related out-of-pocket expenses (Kuhlthau, Smith Hill, Yucel, & Perrin, 2005).

Out-of-pocket spending is not solely a North American phenomenon. A study of Kenyan caregivers found their care-related out-of-pocket spending included health care services, transportation, food, and costs of food and accommodation for caregivers (McIntyre, Thiede, Dahlgren, & Whitehead, 2006). In a Hong Kong study, nearly half of the predominantly female caregivers to older adults living with cognitive impairments spent at least \$128 per month, and a small proportion of caregivers (13.1%) spent over \$641 per month out-of-pocket (You, Ho, & Sham, 2008). Although costs were not calculated as out-of-pocket expenditures explicitly, Beeri and colleagues (2002) reported that, in Israel, a significant proportion of both direct and indirect costs of care are paid by the families of older adults living with Alzheimer's disease, particularly those living in the community. Direct costs were \$10,060 for individuals living in institutions and \$4,330 for those living in the community; indirect costs were \$2,485 and \$10,700, respectively (Beeri, Werner, Adar, Davidson, & Noy, 2002). In India, Dias and colleagues (2004) compared differences in reported economic strain between caregivers for dementia patients, those caring for older individuals not living with dementia, and those caring for patients suffering from depression. They found that the caregivers of dementia patients reported greater costs of health care due to expensive medications.

In summary, the research on care-related out-of-pocket expenses reveals that caregivers spend out of pocket on a number of different expenses, expenses are often high, and the extent of spending may well be underestimated in survey data.

3.3 Predictors of Out-of-Pocket Costs

A number of variables have been associated with care-related out-of-pocket spending. In this section, research on the predictors of out-of-pocket spending is organized by caregiver, care receiver, caregiver-care receiver dyad, and caregiving context characteristics.

Caregiver characteristics. Gender. Literature on the relationship between gender and out-of-pocket expenses is scant; however, there is a vast literature on the gendered nature of caregiving. In a companion project to this one, analysis of the 2007 General Social Survey

data showed that 56.5% of caregivers aged 45 and older were female and 43.5% were male (Fast, Dosman, Lero, & Lucas, 2012). Duxbury, Higgins, and Schroeder (2009) reported that unpaid caregivers in Canada are most often daughters or daughters-in-law, or female spouses, mostly over the age of 65.

It is clear from the literature that female caregivers typically provide more hours of personal care and experience more financial, physical, and emotional costs as a result of caregiving (Habtu & Popovic, 2006; Lero et al., 2007; National Alliance for Caregiving [NAC] and AARP, 2004; NAC, AARP and MetLife Foundation, 2009). When women provide elder care, for example, they are more likely than men to: provide more hours of care, have more care episodes that last for more years, perform tasks that can be difficult to schedule around other demands on their time, perform a broader variety of tasks including personal care, receive less support, and experience more caregiver burden and depression (Fast et al., 2012; Lero et al., 2007).

Women tend to care for multiple people at a time more often than men do, such as aging parents or sick family members as well as their own children (Berg & Woods, 2009; Duxbury et al., 2009). As the time women spend in the paid labor force is increasing, responsibility for caring for children or older family members is not decreasing, and women continue to spend more time than men on child care and household work (Marshall, 2006).

Women are also over-represented in lower paid jobs and, as a result, their income is often considered expendable when care needs arise, prompting them to leave their paid work to provide unpaid care (Berg & Woods, 2009; Habtu & Popovic, 2006). The reduction in public services through which care was once provided has meant that a considerable amount of this work, formerly done by women for pay in the market, is now done by women without pay in the home (Armstrong & Armstrong, 2002).

While Canadian estimates of gender differences in out-of-pocket costs of care are rare, Keating and colleagues (1999) found that a slightly higher proportion of women (45.3%) than men (41.8%) reported making care-related out-of-pocket expenditures. Nevertheless, because the experience of caregiving is gendered, particular attention will be paid in this study to gender differences in out-of-pocket expenses and the factors associated with these differences.

Education. Few studies have measured the relationship between caregiver education and out-of-pocket spending. However, given that higher levels of education tend to be associated with higher levels of income, it is important to control for education in studies of out-of-pocket spending. A study of mothers caring for children living with chronic illness, disabilities, and long-term injuries showed that a large portion of families experienced some

financial burden related to costs of caring for their children living with special health care needs, including mothers with at least four years of college education: 34% of mothers in this category reported at least one financial difficulty (Kuhlthau et al., 2005). You and colleagues (2008) found that having completed higher levels of education was associated with monthly spending of greater than \$128 in their study of caregivers in Hong Kong.

Income. Out-of-pocket costs have been found to be greater for those in lower income levels in Canada and the United States. In Canada, Duxbury and colleagues (2009) found that the lower a caregiver's income level, the higher the perceived financial strain, with 60% of the caregivers in the lowest income category reporting financial strain. According to Evercare (2007), the absolute annual dollar costs in the US were similar across income levels, meaning that the costs represented a high percentage of total income (20%) for those in the lowest income category. To cover the extra costs, caregivers in the lowest income category reported using credit or their own savings, cutting back on spending for their own needs such as for things like health care, household expenses, food, recreation and vacation, and savings for their children.

Immigrant status. Although no studies were located that estimate the out-of-pocket costs of care among immigrant family/friend caregivers, both cultural background and immigrant status impact access to services and so might be expected to influence both the probability and the scale of out-of-pocket expenses. Individuals who have recently immigrated to Canada may access fewer services due to language barriers, lack of knowledge about how to access services, and cultural differences between service providers and receivers (Lero et al., 2007). Stewart and colleagues (2006) found that female caregivers from Hong Kong, Taiwan, India and Pakistan who had been sponsored to immigrate to Canada faced barriers in accessing supports such as income support because they were not eligible unless they had been in Canada for 10 years or more. It is likely, then, that immigration status has an impact on out-of-pocket costs of care.

Care receiver characteristics. Nature and severity of health condition. The type of health problem(s) if the care receiver has an impact on the costs of care to the caregiver. For instance, costs to family/friend caregivers were reported to increase with disease severity and dementia-related behaviors among caregivers for elderly community-dwelling veterans and other individuals living with dementia (Moore, Zhu, & Clipp, 2000; Small, McDonnell, Brooks, & Papadopoulos, 2002). Most of this increase derived from the increased caregiving time required for the provision of physical care. Out-of-pocket costs have been found to increase as the functional limitations increased in veterans living with dementia symptoms because caregivers paid increasingly for the purchase of formal services.

Chappell and colleagues (2004) found out-of-pocket costs increased with the level of care required by the care receiver.

Age. Age of the care receiver has been found to be related to the supports available to caregivers. Among caregivers to individuals 50 years of age and older, 65% stated that they received help from friends or family, while 38% of caregivers to individuals aged 18 to 49 years reported that they received help (National Alliance for Caregiving and AARP, 2004). Moreover, 46% of caregivers to the older age group reported that the care receiver also received paid help from formal services while only 23% of the caregivers to the younger age group did. However, the types of conditions giving rise to the need for care also varied considerably between the younger and older care receivers: those over the age of 50 required care due to age-related frailty and illnesses such as diabetes, cancer, heart disease, Alzheimer's, or dementia, whereas mental health concerns, including depression, were the primary reasons underlying younger care receivers' needs (National Alliance for Caregiving and AARP, 2004).

Caregiver-care receiver dyad characteristics. Relationship. Although we would expect the relationship of the caregiver to the care receiver (for example, spouse, parent, or friend) to influence the amount of out-of-pocket spending, there has been little research in this area. In one study, care-related out-of-pocket expenses were more likely to be incurred by family members than by friends or neighbours (Keating et al., 1999).

Proximity. Geographic proximity of the caregiver to the care receiver has been found to predict out-of-pocket costs. However, findings differ across studies. According to Vezina and Turcotte (2010), providing care for a parent who lives far away (more than half a day's drive from the care receiver) increases out-of-pocket spending. Based on 2007 General Social Survey data, one fifth of a sample of 2,700 caregivers lived over an hour away from the parents for whom they were providing care, yet they still provided a great deal of assistance (Vezina & Turcotte, 2010). Further, 39% of long distance caregivers reported spending over \$500 per month, compared to only 11% of caregivers living in the same neighborhood as the care receiver (Vezina & Turcotte, 2010).

Other studies have reported similar results, but have made an additional significant observation. In the study conducted by Evercare (2007), survey participants who provided long distance care reported higher average total out-of-pocket expenses than those who lived close to care receivers. However, caregivers who lived with their care receivers and kept monthly diaries of expenditures reported the highest out-of-pocket costs. The co-residing caregivers who kept diaries reported average spending of \$1,236 per month compared to an average of \$1,172 per month reported by long-distance caregivers who

completed survey reports. This is consistent with the findings of Duxbury et al. (2009), whereby caregivers who lived with care receivers reported the highest level of financial strain, compared to those who lived separately. However, what this observation might actually suggest is that expenditure diaries capture out-of-pocket costs more accurately than recall survey data.

Caregiving context. End-of-life care. End-of-life care can be an indicator of the intensity of caregiving. With more end-of-life care being provided in the home rather than in hospitals, there is growing interest in the out-of-pocket costs incurred by family and friend caregivers in this situation. In a study of 988 patients with terminal illnesses, a large portion of the patients reported that 10% of their household income was spent on health care costs (not including insurance) and that they or their family members had to sell assets, take on an extra job, loan, or mortgage in order to pay for medical costs (Emmanuel, Fairclough, Slutsman, & Emanuel, 2000).

Guerriere and colleagues (2010) estimated the total costs incurred at end of life across 136 participants admitted to a palliative care program in community based care in Toronto, including out-of-pocket costs to caregivers up to the time of the care receivers' death. Almost all participants reported out-of-pocket spending, averaging \$688, with the highest expenditures being for home-based appointments, paid housework, ambulatory appointments, and medications. As the time to death grew closer, average monthly costs increased (Guerriere, Zagorski, Fassbender, Masucci, Librach, & Coyte, 2010).

In a study of the costs are associated with providing end-of-life care and who covers them in five community health care settings in Halifax, Montreal, Winnipeg, Edmonton, and Victoria, Dumont and colleagues (2009) calculated the total costs of care from the time the care receiver was enrolled in a palliative care program until six months later, or until death. Caregivers were found to pay out-of-pocket for 26.6% of the total costs, most of which were for home care, transportation, and medical equipment (Dumont, Jacobs, Fassbender, Anderson, Turcotte, & Harel, 2009). Costs to families also increased by 129% (peak) during the fifth to the third month preceding death, decreasing thereafter until the time of death (Dumont, Turcotte, Anderson, & Harel, 2010). Families reported spending an average of \$500 per month during the fifth month prior to death, which increased to an average of \$1,200 per month for the third month preceding death. This may be because individuals receiving palliative care often wish to spend time at home, rather than in a hospital or care facility, which puts the burden of the costs of care on the family. As a condition progresses many families cannot afford to maintain specialized care at home and, therefore, care is moved to a facility (Dumont et al., 2010).

Number of care receivers. Number of care receivers can also be an indicator of the intensity of the caregiving experience. Caregivers providing care simultaneously for more than one receiver may incur greater costs. The 2002 General Social Survey revealed that 16.8% of employed caregivers had both eldercare and child care responsibilities, and these caregivers reported experiencing financial burden. Small et al. (2002) also noted that many of the caregivers of individuals living with Alzheimer's also had children living at home, which meant higher costs for child care so that caregivers could meet multiple care demands.

Living arrangements. Out-of-pocket spending may vary with care receivers' living arrangements. In one study, caregivers of family members living with dementia in residential care facilities spent an average of \$500 per month out-of-pocket, and caregivers with a family member living in nursing homes reported spending an average of \$400 per month; expenses included facility costs, medical care, transportation, and costs for additional services (Williams, Port, Dobbs, Zimmerman, Preisser, & Williams, 2005). Survey data collected by Evercare (2007) revealed that caregivers who paid for nursing home or assisted living fees had the highest costs, averaging \$980 per month, compared with an average of \$400 (Williams et al., 2005).

Insurance/access to services or supports. The inability to access services is associated with caregiver burden or isolation. Fast et al. (2008) reported that nearly half of caregivers interviewed lacked needed assistance, and 72% felt that they lacked the support they would need in order to continue providing care. For those providing care to friends and family living with schizophrenia, this figure rose to 92%. Most caregivers in the study reported that the cost of services was a barrier to accessing help (60%), and many caregivers reported that services are not covered by insurance (67%). For those caring for individuals living with schizophrenia, 80% said that lack of insurance coverage was a barrier to accessing needed services. Caregivers of individuals living with cerebral palsy were the most likely to report that supports were not available or that they were not aware of where to access them, and these caregivers were especially at risk for becoming socially isolated. Gibson and Houser (2007) found that when care receivers have insurance coverage to help cover costs of formal services, caregivers are four times more likely to remain employed than those caring for individuals without coverage (35% versus 9%).

Health care policy. Researchers have pointed to a shift in Canadian policy towards community and home-based care. Fast and colleagues (1999) have argued that, in the context of rising health care costs, there has been a shift toward less government involvement in caregiving (in terms of institutional care or social programs) in order to reduce costs related to health care and social programs. This shift towards encouraging

personal and community responsibility for health care due to the assumption that care provided by family or friends is better since it is done out of affection and obligation, and cheaper because it substitutes “free” family/friend care for government-funded formal care. However, as Fast et al. (1999) note, costs are not necessarily eliminated by this strategy but rather are merely redistributed from the public sector to caregivers and care receivers themselves.

The extent to which individuals will incur out-of-pocket expenses is influenced by what is covered by the public health care system. Inpatient hospital care and over 91% of the costs of ambulatory care, long-term care, and out-patient prescription medications were covered by the public health care system for palliative care patients in a study by Dumont and colleagues (2009). However, for many care receivers, expenses such as medications and specialized equipment that are covered when the care receiver is in a hospital are not covered upon discharge, leading to out-of-pocket spending to cover the gaps (Keating et al., 2012).

Policies and programs differ by province and can affect out-of-pocket spending for caregivers to seniors. Drug coverage varies among provinces as well. Demers and colleagues (2008) estimated annual drug costs for a variety of clinical scenarios and noted that, regardless of their “prescription burden”, low-income seniors pay 0-35% of their prescription costs in BC, Ontario, PEI, New Brunswick and Newfoundland and Labrador and 35-100% of their prescription costs and professional fees in Alberta and Nova Scotia. When the funding that seniors receive is not adequate to pay for services and programs that they require, their caregivers often end up paying out of their own pockets to cover some or all of the costs (Fast et al., 2008).

Wimo and colleagues (2010) conducted a review of the literature related to costs of caring for individuals living with dementia across sixteen countries in Europe and found differences in costs to family caregivers across countries. These differences arose from differently patterned care systems. Higher direct costs to family/friend caregivers were found in southern Europe while higher direct costs of care (due to the use of professional care providers) were found in Sweden and the UK, a difference considered to be the result of a higher reliance on family care providers in southern Europe (Wimo et al., 2010).

3.4 Outcomes of Out-of-Pocket Spending

Out-of-pocket spending has been associated with a wide range of consequences or outcomes for caregivers. Much of the attention has been on the financial hardships imposed by out-of-pocket spending; however, literature showing the social and health

consequences of caregiving in general indicates the need for further exploration of these outcomes as well.

Financial and economic security consequences. Lauzier and colleagues' (2005) research with breast cancer patients revealed that patients felt that costs resulted in significant financial burden for families, and that this burden varied according to family income and ability to pay. Of those patients and caregivers reporting that radiotherapy or chemotherapy-related costs were very high, actual cost estimates were twice as high as those who reported treatments to be not at all costly (\$564 per week of treatment versus \$254). (Lauzier et al., 2010).

Significant or unmanageable financial burden as a result of out-of-pocket spending for costs associated with treatments such as chemotherapy or radiotherapy was found for over 20% of a sample of Ontario cancer patients, and those who reported this level of burden had the highest costs (Longo et al., 2006). Those who reported significant financial burden had average costs of \$452 per month plus \$353 for travel, and those who reported unmanageable burden had costs of \$544 per month plus \$324 travel costs. The study showed that respondents' perceived financial burden was related to their income level, with those whose costs represented a higher percentage of their income level reporting higher burden (Longo et al., 2006).

Out-of-pocket spending can have long-term financial consequences. In one Saskatchewan study, nearly all of the eleven caregivers to family members living with conditions such as Alzheimer's Disease, cancer, multiple sclerosis, cerebral palsy, and autism said that they incurred significant out-of-pocket costs related to home renovations, transportation, medications, and funeral costs. As a result they noted that, although they were able to make ends meet every month, they no longer had disposable income and worried about whether they would have enough financial resources in their own futures (Sawatzky & Fowler-Kerry, 2003).

Caregivers have also been found to spend less money on themselves for things such as home improvements, investments, or savings for the future, as a result of out-of-pocket spending related to care (Carers UK, 2007; Evercare, 2007; MetLife, 1999). Of the caregivers surveyed by Evercare (2007), 38% reported that they stopped saving as the result of caregiving, and 34% reported that they had to postpone major purchases or home improvements. Those with the highest out-of-pocket costs were most likely to report taking out loans, cutting back on necessities such as clothing, transportation, and utilities, and reducing expenditures on their own dental and health care. Of the nearly 3,000 caregivers in the United Kingdom, surveyed by Carers UK (2007), one-third reported that they had

been or still were in debt due to their caregiving activities. In addition, one-third of caregivers could not afford to make home repairs, a third found it difficult to pay utility bills, and ten percent could not afford their housing costs. As a result of financial burden due to caring for children living with special health care needs, 18% of the families surveyed by Kuhlthau and colleagues (2005) reported that they needed to find additional sources of income to make ends meet.

As a result of out-of-pocket spending, caregivers also report having to use savings to cover extra costs. Of the caregivers interviewed by Lai and Leonenko (2007), over half reported that their family had to give up some necessities as a result of caring for an older relative and an even greater percentage (75%) said that savings had to be used as a result of providing care.

Retirement plans also may be affected by out-of-pocket spending. Fast and colleagues (2008) found that those caring for friends or family living with cerebral palsy expected to work longer in order to cover financial costs of care. Caregivers also put life goals on hold as a result of their care-related out-of-pocket expenses (Sawatzky & Fowler-Kerry, 2003).

An examination of international literature related to the economic costs of illness, including out-of-pocket payments for health care services by households caring for individuals with illnesses revealed that the total cost of out-of-pocket expenditures for health care services was often over 10% of many lower income households' annual income (McIntyre et al., 2006). In Kenya, costs for health care related to malaria were estimated at 18% of annual household income, and households coped by reducing food consumption, borrowing money, or selling assets. However, selling assets such as land or livestock can lead to a cycle of economic vulnerability that perpetuates the financial difficulty that these families are trying to escape (McIntyre et al., 2006).

Social or health-related consequences. Caregivers have reported high levels of stress or worry as the result of caregiving and out-of-pocket spending (Carers UK, 2007; Duxbury et al., 2009; Evercare, 2007; Fast et al., 2008) particularly when caregiving is provided on a long-term basis. Sleep deprivation and exhaustion were common as well and, again, the lack of a break was cited as the primary reason for sleep disruption (Duxbury et al., 2009; Fast et al., 2008). Nearly half of all the caregivers interviewed by Fast and colleagues (2008) rated their lives as always or almost always stressful, and many of the caregivers (41 to 45%) reported that their quality of life was negatively affected by the financial consequences of providing care. About 19% of women and 8% of men reported their health has suffered due to providing care to someone else (Fletcher, Fast, & Eales, 2011). Duxbury and colleagues (2009) also found that financial strain was associated with

depressed mood and lower perceived health and quality of life, even when level of financial strain was rated as moderate.

Changes in vacations have also been reported. Evercare (2007) found that the most common ways to cope with the out-of-pocket costs of care were reducing leisure activities (reported by 49% of the study participants), and cutting back on vacation or travel (47% reported). Caregivers in the Carers UK (2007) survey often cut back on holidays, social and leisure activities as a response to the impact of the costs of caregiving, including out-of-pocket expenses, to their financial health. Fletcher and colleagues (2011) note that reducing social activities, cancelling holiday plans, and spending less time with one's partner or children were common among Canadian caregivers. Duxbury and colleagues (2009) found that 33% of the caregivers they surveyed changed holiday plans and 17% altered vacation plans, as a result of caregiving responsibilities.

4. Methods

4.1. Study Design

The research involves secondary analysis of cross-sectional data from two national surveys:

- The 2007 General Social Survey (Cycle 21), and
- Data from a survey of caregivers from across Canada to non-senior adults with high levels of disability conducted by the Hidden Costs/Invisible Contributions (HCIC) research team in 2007 (Fast et al., 2008).

The GSS data yields population estimates for Canadians age 45 and over; the HCIC data, although not representative of the Canadian population aged 19-64, are useful both because they apply to a high needs subgroup of caregivers and because more detailed information on sources of costs was collected. Although the GSS data are not nearly as rich as the HCIC data in terms of information on out-of-pocket costs, they are of high quality and allow us to estimate the prevalence of out-of-pocket expenses and obtain information on the correlates of this spending at the population level.

4.2. Data Sources

The 2007 GSS (Cycle 21) was focused on family, social support, and retirement for Canadians aged 45 years and over. Its aim was to enhance our knowledge of the needs and experiences of Canadians aged 45 and older regarding key transitions related to their

families, caregiving, care receiving, work and retirement. Thus, it includes data with which to explore the consequences of caregiving.

The target population was non-institutional persons aged 45 or older, living in the ten provinces. A total of 23,404 individuals participated for a response rate of 57.7%. Interviews by proxy were permitted, and these interviews constituted 2.6% of the completed interviews. We selected for our analyses a sub-sample of 6,366 respondents who reported providing care to family members, close friends and neighbors.

HCIC 2007 was a national telephone survey “conducted to evaluate the experiences of family members and friends who support individuals between the ages of 19-65 who have a disability” (Fast, et al., 2008). Both caregivers and care receivers were interviewed, with many questions mirroring those in the GSS questionnaire. The data include both detailed cost estimates of out-of-pocket expenses in a number of expenditure categories and information on the consequences of care for caregivers. The sample was recruited through partner organizations: Canadian Paraplegic Associations of Alberta, Saskatchewan and Manitoba; Schizophrenia Societies of Saskatchewan and Nova Scotia; Cerebral Palsy Association of Alberta; Canadian Association for Community Living and Veterans Affairs Canada. Response rates were low; 260 matched interviews of caregivers and care recipients were completed from the sample of 600 (43.4%) (Yacyshyn, Fast, Keating, & Eales, 2008). However, Fast and colleagues (2008) note there is evidence of strong agreement among the partner organizations that the experiences of caregivers are representative of their clientele.

4.3. Variables

Dependent variables. In both the GSS and HCIC data, out-of-pocket expenses was measured by a dummy variable indicating whether or not the caregiver had incurred care-related out-of-pocket expenses in the previous twelve month period. In the GSS, an ordinal variable allowed categorization of this spending into three levels: less than \$500 per month, \$500 to \$2,000 per month, and more than \$2,000 per month. In the HCIC data, a continuous variable measured the amount of out-of-pocket expenses over the previous twelve months.

In the GSS, a dummy variable was constructed that indicated whether or not the caregiver experienced an impact of caregiving in one or more of the following areas in the previous twelve months: reducing social activities, cancelling holiday plans, postponing enrolment in an educational or training program, turning down a job offer or promotion, or moving in with the care receiver.

The HCIC survey contained extensive information on the impacts of caregiving. From this information we created four dummy variables that measured the impact of caregiving in four areas: employment, economic security, social, and health. However, due to the high proportions of HCIC caregivers who reported experiencing each type of consequence, there were not enough variations in the data to perform multivariate analyses on the consequences of caregiving for HCIC caregivers.

Independent Variables. The potential correlates were selected based on both the review of literature and their availability from the source surveys. Congruent with human ecology theory, these variables were organized as follows, based on prior research by Keating and colleagues (2011):

- Caregiver characteristics
- Care receiver characteristics
- Characteristics of the caregiver-care receiver dyad
- Caregiving context

A summary of the definitions and operationalization of all variables in the study for both surveys is provided in Table 1.

4.4. Data Access

Since Dr. Fast was PI on the project in which the HCIC data were collected, we have full ownership of and access to these data. These data were collected under ethics approval from the Human Ethics Review Board, Faculty of Agriculture, Forestry and Home Economics, University of Alberta (Fast et al., 2008). The GSS data were obtained from the master data files at the Statistics Canada Research Data Centres (Manitoba and Alberta), where we have access to full data on all the variables. Ethics approval for the analyses reported here was granted by the Joint Research Ethics Board, University of Manitoba.

4.5 Data Analysis

Frequencies and cross tabulations were run separately on each data file to describe demographic, socio-economic, and health-related characteristics of caregivers and care receivers. Bivariate analyses were conducted to address research objectives 1, 2 and 4 and multivariate analyses (logistic regression) were conducted to address research objectives 3 and 5.

Because the prevalence and experience of caregiving is different for men and women (Lero, et al., 2007), multivariate analyses of the GSS data were conducted by splitting the sample on sex and comparing the findings. For the HCIC data, the distribution of women and men in the sample made splitting the sample by inadvisable. Instead, we accounted for gender in the HCIC multivariate analyses by including gender as an explanatory variable.

Statistics Canada employs a complex, stratified survey design, and the data must be weighted to account for under- and over-representation. [See Pelot & Kemeny (2009) for detailed information on the survey methodology.] To fully account for the survey design effect, bootstrap weights in the master data file were used to estimate the standard errors and coefficients of variation to ensure that findings were representative of the population. All analyses were conducted using the statistical software program STATA.

5. Findings

Univariate and bivariate sample descriptive statistics from the analysis are presented in Tables 2-10. The results of the multivariate analyses may be found in Tables 11-13.

5.1 Sample Characteristics

In this section, relevant characteristics of both the GSS and HCIC samples are described for caregivers, care receivers, the caregiver-care receiver dyad, and the caregiving context.

Caregiver characteristics. Caregiver characteristics are reported in Table 2. Both GSS and HCIC caregivers tended to be less than 65 years of age (77.7% GSS; 90.0% HCIC), female (57.0% GSS; 80.8% HCIC), married or living common law (75.6% GSS; 87.3% HCIC), and Canadian born (71.2% GSS; 89.2% HCIC). In each instance, a higher proportion of HCIC than GSS caregivers reported these characteristics. Both GSS and HCIC caregivers were also well-educated (55.0% GSS and 46.7% HCIC held a post-secondary degree or diploma), and the majority were in the labour force (59.1% GSS; 50.4% HCIC), with higher proportions of GSS than HCIC caregivers holding a post-secondary degree or diploma and being in the labour force.

The major sources of GSS caregivers' incomes were wages and salaries (45.8%), pensions (15.7%) and self-employment (12.1%), whereas for HCIC caregivers, the major sources were pensions (26.9%), the Child Tax Benefit (13.5%) and wages and salaries (13.1%) (Table 2). Almost one-third of GSS caregivers reported annual personal incomes in the range of \$20,000-\$49,900. Not surprisingly, household incomes were higher, with

45.6% of GSS respondents reporting annual household incomes of \$60,000 or higher. In contrast, among HCIC caregivers, 39.7% had annual household incomes in the \$60,000 plus range.

Although nearly 35% of GSS caregivers reported daily limitations due to health, the vast majority (88.6%) reported their health as good, very good or excellent (Table 2). Nearly 40% reported feeling stress sometimes and a further 28.8% reported that they were often or always under stress. In comparison, a much smaller proportion of HCIC caregivers reported daily limitations due to health (12%). Among HCIC caregivers, 78.1% reported their health as good, very good or excellent, and whereas the proportion experiencing stress sometimes was similar to GSS caregivers (at 37.8%), 48.2% stated that they were often or always under stress.

Care receiver characteristics. The data contain less information on care receiver than caregiver characteristics. GSS care receivers were female (66.7%); whereas HCIC care receivers were male (74.2%) (Table 3). Among GSS care receivers, 67.6% were aged 65 or older; among HCIC care receivers, the majority were in the targeted age range of 45-64. The majority of GSS care receivers were receiving care due to a physical health problem (69.1%) or a combination of physical and mental health problems (21.5%). Only 6.8% were receiving care solely because of a mental health problem. Among HCIC care receivers, the majority were receiving care for a combination of physical and mental health problems (57.3%); care for physical health problems or mental health problems only as the reason for care were less common (38.9% and 3.1% respectively).

Caregiver-care receiver dyad characteristics. In Table 4, the characteristics of the caregiver-care receiver dyad are reported. The majority of GSS caregivers and care receivers lived in the same area (63.2%) or cohabitated (21.6%). In contrast, the vast majority of HCIC caregivers and care receivers were co-resident (84.2%), and in 71.9% of the cases, the care receiver was the partner of the caregiver. GSS caregivers tended to be caring for parents (46.3%), friends or neighbors (23.8%) or spouses/partners (10.6%), whereas HCIC caregivers were overwhelmingly caring for spouses/partners (71.9%) followed by parents (11.2%).

Caregiving context. Characteristics of the caregiving context are reported in Table 5. Most of the GSS caregivers did not receive complementary funding from any sources such as government programs, tax benefits, gifts from the care receiver, or support from family and friends that might defray caregiving costs. Higher proportions of HCIC caregivers received such support. In the two categories of support that were most comparable, 33.5% of HCIC caregivers received support from public programs, compared to 3.9% of GSS

caregivers, and 57.9% of HCIC caregivers reported financial support from family and friends compared to 4.7% of GSS caregivers.

Over one-third of the GSS caregivers had provided end-of-life care at some point in their caregiving history and 2.5% of respondents were currently providing end-of-life care to a care receiver (Table 5). Most GSS caregivers lived in an urban area (79.2%). Information on the provision of end-of-life care and urban or rural location was not available for HCIC caregivers.

The most common consequences of caregiving for the GSS caregivers in the past 12 months were reducing social activities (36.3%) and cancelling holiday plans (19.8%) (Table 6). As noted previously, the HCIC data obtained information on a large number of caregiving consequences. For four of the five consequences reported in the GSS, HCIC caregivers reported experiencing that consequence in much higher proportions: 84.6% reduced social activities, 40.4% cancelled holiday plans, 25.0% postponed enrolment in an educational or training program, and 31.9% turned down a job offer or promotion.

5.2 Objective 1: Estimate the proportion of family/friend caregivers who have incurred out-of-pocket expenses for providing care and examine differences by characteristics of the caregiver and the care receiver.

In 2007, 35.1% of GSS caregivers aged 45 years or older, or over 1.2 million Canadians, reported incurring care-related out-of-pocket spending (Table 7). Among the HCIC caregivers to care receivers with high needs, a much higher proportion (71.5%) had expenditures related to their caregiving responsibilities.

The characteristics of caregivers who incurred care-related out-of-pocket expenses differed significantly from those who did not on age, marital status, education, employment status, source and amount of household income (Table 8). Caregivers who incurred out-of-pocket expenses were younger (aged less than 65 years as opposed to 65 and older), married or living common law, had completed post-secondary education, were employed, and had employment income compared to those caregivers who did not incur out-of-pocket expenses. Caregivers who incurred care-related expenses were also significantly more likely to report higher levels of stress and daily limitations due to health than caregivers who did not incur out-of-pocket expenses. HCIC caregivers who incurred out-of-pocket expenses differed from those who did not only on the characteristics of education. Caregivers who had care-related expenditures were more likely to have finished post-secondary education than those who did not (Table 9).

GSS caregivers who incurred out-of-pocket expenses were more likely than those who did not to be caring for a family member or friend who was younger than 45 years and who had a combination of physical and mental health problems (Table 8), HCIC caregivers were also more likely to be providing care for a family member or friend who was younger than 45 years if they were spending money on care-related out-of-pocket expenses (Table 9).

4.3 Objective 2: Estimate the average annual amount of out-of-pocket expenses due to care provision.

Of the 35.1% of GSS caregivers who reported incurring care-related out of pocket expenses, 80.2% reported spending less than \$500 per month on average, 16.6% spent between \$500-\$2,000 per month, and 3.2% spent more than \$2,000 per month (Table 10). Thus, whereas most GSS respondents spent \$6,000 or less per year on out-of-pocket expenses, 3% spent more than \$24,000 annually. Among those with annual household incomes less than \$30,000, 81.8% spent less than \$6,000 per year, 13.9% spent \$6,000-\$24,000 per year, and 4.3% spent over \$24,000 per year on care-related out-of-pocket expenses.

We calculated a rough estimate of aggregate out-of-pocket expenditures by using the midpoint of the ranges and a top code of \$3,000 for the top category of expenditures. In total, Canadian caregivers spent approximately \$1,049,600 per month on care-related out-of-pocket expenditures in 2007, or almost \$12.6 million annually.

Because information on out-of-pocket expenses was more detailed in the HCIC survey and the care receivers had high care needs, we expected to see higher levels of care-related out-of-pocket spending in the HCIC than in the GSS data. For the 71.5% of HCIC caregivers who had out-of-pocket expenditures, spending averaged \$7,599 per year, ranging from \$15 to \$120,000 (Table 11). For these caregivers of high needs care receivers, care-related out-of-pocket spending takes a higher proportion of income for lower-income caregivers, which supports previous findings in the literature.

Among those with annual household incomes of less than \$30,000, annual out-of-pocket spending was \$7,610. Using the mid-point of each income category, care-related out-of-pocket expenses were 50.7% of a \$15,000 income (for caregivers with annual household incomes of less than \$30,000) (Table 11). In comparison, out-of-pocket spending was lower both in absolute and relative terms among those with household incomes between \$30,000 and \$59,999. Spending averaged \$3,516 or 7.8% of annual household income (based on an annual income of \$45,000), and \$9,326 per year or 12.4% for those with household incomes greater than \$60,000 (based on income of \$75,000). Thus those caregivers with less financial means have significant care-related expenses that represent

a larger proportion of their household income compared to those caregivers with higher incomes. The higher absolute out-of-pocket spending among lower-income compared to middle-income caregivers may reflect higher needs among the care receivers of the lower-income caregivers and perhaps lower complementary funding to offset these costs. We will return to the exploration of complementary funding sources in Objective 4.

5.4 Objective 3: Determine the factors that are associated with out-of-pocket expenses including characteristics of the caregiver, the care receiver, the caregiver-care receiver dyad, and the context in which they live.

To address this objective, logistic regression models were run on the GSS data for the total population and men and women separately (Table 12) and on the HCIC data for the entire sample (Table 13) as the distribution of the data did not permit separate equations for men and women. In each equation, variables were included based on the literature review and availability in the data sets to control for characteristics of the caregiver, the care receiver, the caregiver-care receiver dyad, and the caregiving context.

General Social Survey

A number of variables were significant predictors of out-of-pocket spending and, where variables were significant in more than one equation, both the direction and magnitude of effect were consistent. However, the models did not fit the data well by the goodness of fit statistic (Archer & Lemeshow, 2006), indicating that other variables and/or better measures of the variables, not available in the data, are relevant in explaining out-of-pocket spending in the GSS.

Caregiver characteristics. Only four of the variables representing caregiver characteristics were statistically significant in more than one equation: caregiver's age, education, employment status, and level of stress. Being a caregiver aged 65 or older was associated with a reduction in the odds of out-of-pocket spending of 28% for the total population and 50% for men (Table 12). Caregivers with a secondary school or less education were less likely to spend out-of-pocket; those with less than a high school education were 40% less likely and those with a high school education were 23% less likely to report out-of-pocket expenses compared to caregivers with post-secondary degrees or diplomas. Women with less than a high school education were 50% less likely and those with a high school education were 27% less likely to spend out of pocket than female caregivers with post-secondary degrees and diplomas. In all three equations, retired caregivers were more likely to have spent out-of-pocket compared to employed caregivers. Overall, retired caregivers were 44% more likely to have incurred out-of-pocket expenses; retired female and retired male caregivers were 31% and 74% more likely to

have spent out-of-pocket, respectively. Finally, experiencing stress sometimes, often or always compared to never experiencing stress, was consistently associated with out-of-pocket spending. For the overall sample, those reporting stress sometimes were 1.4 times more likely, those reporting stress often were 2.3 times more likely and those reporting stress always were 2.5 times more likely to report out-of-pocket expenses than those who reported they never experience stress. The results were consistent for both women and men: women were more likely to report spending out-of-pocket if they reported stress sometimes, often or always, as were men who reported stress often or always.

Care receiver characteristics. Both age of the care receiver and the type of illness/disability were associated with out-of-pocket spending. Overall, if the care receiver was aged 65 or older, the caregiver was 65% less likely to have spent out-of-pocket than if the care receiver was under 20 years of age (Table 12). Similarly, female caregivers were 68% less likely to have spent out of pocket if the care receiver was 65 or older than if the care receiver was under 20 years old. Across all three equations, caregivers were more likely to have spent out-of-pocket if the care receiver had a combination of physical and mental health problems (1.7 times overall, 1.6 times for women, 2.1 times for men) compared to caregivers who provided care to care receivers with only physical health problems. In both the equation for the total sample and for female caregivers, the caregiver was less likely to incur out-of-pocket expenses if the care receiver had a condition other than physical or mental health problems; however, we do not know what kinds of care situations fell into this “other” category.

Caregiver-care receiver dyad characteristics. Both the proximity of the caregiver to the care receiver and the relationship between the caregiver and the care receiver were strongly associated with out-of-pocket spending. Caregivers who lived in the same area as the care receiver were less likely to report spending out-of-pocket (25% less overall, 32% less for female caregivers) compared to co-resident caregivers; whereas those who lived less than half a day away were more likely to report spending out-of-pocket (1.5 times more overall, 1.9 times more for male caregivers) as were those who lived more than half a day away (roughly 2.5 times more in all three equations) (Table 12). Overall, caregivers were less likely to report spending out-of-pocket if the care receiver was a sibling, an uncle or aunt, another relative, or a friend or neighbour (42%, 48%, 56% and 69% less, respectively) than if the care receiver was the spouse/partner of the caregiver. For women, out-of-pocket spending was 56% less likely if the care receiver was a friend or neighbor; for men, out-of pocket spending was significantly less likely if the care receiver was a parent, a sibling, an uncle or aunt, another relative or a friend or neighbour, compared to being the spouse/partner of the caregiver.

Caregiving context. Among the contextual characteristics, only the variables controlling for complementary sources of funding were significant, and they were significant across the three equations. Overall, if the caregiver received tax benefits for care expenses, gifts from the care receiver, or financial support from family or friends, the caregiver was more likely to have had care-related out-of-pocket expenses (by 2.4 times, 1.3 times, and 2.3 times, respectively) (Table 12). The magnitude of the effect of tax benefits varied in the equations for female and male caregivers. Women were 3 times more likely and men 1.7 times more likely to report spending out-of-pocket if they received tax benefits than if they did not.

HCIC Survey

Although the model for predictors of out-of-pocket spending fit the HCIC data well (Table 13), fewer variables were significant than in the model using the GSS data (Table 12). Although few variables were significant, in all cases the direction of effect of those that were significant was the same as in the GSS model. Significant factors were either characteristics of the caregiver or of the caregiving context; no characteristics of the care receiver or the caregiver-care receiver dyad were significant in the models estimated with the HCIC data.

Caregiver characteristics. The caregiver's level of education and health status were significantly associated with out-of-pocket spending. Caregivers with a secondary school education were 63% less likely to spend out-of-pocket than those with post-secondary degrees or diplomas (Table 13). Caregivers who reported their health as very good were 77% less likely and those who reported their health as fair or poor were 79% less likely than those reporting excellent health to spend out-of-pocket. In addition, caregivers were 2.5 times more likely to incur out-of-pocket expenses if they reported experiencing daily limitations due to health, compared to caregivers who did not report such limitations.

Caregiving context. Two of the three complementary sources of funding were associated with out-of-pocket spending. Caregivers who received financial support from private sources were almost three times more likely to have spent out-of-pocket than those who did not (Table 13). Caregivers who received financial support from family or friends were also nearly three times more likely than those who did not to have care-related out-of-pocket expenditures.

5.5 Objective 4: Explore sources of funding that could help off-set some of the out-of-pocket costs of caregiving.

Most GSS respondents who reported being caregivers received no financial supports that could help defray some of their out-of-pocket expenses. Yet nearly 18% of GSS caregivers received gifts from the care receiver. The proportions that received supports from other

sources were much lower: 3.9% from government programs, 5.0% from tax benefits, and 4.7% from family or friends (Table 5).

However, caregivers who received such complementary sources of financial support were much more likely to make out-of-pocket expenditures than those who did not (Table 14) suggesting that caregivers with the greatest demands do what is required to meet care receivers' needs. For example, 21.0% of caregivers who had care-related expenditures or 254,419 Canadians aged 45 and older received gifts from care receivers, acknowledging that care receivers contribute where possible to their own care-related expenses. Some caregivers (8.0%) received financial support from family members or friends, perhaps those at a distance who contribute financially to the purchase of supports for care receivers rather than providing hands on care. Only 10% of caregivers who incurred out-of-pocket expenses, or over 116,000 Canadians aged 45 and older, received tax benefits for care expenses.

Not surprisingly, among the HCIC caregivers of care receivers who had high care needs, those respondents who had care-related expenses were significantly more likely to receive financial support from private sources, and family or friends than those who did not have care-related expenses: 27% received support from private sources, and 65% received support from family or friends (Table 14).

5.6 Objective 5: Examine social and economic consequences associated with caregivers' out-of-pocket expenditures.

To address this objective, logistic regression models were run on the GSS data for the total population and men and women separately (Table 15). Similar equations were not run on the HCIC data, due to the high proportion of respondents who reported experiencing consequences of caregiving.

General Social Survey

Logistic regression estimates of the effect of out-of-pocket spending on the consequences of caregiving (reporting one or more of reducing time in social activities, cancelling holiday plans, postponing plans to enroll in an educational or training program, turning down a job offer or promotion or moving in with the care receiver), while controlling for caregiver, care receiver, dyad, and other characteristics are reported in Table 15 for the entire sample and for male and female caregivers separately. The models fit the data well, and where variables were significant in more than one equation, the direction and magnitude of effect were consistent.

Caregiver characteristics. Women who were caregivers were 1.5 times more likely to experience caregiving consequences than men (Table 15). Caregivers' level of education, marital status and stress levels were significant predictors of experiencing caregiving consequences in more than one equation. Both overall and for women, having less than a high school education was associated with lower odds of experiencing consequences of caregiving, compared to having a post-secondary degree or diploma (26% and 33% less, respectively). Reporting stress at least sometimes was associated with increased likelihood of experiencing consequences of caregiving, with those caregivers who reported always experiencing stress between 2.2 and 3.8 times more likely to experience caregiving consequences. Marital status also mattered; caregivers who were not married or in a common-law relationship were 37% to 45% more likely to experience social and economic consequences of caregiving, reflecting the supportiveness of having a partner.

Care receiver characteristics. The only characteristic of care receivers that was significant in more than one equation was reason for needing care. If the care receiver required care for a combination of physical and mental health problems, the caregiver was 56% to 68% more likely to experience social and economic consequences, depending on the equation (Table 15).

Caregiver-care receiver dyad characteristics. Caregivers were less likely to experience consequences of care if they did not co-reside with the care receiver. This result was consistent across equations and the odds ratios tended to decline as distance increased. For example, in the equation for the total sample, the caregiver was 37% less likely to report experiencing social and economic consequences of caregiving if they lived in the same area as the care receiver, 43% less likely if residing less than half a day away, and 59% less likely if residing more than half a day away compared to co-residing with the care receiver (Table 15). The relationship between the caregiver and care receiver mattered also. Caregivers were less likely to report consequences of caregiving if the care receiver were an ex-spouse or partner, a child, a sibling an uncle or aunt, another relative, or a friend or neighbour than if the care receiver were a spouse or partner (between 52% and 84% less likely, depending on the relationship and the equation).

Caregiving context. Caregivers who received complementary funding from government programs, tax benefits for care expenses, gifts from the care receiver, or financial support from family or friends were between 41% and almost 3 times more likely to report experiencing consequences of caregiving than if they did not receive the funding support (Table 15) indicating that spending out-of-pocket may be facilitated by receipt of complementary sources of funding. In both the equation for the total sample and for

women, caregivers in rural locations were 19% and 25%, respectively, less likely to report social and economic consequences of caregiving.

In the most dramatic result, out-of-pocket spending was significantly associated with experiencing caregiving consequences in all three equations. Caregivers who had out-of-pocket expenses were roughly six times more likely to experience social and economic consequences of caregiving, all else equal.

6. Summary and Implications

This research project utilized nationally representative data from the 2007 General Social Survey and data from the Hidden Costs/Invisible Contributions survey of caregivers to care receivers with high needs to examine the prevalence, correlates, and consequences of care-related out-of-pocket spending. To the best of our knowledge, this research project is the first to focus on providing national estimates of the expenses associated with providing unpaid caregiving to family members or friends with long-term disabilities or health problems.

We find that care-related out-of-pocket spending is common among caregivers. Just over 35% of Canadian caregivers—over 1.2 million Canadians—incurred out-of-pocket expenses in 2007. Most of these caregivers (about 78%) spent less than \$6,000 per year out-of-pocket, but a minority (3%) spent more than \$24,000 per year. Collectively, their spending amounted to almost \$12.6 million dollars annually. Among caregiver of high needs care receivers, just over 71% had care-related out-of-pocket expenses, and they spent \$7,599 per year on average. And among these caregivers, those with lower incomes spent proportionately more money on care-related expenditures than those with higher incomes.

A number of factors were associated with out-of-pocket spending. Risk factors, those factors associated with an increase in the odds of out-of-pocket spending, were: if the caregiver is retired, if the caregiver reports stress sometimes, always or often; if the care receiver has a combination of physical and mental health problems, and if the caregiver lives outside the same area as the care receiver. Out-of-pocket spending was also associated with caregivers' receipt of complementary funding from tax benefits for care expenses, gifts from the care receiver, or financial support from family or friends. These factors were observed for both women and men.

Of note, very few of the above factors are within the caregiver's control, once the individual becomes a caregiver. More promising is the role of complementary sources of funding. Although support from government programs was not significant, receipt of financial

support in the form of tax benefits was, as were gifts from the care receiver, and financial support from family and friends. These sources of financial supports increased the odds of spending out-of-pocket by off-setting some of the costs incurred by caregivers. These financial supports do not benefit caregivers personally, rather they are used to ensure care receivers' needs are met.

The relationship between stress and out-of-pocket expenses warrants further investigation. Higher levels of stress were associated with an increased likelihood of out-of-pocket spending all else equal, but because the data are cross sectional, we don't know if it is stress that is leading to out-of-pocket spending or vice versa. Care-related out-of-pocket spending can lead to increasing levels of stress due to financial pressures, but it could also be the case that if stress is due to a complex care situation, spending on care-related supports may be incurred as a way to mitigate stress. We also lack information as to the underlying causes of stress for these caregivers, and financial worries maybe one such source of stress. Longitudinal data on these factors would allow further investigation of this observed relationship.

Protective factors, factors associated with a decrease in the odds of out-of-pocket spending, were: caregiver aged 65 or older, the caregiver having a secondary school level of education or less, the care receiver being age 65 or older, the care receiver having something other than a physical or mental health problem, the caregiver living in same area as the care receiver, and relationship (sibling, uncle or aunt, another relative, friends and others). Caregiver age and relationship were also important factors for men but not for women, and education, care receiver age, care receiver's reason for care, and living in the same area as the care receiver were important factors for women, but not for men.

Being a caregiver aged 65 or older was not significantly associated with out-of-pocket spending for women, but it reduced the odds of out-of-pocket spending by 50% for men (and by 28% overall). It may be that prior to retirement men spend more to get the assistance they need because they have more income to spend, whereas women do more of the work themselves. Post-retirement men may reduce their expenditures more than women in response to the drop in their income and increase in their "free" time.

The reduction in the odds of out-of-pocket spending associated with lower levels of education is consistent with the association between lower levels of education and lower incomes and, thus, less ability to spend. Income was controlled for in these equations, but was not significant. Because women's incomes continue to be lower than men's, on average, it is not surprising that this result was significant in the equation for women caregivers.

More information on the health condition of the care receiver is needed to better understand the relationship between this factor and out-of-pocket spending. The odds of out-of-pocket spending were lowered if the care receiver had something other than a physical or mental health problem and increased if the care receiver had some combination of physical and mental health problems, as opposed to having only physical health problems. Further investigation is needed to determine why the combination of physical and mental health conditions increases out-of-pocket spending. Clearly, different health conditions require different supports, and the results here mirror the lack of understanding of mental health issues in general and what is needed for support.

Caregivers who lived in the same area as the care receiver were less likely to spend out-of-pocket than those who co-resided. It may be that the care receivers of these caregivers had lower levels of need than co-resident care receivers. Caregivers who lived at greater distances were significantly more likely to spend out-of-pocket and are probably spending more on commuting, or are sending money for support services because they are too far away to provide hands-on care. More detailed national data on care-related expenditures would help to clarify this relationship.

Multivariate analyses of the social and economic consequences of caregiving reinforced the importance of care-related out-of-pocket spending. Out-of-pocket spending had the largest effect on the odds of experiencing social and economic consequences of caregiving: caregivers who reported out-of-pocket spending were 5.8 times more likely than those who did not to experience social and economic consequences of caregiving, all else constant. Thus, spending out-of-pocket is an important predictor of caregiving consequences even when the effects of other variables are controlled. This association is not surprising as most of the consequences have a financial element to them. If a caregiver is incurring out-of-pocket expenses, less money may be available for social activities, holiday plans or enrolment in an educational or training program, and it may be more likely that a caregiver moves in with the care receiver to save money.

Further research establishing the relationship of out-of-pocket expenses with consequences of caregiving is warranted. It is noteworthy that among the HCIC caregivers – caregivers to care receivers with high needs – most experienced caregiving consequences. Research that delves into the difference between out-of-pocket spending in low and high care needs situations would be useful in documenting needs for external support. In addition, work on how people come to define consequences is important. Do some caregivers experience more community support, and as a result, report fewer consequences? We found that living in a rural area was associated with lower odds of reporting having experienced consequences of caregiving, and more community support –

or perhaps increased levels of stoicism among rural as opposed to urban caregivers – may explain the relationship.

The national data do not contain enough detail to calculate more than a rough aggregate estimate of care-related out-of-pocket spending, yet we find evidence of substantial spending on these expenses. Aggregate out-of-pocket spending by Canadian caregivers in 2007 amounted to almost \$12.6 million. The HCIC data revealed average expenditures of \$7,599 per year. Importantly, both estimates are likely lower bounds, as both are based on recall data, and data collected via diaries show higher levels of spending (Evercare, 2007).

This spending can play an important role in ensuring the social inclusion of care receivers, but may have negative consequences for the social inclusion of their caregivers. More detailed care-related expenditure data at the national level are needed to more fully understand the range of care-related out-of-pocket expenses and the consequences of this spending for Canadians.

7. References

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8. Appendices

Table 1: Operationalization of Variables

Variable	Description of Variable	
	General Social Survey	HCIC ²
Dependent variables: Objectives 1-4		
Incidence of out-of-pocket expenses	A dichotomous variable indicating whether the respondent incurred care-related out-of-pocket expenses within the past 12 months (yes/no).	A dichotomous variable indicating whether the respondent incurred care-related out-of-pocket expenses within the past 12 months.= (yes/no).
Amount of out-of-pocket spending	An ordinal variable with three categories for average monthly amount of care-related out-of-pocket expenses: 1. Less than \$500 2. \$500-\$2000 3. More than \$2000	A continuous variable measuring the annual amount of out-of-pocket spending.
Dependent variable: Objective 5		
Impact of caregiving on the caregiver	A dichotomous variable indicating whether the caregiver experienced one or more of the following other consequences of caregiving in the past 12 months: <ul style="list-style-type: none"> • Reduced social activities • Cancelled holiday plans • Postponed enrolment in an educational or training program • Turned down a job offer or promotion • Moved in with the care receiver. 	A set of dichotomous variables, each indicating whether the caregiver experienced one or more of the following other consequences of caregiving: <ul style="list-style-type: none"> • Employment • Economic security • Health • Social
Caregiver Characteristics		
Sex	A dummy variable indicating sex of the caregiver: 1. Male 2. Female	A dummy variable indicating sex of the caregiver: 1. Male 2. Female
Age	A dummy variable indicating age of the caregiver: 1. Age 45-64 years 2. 65 and above	A dummy variable indicating age of the caregiver: 1. Less than 65 years 2. 65 and above

Table 1: Operationalization of Variables, continued

Variable	Description of Variable	
	General Social Survey	HCIC ²
Marital status	A dummy variable indicating marital status of the caregiver: 1. Married or living common law 2. Separated, divorced, widowed or single	A dummy variable indicating marital status of the caregiver: 1. Married or living common law 2. Separated, divorced, widowed or single
Place of birth	A dummy variable indicating where the caregiver was born: 1. Born in Canada 2. Not born in Canada	A dummy variable indicating where the caregiver was born: 1. Born in Canada 2. Not born in Canada
Education	A set of dummy variable indicating highest level of education attained by the caregiver : 1. Less than secondary education 2. Secondary school 3. Some post-secondary 4. Post-secondary degree or diploma	A set of dummy variable indicating the highest level of education attained by the caregiver : 1. Less than secondary education 2. Secondary school 3. Some post-secondary 4. Post-secondary degree or diploma
Employment status	A set of dummy variables indicating the employment status of the caregiver : 1. Labour force participant 2. Unemployed 3. Retired 4. Long-term illness	A set of dummy variables indicating the employment status of the caregiver : 1. Labour force participant 2. Unemployed 3. Retired 4. Long-term illness
Source of income	A set of dummy variables indicating the source of income received : 1. Wages and salaries 2. Self-employment 3. Dividends and interest 4. Employment Insurance, Worker's Compensation, or provincial social assistance 5. Quebec or Canada Pension Plan 6. Retirement pensions or annuities 7. Old Age Security, Guaranteed Income Supplement 8. Child Tax Benefit 9. Child support or alimony 10. Other	A set of dummy variables indicating the source of income received : 1. Wages and salaries 2. Self-employment 3. Dividends and interest 4. Employment Insurance, Worker's Compensation, or provincial social assistance 5. Quebec or Canada Pension Plan 6. Retirement pensions or annuities 7. Old Age Security, Guaranteed Income Supplement 8. Child Tax Benefit 9. Child support or alimony 10. Other

Table 1: Operationalization of Variables, continued

Variable	Description of Variable	
	General Social Survey	HCIC ²
Annual household income ³	An ordinal variable indicating annual household income : 1. No income or loss 2. Less than \$5,000 3. \$5,000-\$9,999 4. \$10,000-\$14,999 5. \$15,000-\$19,999 6. \$20,000-\$29,999 7. \$30,000-\$39,999 8. \$40,000-\$49,999 9. \$50,000-\$59,999 10. \$60,000-\$79,999 11. \$80,000-\$99,999 12. \$100,000-\$119,999 13. \$120,000 or more	An ordinal variable indicating annual household income : 1. No income or loss 2. Less than \$5,000 3. \$5,000-\$9,999 4. \$10,000-\$14,999 5. \$15,000-\$19,999 6. \$20,000-\$29,999 7. \$30,000-\$39,999 8. \$40,000-\$49,999 9. \$50,000-\$59,999 10. \$60,000-\$79,999 11. \$80,000-\$99,999 12. \$100,000-\$119,999 13. \$120,000 or more
Annual personal income	An ordinal variable indicating annual personal income: 1. No income or loss 2. Less than \$5,000 3. \$5,000-\$9,999 4. \$10,000-\$14,999 5. \$15,000-\$19,999 6. \$20,000-\$29,999 7. \$30,000-\$39,999 8. \$40,000-\$49,999 9. \$50,000-\$59,999 10. \$60,000-\$79,999 11. \$80,000-\$99,999 12. \$100,000-or more	Not available

³ Due to the high proportion of missing values, for the multivariate analyses, annual household income was recoded into a set of 3 dummy variables: 1. Less than \$50,000; 2. \$50,000 or more; and 3. Missing. Use of this coding allowed the retention of respondents with missing values for income in the multivariate analyses.

Table 1: Operationalization of Variables, continued

Variable	Description of Variable	
	General Social Survey	HCIC ²
Health status	A set of dummy variables indicating the self-reported health status of the caregiver: 1. Excellent 2. Very good 3. Good 4. Fair 5. Poor	A set of dummy variables indicating the self-reported health status of the caregiver: 1. Excellent 2. Very good 3. Good 4. Fair 5. Poor
Level of stress	A set of dummy variables indicating the level of self-reported stress of the caregiver: 1. Never 2. Rarely 3. Sometimes 4. Often 5. Always	A set of dummy variables indicating the level of self-reported stress of the caregiver: 1. Never 2. Rarely 3. Sometimes 4. Often 5. Always
Daily limitations due to health	A set of dummy variable indicating whether the caregiver had daily limitations due to health: 1. Yes, often 2. Yes, sometimes 3. No	A set of dummy variable indicating whether the caregiver had daily limitations due to health: 1. Yes, often 2. Yes, sometimes 3. No
Care Receiver Characteristics		
Sex	A dummy variable indicating sex of the care receiver: 1. Male 2. Female	A dummy variable indicating sex of the care receiver: 1. Male 2. Female
Age	A set of dummy variables indicating the age of the care receiver: 1. Less than 20 years 2. 20 to less than 45 years 3. 45 to less than 65 years 4. 65 and above 5. Deceased	A set of dummy variables indicating the age of the care receiver: 1. Less than 20 years 2. 20 to less than 45 years 3. 45 to less than 65 years 4. 65 and above 5. Deceased

Table 1: Operationalization of Variables, continued

Variable	Description of Variable	
	General Social Survey	HCIC ²
Care Receiver Characteristics		
Reason for care	A set of dummy variables indicating the type of health problem the care receiver needed assistance with: <ol style="list-style-type: none"> 1. Physical health problem 2. Mental health problem 3. Both physical and mental health problems 4. Other health problems 	A set of dummy variables indicating the type of health problem the care receiver needed assistance with: <ol style="list-style-type: none"> 1. Physical health problem 2. Mental health problem 3. Both physical and mental health problems
Caregiver—Care Receiver Dyad Characteristics		
Relationship to caregiver	A set of dummy variables indicating the relationship of the care receiver to the caregiver: <ol style="list-style-type: none"> 1. Spouse/partner 2. Ex-spouse/partner 3. Parent or parent-in-law 4. Child 5. Sibling 6. Uncle or aunt 7. Grandparent 8. Other relative 9. Friend or neighbour 	A set of dummy variables indicating the relationship of the care receiver to the caregiver: <ol style="list-style-type: none"> 1. Spouse/partner 2. Ex-spouse/partner 3. Parent or parent-in-law 4. Child 5. Sibling 6. Uncle or aunt 7. Grandparent 8. Other relative 9. Friend or neighbour
Proximity to care receiver	A set of dummy variables indicating the proximity of the caregiver to the care receiver: <ol style="list-style-type: none"> 1. Co-residence 2. Same area 3. Less than 1/2 day drive 4. More than 1/2 day drive 	A set of dummy variables indicating the relationship of the care receiver to the caregiver: <ol style="list-style-type: none"> 1. Co-residence 2. Same area 3. Less than 1/2 day drive 4. More than 1/2 day drive

Table 1: Operationalization of Variables, continued

Variable	Description of Variable	
	General Social Survey	HCIC ²
Caregiving Context		
Complementary sources of financial support	A set of dummy variables, each indicating whether the caregiver received financial support from the source: 1. Government programs 2. Tax benefits for care expenses 3. Gifts from care receiver 4. Financial support from family or friends	A set of dummy variables, each indicating whether the caregiver received financial support from the source 1. Public 2. Private 3. Financial support from family or friends
Urban/rural indicator	A dummy variable indicating the location of the caregiver: 1. Urban 2. Rural 3. Prince Edward Island	Not available
Ever provided end-of-life care	A dummy variable indicating whether the respondent had ever provided end-of-life care (yes/no)	Not available
Currently providing end-of-life care	A dummy variable indicating whether the respondent was currently providing end-of-life care (yes/no).	Not available
Years provided support	A continuous variable indicating the number of years the caregiver has provided support to the care receiver.	A continuous variable indicating the number of years the caregiver has provided support to the care receiver.
Number of people caregiver has ever supported	A continuous variable for the number of people the caregiver has supported for 6 months or longer.	A continuous variable for the number of people the caregiver has supported for 6 months or longer.

Table 2: Caregiver Characteristics

Variables	General Social Survey		HCIC	
	Population N	Percent	Sample N	Percent
Sex				
Male	1,538,892	43.0	50	19.2
Female	2,038,781	57.0	210	80.8
Total	3,577,673	100.0	260	100.0
Age				
Less than 65 years	2,781,207	77.7	234	90.0
65 and above	796,466	22.3	26	10.0
Total	3,577,673	100.0	260	100.0
Marital status				
Married/living common law	2,702,756	75.6	227	87.3
Separated / divorced / widowed / single	873,717	24.4	33	12.7
Total	3,576,473	100.0	260	100.0
Born in Canada				
Yes	1,412,766	71.2	232	89.2
No	571,112	28.8	28	10.8
Total	3,577,673	100.0	260	100.0
Highest level of education				
Less than secondary	571,735	16.1	21	8.1
Secondary school	593,591	16.7	59	22.8
Some post-secondary	431,481	12.2	58	22.4
Post-secondary degree or diploma	1,951,545	55.0	121	46.7
Total	3,548,352	100.0	259	100.0

Table 2: Caregiver Characteristics, continued

Variables	General Social Survey		HCIC	
	Population N	Percent	Sample N	Percent
Employment status				
In labour force	2,113,007	59.1	131	50.4
Unemployed	324,444	9.1	39	15.0
Retired	1,050,740	29.4	83	31.9
Long-term illness	86,825	2.4	7	2.7
Total	3,575,017	100.0	260	100.0
Source of income				
Wages and salaries	1,637,167	45.8	34	13.1
Self-employment	431,004	12.1	7	2.7
Dividends and interest	154,422	4.3	9	3.5
EI/WC/or provincial social assistance	88,253	2.5	14	5.4
Canada/Quebec pension Plan	272,772	7.6	31	11.9
Retirement pensions or annuities	560,366	15.7	70	26.9
Old Age Security/Guaranteed Income Supplement	145,803	4.1	27	10.4
Child Tax Benefit	8,667	0.2	35	13.5
Child support or alimony	8,701	0.2	2	0.8
Other	78,457	2.2	31	11.9
Missing	192,062	5.4	0	0
Total	3,577,673	100.1	260	100.0

Table 2: Caregiver Characteristics, continued

Variables	General Social Survey		HCIC	
	Population N	Percent	Sample N	Percent
Household income				
No income or loss	5,744	0.2	-	-
Less than \$5,000	3,100	0.1	2	0.8
\$5,000 to \$9,999	19,331	0.5	3	1.2
\$10,000 to \$14,999	74,087	2.1	6	2.3
\$15,000 to \$19,999	103,821	2.9	1	0.4
\$20,000 to \$29,999	237,376	6.6	14	5.4
\$30,000 to \$39,999	287,256	8.0	25	9.6
\$40,000 to \$49,999	269,226	7.5	21	8.1
\$50,000 to \$59,999	318,899	8.9	26	10.0
\$60,000 to \$79,999	454,923	12.7	54	20.8
\$80,000 to \$99,999	382,103	10.7	23	8.9
\$100,000 to \$119,999	793,997	22.2	26	10.0
\$120,000 +	-	-	19	7.3
Missing	627,810	17.5	40	15.4
Total	3,577,673	100.0	260	100.0

Table 2: Caregiver Characteristics, continued

Variables	General Social Survey		HCIC	
	Population N	Percent	Sample N	Percent
Personal income (GSS)				
No income or loss	113,664	3.2	-	-
Less than \$5,000	61,582	1.7	-	-
\$5,000 to \$9,999	124,481	3.5	-	-
\$10,000 to \$14,999	194,120	5.4	-	-
\$15,000 to \$19,999	177,373	5.0	-	-
\$20,000 to \$29,999	382,134	10.7	-	-
\$30,000 to \$39,999	411,574	11.5	-	-
\$40,000 to \$49,999	371,117	10.4	-	-
\$50,000 to \$59,999	300,517	8.4	-	-
\$60,000 to \$79,999	395,546	11.1	-	-
\$80,000 to \$99,999	118,097	5.3	-	-
\$100,000 or more	277,861	7.8	-	-
Missing	579,607	16.2	-	-
Total	3,577,673	100.0	-	-
Daily limitations due to health				
Yes, often	664,392	18.6	9	3.5
Yes, sometimes	582,492	16.3	22	8.5
No	2,329,205	65.1	168	64.6
Missing	-	-	61	3.5
Total	3,576,088	100.0	260	100.0

Table 2: Caregiver Characteristics, continued

Variables	General Social Survey		HCIC	
	Population N	Percent	Sample N	Percent
Health status				
Excellent	900,690	25.2	33	12.7
Very good	1,308,196	36.6	72	27.7
Good	959,298	26.8	98	37.7
Fair	314,301	8.8	44	16.9
Poor	91,388	2.6	13	5.0
Total	3,573,874	100.0	260	100.0
Level of stress				
Never	359,142	10.1	6	2.3
Rarely	739,397	20.8	30	11.6
Sometimes	1,436,504	40.4	98	37.8
Often	857,990	24.1	85	32.8
Always	166,106	4.7	40	15.4
Total	3,559,140	100.0	259	100.0

Table 3: Care Receiver Characteristics

Variables	General Social Survey		HCIC	
	Population N	Percent	Sample N	Percent
Sex				
Male	1,189,184	33.3	193	74.2
Female	2,383,138	66.7	67	25.8
Total	3,572,322	100.0	260	100.0
Age				
Less than 20	50,151	1.4	3	1.2
20 to less than 45	229,045	6.4	82	31.5
45 to less than 65	640,018	17.9	171	65.8
65 and above	2,418,161	67.6	4	1.5
Deceased, not asked, not stated	240,299	6.7	0	0.0
Total	3,577,673	100.0	260	100.0
Reason for care				
Physical health problem	2,465,648	69.1	101	38.9
Mental health problem	242,470	6.8	8	3.1
Both physical and mental problems	766,608	21.5	149	57.3
Something else	94,989	2.7	2	0.8
Total	3,569,716	100.0	260	100.0

Table 4: Caregiver—Care Receiver Dyad Characteristics

Variables	General Social Survey		HCIC	
	Population N	Percent	Sample N	Percent
Proximity to care receiver				
Co-residence	770,877	21.6	219	84.2
Same Area	2,255,012	63.2	25	9.6
Less than 1/2 day	380,938	10.7	15	5.8
More than 1/2 day	159,773	4.5	1	0.4
Total	3,566,601	100.0	260	100.0
Relationship to caregiver				
Spouse/partner	375,640	10.6	187	71.9
Ex-spouse/partner	10,260	0.3	0	0.0
Parent (including in-laws)	1,641,600	46.3	29	11.2
Child	210,180	5.9	0	0.0
Sibling	297,120	8.4	16	6.2
Uncle/Aunt	106,720	3.0	0	0.0
Grandparent	11,610	0.3	2	0.8
Other relative	45,880	1.3	11	4.2
Friend or neighbor	843,910	23.8	13	5.0
Missing	34,763	0	2	0.8
Total	3,577,673	100.0	260	100.0

Table 5: Caregiving Context Characteristics

Variables	General Social Survey		HCIC	
	Population N	Percent	Sample N	Percent
Government programs (GSS)/public programs (HCIC)				
Yes	136,338	3.9	87	33.5
No	3,397,873	96.1	173	66.5
Total	3,534,212	100.0	260	100.0
Tax benefits for care expenses (GSS)				
Yes	176,923	5.0	-	-
No	3,397,873	95.0	-	-
Total	3,534,212	100.0	-	-
Gifts from care receiver (GSS)				
Yes	631,783	17.9	-	-
No	2,902,423	82.1	-	-
Total	3,534,206	100.0	-	-
Support from private sources (HCIC)				
Yes	-	-	58	22.3
No	-	-	202	77.7
Total	-	-	260	100.0
Support from family or friends				
Yes	165,153	4.7	148	56.9
No	3,376,972	95.3	112	43.1
Total	3,542,125	100.0	260	100.0

Table 5: Caregiving Context Characteristics, continued

Variables	General Social Survey		HCIC	
	Population N	Percent	Sample N	Percent
Rural/Urban Indicator (GSS)				
Urban	2,832,448	79.2	-	-
Rural	729,741	20.4	-	-
Prince Edward Island	15,484	0.4	-	-
Total	3,577,673	100.0	-	-
Ever provided end-of-life care (GSS)				
Yes	1,250,915	35.0	-	-
No	2,304,811	64.4	-	-
Missing	21,948	0.6	-	-
Total	3,577,673	100.0	-	-
Currently providing end-of-life care (GSS)				
Yes	87,862	2.5	-	-
No	1,159,933	32.4	-	-
Missing	2,329,879	65.1	-	-
Total	3,577,673	100.0	-	-

Table 6: Other Consequences of Caregiving for the Caregiver (in the past 12 months)

Variables	General Social Survey		HCIC	
	Population N	Percent	Sample N	Percent
Reduced social activities				
Yes	1,284,598	36.3	220	84.6
No	2,255,696	63.7	40	15.4
Total	3,540,294	100.0	260	100.0
Cancelled holiday plans				
Don't make plans	148,309	4.1	-	-
Yes, quite often	194,894	5.5	-	-
Yes, sometimes	278,254	7.8	-	-
Yes, rarely	235,455	6.6	-	-
Yes (HCIC)	-	-	104	40.0
No, never	2,689,583	75.2	156	60.0
Missing	31,179	0.9	-	-
Total	3,577,673	100.1	260	100.0
Postponed enrolment in education or training program				
Yes	174,051	4.9	65	25.0
No	3,369,076	95.1	195	75.0
Total	3,543,127	100.0	260	100.0
Moved in with care receiver				
Yes, saved money	18,802	0.5	-	-
Yes, did not save money	114,971	3.3	-	-
Yes (HCIC)	-	-	2	0.8
No	3,368,639	96.2	258	99.2
Total	3,502,413	100.0	260	100.0

Table 6: Other Consequences of Caregiving for the Caregiver (in the past 12 months), continued

Variables	General Social Survey		HCIC	
	Population N	Percent	Sample N	Percent
Turned down job offer or promotion				
Yes, not important at all (1 on a scale of 1-5)	8,173	0.2	-	-
Yes (2)	9,630	0.3	-	-
Yes, somewhat important (3)	33,661	1.0	-	-
Yes (4)	24,043	0.7	-	-
Yes, very important (5)	32,805	0.9	-	-
Yes (HCIC)	-	-	83	31.9
No	3,426,887	96.9	177	68.1
Total	3,535,200	100.0	260	100.0

Table 7: Prevalence of Out-of-Pocket Costs

Prevalence of Out-of-Pocket Costs	General Social Survey		HCIC	
	Population N	Percent	Sample N	Percent
Yes	1,243,929	35.1	186	71.5
No	2,298,984	64.9	74	28.5
Total	3,542,913	100.0	260	100.1

Table 8: Out-of-Pocket Spending by Caregiver, Care Receiver and Caregiver-Care Receiver Dyad Characteristics, General Social Survey

Variables	Out-of-Pocket Spending				
	Yes		No		X ²
	N	% (95% CI)	N	% (95% CI)	
Caregiver Characteristics					
Sex					5.45
Male	510,818	41.06 (38.61-43.57)	101,451	44.11 (42.31-45.93)	
Female	733,122	58.94 (56.43-61.39)	1,284,833	55.89 (54.07-57.69)	
Total	1,243,929	100.00	2,298,984	100.00	
Age					46.52***
Less than 65 years	1,027,876	82.63 (80.08-84.30)	1,727,689	75.15 (73.60-76.60)	
65 and above	216,054	17.37 (15.67-19.20)	571,295	24.85 (23.40-26.40)	
Total	1,243,929	100.00	2,298,984	100.00	
Marital Status					5.91**
Married/living common law	962,670	77.42 (75.52-79.20)	1,716,106	74.66 (73.21-76.06)	
Separated/divorced/ widowed/single	280,825	22.58 (20.80-24.48)	582,397	25.34 (23.94-26.79)	
Total	1,243,495	100.00	2,298,503	100.00	
Born in Canada					3.77
Yes	468,351	69.15 (65.76-72.35)	934,792	72.29 (69.97-74.49)	
No	208,921	30.85 (27.65-34.24)	358,411	27.71 (25.51-30.03)	
Total	677,272	100.00	1,293,203	100.00	

Table 8: Out-of-Pocket Spending by Caregiver, Care Receiver and Caregiver-Care Receiver Dyad Characteristics, General Social Survey, continued

Variables	Out-of-Pocket Spending				
	Yes		No		X ²
	N	% (95% CI)	N	% (95% CI)	
Highest level or education					57.06***
Less than secondary	153,393	12.42 (10.87-14.15)	414,013	18.07 (16.74-19.48)	
Secondary school	180,581	14.62 (12.94-16.47)	410,102	17.90 (16.57-19.31)	
Some post-secondary	152,094	12.31 (10.79-14.02)	275,802	12.04 (10.91-13.26)	
Post-secondary degree/diploma	749,271	60.65 (58.20-63.05)	1,191,479	52.00 (50.19-53.80)	
Total	1,235,339	100.00	2,291,395	100.00	
Employment status					15.25***
In labor force	766,287	61.62 (59.23-63.96)	1,325,855	57.73 (55.96-59.47)	
Unemployed or not working	120,416	9.68 (8.35-11.20)	202,576	8.82 (7.86-9.88)	
Retired	330,841	26.60 (24.54-28.78)	708,146	30.83 (29.26-32.46)	
Long-term illness	25,990	2.09 (1.51-2.89)	60,146	2.62 (2.11-3.25)	
Total	1,243,534	100.00	2,296,724	100.00	

Table 8: Out-of-Pocket Spending by Caregiver, Care Receiver and Caregiver-Care Receiver Dyad Characteristics, General Social Survey, continued

Variables	Out-of-Pocket Spending				
	Yes		No		X ²
	N	% (95% CI)	N	% (95% CI)	
Caregiver Characteristics					
Source of income					24.43***
No income	25,394	2.09 (1.52-2.86)	73,122	3.25 (2.64-4.01)	
Employment (wages, salaries)	592,848	48.68 (46.18-51.19)	1,036,035	46.11 (44.29-47.94)	
Self-employment	163,614	13.44 (11.74-15.33)	266,562	11.86 (10.69-13.15)	
Investments	62,332	5.12 (4.12-6.34)	91,448	4.07 (3.45-4.80)	
RRIFs	12,210	1.00 (0.65-1.55)	36,468	1.62 (1.25-2.10)	
Government transfers	32,003	2.63 (2.01-3.42)	72,631	3.23 (2.65-3.94)	
Pensions	303,181	24.90 (22.87-27.04)	618,887	27.54 (26.01-29.13)	
Other income	26,207	2.15 (1.55-2.99)	51,812	2.31 (1.84-2.88)	
Total	1,217,789	100.00	2,246,964	100.00	

Table 8: Out-of-Pocket Spending by Caregiver, Care Receiver and Caregiver-Care Receiver Dyad Characteristics, General Social Survey, continued

Variables	Out-of-Pocket Spending				
	Yes		No		X ²
	N	% (95% CI)	N	% (95% CI)	
Annual household income					28.41*
No income	30,546	2.46 (1.83-3.29)	82,509	3.59 (2.96-4.35)	
Less than \$5,000	17,212	1.38 (0.94-2.04)	43,474	1.89 (1.46-2.44)	
\$5,000-\$9,999	42,956	3.45 (2.70-4.41)	81,525	3.55 (2.97-4.23)	
\$10,000-\$14,999	63,558	5.11 (4.20-6.20)	128,358	5.58 (4.85-6.42)	
\$15,000-\$19,999	55,590	4.47 (3.58-5.57)	120,449	5.24 (4.53-6.05)	
\$20,000-\$29,999	134,150	10.78 (9.39-12.35)	247,984	10.79 (9.73-11.94)	
\$30,000-\$39,999	130,073	10.46 (9.07-12.02)	279,539	12.16 (11.05-13.37)	
\$40,000-\$49,999	145,659	11.71 (10.19-13.43)	224,305	9.76 (8.72-10.90)	
\$50,000-\$59,999	112,568	9.05 (7.67-10.65)	186,979	8.13 (7.18-9.20)	
\$60,000-\$79,999	145,202	11.67 (10.13-13.41)	247,862	10.78 (9.68-11.99)	
\$80,000-\$99,999	68,693	5.52 (4.43-6.87)	119,404	5.19 (4.39-6.14)	
\$100,000 or more	111,182	8.94 (7.53-10.58)	166,101	7.22 (6.31-8.27)	
Missing	186,541	15.00 (13.34-16.81)	370,494	16.12 (14.87-17.44)	
Total	1,243,929	100.00	2,298,984	100.00	

Table 8: Out-of-Pocket Spending by Caregiver, Care Receiver and Caregiver-Care Receiver Dyad Characteristics, General Social Survey, continued

Variables	Out-of-Pocket Spending				
	Yes		No		X ²
	N	% (95% CI)	N	% (95% CI)	
Caregiver Characteristics					
Health Status					6.12
Excellent	306,197	24.66 (22.59-26.85)	586,764	25.54 (23.98-27.17)	
Very good	437,473	35.23 (32.91-37.62)	860,271	37.45 (35.72-39.21)	
Good	350,609	28.23 (26.03-30.55)	569,930	25.98 (24.45-27.58)	
Fair	112,967	9.10 (7.80-10.58)	196,678	8.56 (7.66-9.56)	
Poor	34,580	2.78 (2.06-3.75)	56,645	2.47 (1.96-3.10)	
Total	1,241,826	100.00	2,297,288	100.00	
Level of stress					211.44***
Never	80,399	6.50 (5.38-7.84)	272,187	11.89 (10.77-13.11)	
Rarely	195,973	15.85 (14.16-17.71)	537,387	23.48 (22.02-25.01)	
Sometimes	477,013	38.59 (36.20-41.03)	948,631	41.45 (39.68-43.24)	
Often	399,109	32.29 (29.97-34.69)	450,010	19.66 (18.24-21.17)	
Always	83,616	6.76 (5.66-8.07)	80,313	3.51 (2.89-4.25)	
Total	1,236,109	100.00	2,288,528	100.00	

Table 8: Out-of-Pocket Spending by Caregiver, Care Receiver and Caregiver-Care Receiver Dyad Characteristics, General Social Survey, continued

Variables	Out-of-Pocket Spending				
	Yes		No		X ²
	N	% (95% CI)	N	% (95% CI)	
Daily limitations due to health					6.42*
Yes, often	250,714	20.0 (18.0-22.0)	406,356	18.0 (16.0-19.0)	
Yes, sometimes	203,950	17.0 (15.0-18.0)	370,516	16.0 (15.0-17.0)	
No	789,265	63.0 (61.0-66.0)	1,520,527	66.0 (64.0-68.0)	
Total	1,243,929	100.00	2,297,399	100.00	
Care Receiver Characteristics					
Age					87.01***
Less than 20 years	34,518	3.01 (2.24-4.05)	14,832	0.69 (0.44-1.06)	
22-44	104,811	9.15 (7.83-10.67)	122,229	5.65 (4.86-6.56)	
45-64	236,211	20.62 (18.59-22.81)	397,702	18.38 (17.00-19.85)	
65+	769,917	67.21 (64.75-69.59)	1,628,668	75.28 (73.66-76.84)	
Total	1,145,456	100.00	2,163,431	100.00	

Table 8: Out-of-Pocket Spending by Caregiver, Care Receiver and Caregiver-Care Receiver Dyad Characteristics, General Social Survey, continued

Variables	Out-of-Pocket Spending				
	Yes		No		X ²
	N	N	N	N	
Care Receiver Characteristics					
Sex					0.60
Male	421,126	33.85 (31.55-36.24)	754,407	32.89 (31.20-34.62)	
Female	822,804	66.15 (63.76-68.45)	1,539,483	67.11 (65.38-68.80)	
Total	1,243,929	100.00	2,293,890	100.0	
Reason for care					158.80***
Physical health problem	761,650	61.30 (58.86-63.37)	1,681,693	73.26 (71.64-74.81)	
Mental health problem	96,880	7.80 (6.59-9.20)	142,829	6.22 (5.42-7.13)	
Both physical and mental problems	367,145	29.55 (27.34-31.85)	394,006	17.16 (15.85-18.56)	
Something else	16,920	1.36 (0.90-2.06)	77,087	3.36 (2.76-4.08)	
Total	1,242,596	100.00	2,295,616	100.00	
Caregiver-Care Receiver Dyad Characteristics					
Proximity to care receiver					305.71***
Co-resident	364,019	29.31 (27.05-31.69)	399,033	17.39 (16.03-18.84)	
Same area	610,645	49.17 (46.70-51.65)	1,626,387	70.88 (69.20-72.51)	
Less than 1/2 day	174,071	14.02 (12.39-15.82)	203,570	8.87 (7.90-9.95)	

Table 8: Out-of-Pocket Spending by Caregiver, Care Receiver and Caregiver-Care Receiver Dyad Characteristics, General Social Survey, continued

Variables	Out-of-Pocket Spending				
	Yes		No		X ²
	N	N	N	N	
Caregiver-Care Receiver Dyad Characteristics					
Proximity to care receiver					305.71***
More than 1/2 day	93,095	7.50 (6.32-8.87)	65,531	2.86 (2.33-3.49)	
Total	1,241,829	100.00	2,294,520	100.00	
Relationship to Caregiver					373.20***
Spouse/partner	195,320	15.70 (13.97-17.61)	180,310	7.84 (6.92-8.88)	
Ex-spouse/partner	4,660	0.37 (0.21-0.67)	5,600	0.24 (0.14-0.43)	
Parent (and in-laws)	629,110	50.57 (48.06-53.09)	1,012,490	44.04 (42.16-45.94)	
Child	117,880	9.48 (8.11-11.04)	92,300	4.01 (3.38-4.76)	
Sibling	97,050	7.80 (6.70-9.07)	200,070	8.70 (7.81-9.68)	
Uncle/aunt	28,660	2.30 (1.67-3.17)	78,050	3.40 (2.78-4.13)	
Grandparent	5,060	0.41 (0.19-0.89)	6,550	0.28 (0.15-0.53)	
Other relative	15,170	1.22 (0.79-1.88)	30,710	1.34 (0.99-1.81)	
Friend or neighbour	151,020	12.14 (10.69-13.76)	692,900	30.14 (28.52-31.81)	
Total	1,243,930	100.00	2,298,980	100.00	

Table 9: Out-of-Pocket Spending by Caregiver, Care Receiver and Caregiver-Care Receiver Dyad Characteristics, HCIC data

Variables	Out-of-Pocket Spending				
	Yes		No		X ²
	N	%	N	%	
Caregiver Characteristics					
Sex					3.33
Male	41	22.04	9	12.16	
Female	145	77.96	65	87.84	
Total	186	100.00	74	100.00	
Age					2.72
Less than 65 years	171	91.94	63	85.14	
65 and above	15	8.06	11	14.86	
Total	186	100.00	74	100.00	
Marital Status					0.44
Married/living common law	164	88.17	63	85.14	
Separated/divorced/widowed/single	22	11.83	11	14.86	
Total	186	100.00	74	100.00	
Born in Canada					0.02 ^{e-2}
Yes	166	89.25	66	89.19	
No	20	10.75	8	10.81	
Total	186	100.00	74	100.00	

Table 9: Out-of-Pocket Spending by Caregiver, Care Receiver and Caregiver-Care Receiver Dyad Characteristics, HCIC data, continued

Variables	Out-of-Pocket Spending				
	Yes		No		X ²
	N	%	N	%	
Highest level or education					17.65**
Less than secondary	13	6.99	8	10.81	
Secondary school	32	17.20	27	36.49	
Some post-secondary	43	23.12	15	20.27	
Post-secondary degree/diploma	98	52.69	23	31.08	
Missing	0	0.00	1	1.35	
Total	186	100.00	74	100.00	
Employment status					1.31
In labor force	91	48.92	40	54.05	
Unemployed/not working/ long-term illness	36	19.35	10	13.51	
Retired	59	31.72	24	32.43	
Total	186	100.00	74	100.00	
Household income					1.95
Less than \$50,000	52	27.96	20	27.03	
\$50,000 and more	109	58.60	39	52.70	
Missing	25	13.44	15	20.27	
Total	186	100.00	74	100.00	

Table 9: Out-of-Pocket Spending by Caregiver, Care Receiver and Caregiver-Care Receiver Dyad Characteristics, HCIC data

Variables	Out-of-Pocket Spending				
	Yes		No		X ²
	N	%	N	%	
Caregiver Characteristics					
Health status					0.949
Excellent	25	13.44	8	10.81	
Very good	49	26.34	23	31.08	
Good	72	38.71	26	35.14	
Fair/Poor	40	21.51	17	22.97	
Total	186	100.00	74	100.00	
Level of stress					5.41
Never/rarely	22	11.83	14	18.92	
Sometimes	70	37.63	28	37.84	
Often	63	33.87	22	29.73	
Always	31	16.67	9	12.16	
Missing	0	0.00	1	1.35	
Total	186	100.00	74	100.00	
Daily limitations due to health					2.60
Yes, often or sometimes	106	56.99	34	45.95	
Never	80	43.01	40	54.05	
Total	186	100.00	74	100.00	

Table 9: Out-of-Pocket Spending by Caregiver, Care Receiver and Caregiver-Care Receiver Dyad Characteristics, HCIC data, continued

Variables	Out-of-Pocket Spending				
	Yes		No		X ²
	N	%	N	%	
Care Receiver Characteristics					
Age					4.44*
Less than 45 years	68	36.56	17	22.97	
45 or more	118	63.44	57	77.03	
Total	186	100.00	74	100.00	
Sex					3.64
Male	132	70.97	61	82.43	
Female	54	29.03	13	17.57	
Total	186	100.00	74	100.00	
Reason for care					2.13
Both physical and mental health problems	108	58.08	42	67.74	
Physical problem only	77	41.41	19	30.65	
Missing	1	0.51	1	1.61	
Total	186	100.00	62	100.00	

Table 9: Out-of-Pocket Spending by Caregiver, Care Receiver and Caregiver-Care Receiver Dyad Characteristics, HCIC data

Variables	Out-of-Pocket Spending				
	Yes		No		X ²
	N	%	N	%	
Caregiver-Care Receiver Dyad Characteristics					
Proximity to care receiver					1.50
Co-residence	159	85.48	59	79.73	
Same area	18	9.68	9	12.16	
1/2 days journey	9	4.84	6	8.11	
Total	186	100.00	74	100.00	
Relationship between caregiver and care receiver					5.44
Partner	134	72.04	53	71.62	
Relatives	44	23.66	14	18.92	
Friends and others	6	3.23	7	9.46	
Not stated	2	1.08	0	0.00	
Total	186	100.00	74	100.00	

Table 10: Average Monthly Out-of-Pocket Expenditures, General Social Survey

Average Spending per Month	N	Percent
Less than \$500	973,635	80.24
\$500—\$2,000	200,808	16.55
More than \$2,000	38,891	3.21
Total	1,213,333	100.00

Table 11: Mean Annual Out-of-Pocket Expenditures by Income Category for Those Who Reported Spending, HCIC Data

Annual Income	Mean Annual Out-of-Pocket Expenditures (\$)	n	Percent
Less than \$30,000	7,609.71	17	9.1
\$30,000-\$59,999	3,515.94	53	28.5
\$60,000 or more	9,326.15	91	48.9
Missing	9,916.12	25	13.4
Total	7,599.02	186	99.9

**Table 12: Factors Associated with the Probability of Out-of-Pocket Spending ,
General Social Survey**

Variables	Odds Ratios		
	Total	Women	Men
Caregiver Characteristics			
Age 65 or older	.721**	.952	.498***
Female	1.056		
Education			
Less than secondary	.598***	.504***	.765
Secondary school	.771*	.732*	.845
Some post-secondary	.886	.888	.857
Post-secondary degree/diploma (omitted)			
Born outside Canada	1.046	.986	1.139
Employment status			
Not in labour force	1.185	1.085	1.820
Retired	1.444***	1.305*	1.737**
Long-term illness	.700	.674	.825
In labour force (omitted)			
Household income			
Less than \$50,000	1.076	1.150	1.004
Missing	.888	.911	.882
\$50,000 and more (omitted)			

**Table 12: Factors Associated with the Probability of Out-of-Pocket Spending ,
General Social Survey, continued**

Variables	Odds Ratios		
	Total	Women	Men
Health status			
Very good	1.047	1.089	1.003
Good	1.111	1.115	1.111
Fair	.971	.894	1.111
Poor	1.097	1.290	0.902
Excellent (omitted)			
Level of stress			
Rarely	.997	1.019	1.007
Sometimes	1.373**	1.497*	1.257
Often	2.336***	2.578***	2.201***
Always	2.453***	2.433***	2.830**
Never (omitted)			
Daily limitations due to health			
Often	1.166	1.075	1.295
Sometimes	1.158	1.270*	1.018
No (omitted)			
Marital status			
Separated, divorced, widowed or single	.911	.871	.906
Married (omitted)			

**Table 12: Factors Associated with the Probability of Out-of-Pocket Spending ,
General Social Survey, continued**

Variables	Odds Ratios		
	Total	Women	Men
Care Receiver Characteristics			
Age			
20 to less than 45 years	.540	.570	.578
45-64	.549	.558	.608
65 or above	.345**	.316*	.443
Deceased	.939	.742	1.699
Less than 20 years (omitted)			
Female	1.075	1.038	.995
Reason for Care			
Mental health problem	1.207	1.303	1.032
Both physical & mental health problems	1.760***	1.615***	2.061***
Something else	.561*	.541*	.617
Physical health problem (omitted)			
Caregiver-Care Receiver Dyad Characteristics			
Proximity to care receiver			
Same area	.747*	.682**	.860
Less than 1/2 day	1.466**	1.279	1.866**
More than 1/2 day	2.469***	2.589***	2.455**
Co-residence (omitted)			

**Table 12: Factors Associated with the Probability of Out-of-Pocket Spending ,
General Social Survey, continued**

Variables	Odds Ratios		
	Total	Women	Men
Relationship between caregiver and care receiver			
Ex-partner	.948	1.478	.579
Parent	.782	1.218	.454**
Child	.881	1.018	.789
Sibling	.584**	.845	.348**
Uncle/Aunt	.517**	.841	.247**
Grandparent	1.034	4.002	.353
Other relative	.436*	.774	.188**
Friends and others	.310***	.440***	.190***
Spouse/Partner (omitted)			
Caregiving Context			
Complementary funding sources			
From government programs	1.251	1.554	1.002
From tax benefits for care expenses	2.337***	3.048***	1.676*
Gifts from care receiver	1.326**	1.275*	1.484*
Financial support from family/friends	2.290***	2.516***	2.068*
Rural	1.023	1.042	.991
Years provided support	1.000	1.000	1.000
Number of people caregiver has supported	1.003	1.003	1.003
Constant	1.054	.848	1.287
F	15.24	8.50	6.64
Goodness of fit	0.53	1.03	0.97
n	3,407,558	1,936,951	1,470,607

*** p < .001, ** p < .01, * p < .05

**Table 13: Factors Associated with the Probability of Out-of-Pocket Spending ,
HCIC Data**

Variables	Odds Ratios
Caregiver Characteristics	
Age 65 or older	.422
Female	.348
Education	
Less than secondary	.335
Secondary school	.373*
Some post-secondary	1.070
Post-secondary degree/diploma (omitted)	
Employment status	
Unemployed/unable to work	1.622
Retired	1.810
Employed (omitted)	
Household income	
Less than \$50,000	1.393
Missing	.783
\$50,000 and more (omitted)	
Health status	
Very good	.356
Good	.466
Fair/Poor	.207*
Excellent (omitted)	
Level of stress	
Sometimes	1.741
Often	2.332
Always	3.399
Never (omitted)	

**Table 13: Factors Associated with the Probability of Out-of-Pocket Spending ,
HCIC Data**

Variables	Odds Ratios
Yes, daily limitations due to health	2.508*
Separated, divorced, widowed or single	1.850
Care Receiver Characteristics	
45 years or older	.296*
Female	1.738
Reason for care—physical problems	.972
Caregiver-Care Receiver Dyad	
Proximity to care receiver	
Same area	1.008
Half days journey	.345
Co-residence (omitted)	
Relationship between caregiver and care receiver	
Relatives	1.004
Friends and others	.192
Spouse/Partner (omitted)	
Caregiving Context	
Complementary funding sources	
Financial support from family/friends	2.775**
Support from private sources	2.873*
Support from public programs	.916
Years provided support	1.002
Number of people supported	.852
Constant	7.006
Pseudo R2	0.235
n	254

Table 14: Out-of-Pocket Spending by Complementary Sources of Funding

Complementary Sources of Funding	Out-of-Pocket Spending				χ^2
	Yes		No		
	N	Percent (95% CI)	N	Percent (95% CI)	
General Social Survey					
Government programs					61.36***
Yes	79,699	6.0 (5.0-8.0)	56,139	2.0 (2.0-3.0)	
No	1,159,498	94.0 (92.0-95.0)	2,235,008	98.0 (97.0-98.0)	
Total	1,239,197	100.0	2,291,148	100.0	
Tax benefits for care expenses					141.48***
Yes	116,719	10.0 (8.0-11.0)	59,765	3.0 (2.0-3.0)	
No	1,112,056	91.0 (89.0-92.0)	2,225,948	97.0 (97.0-98.0)	
Total	1,228,776	100.0	2,285,714	100.0	
Gifts from care receiver					16.54***
Yes	254,419	21.0 (19.0-22.0)	376,864	16.0 (15.0-18.0)	
No	983,357	79.0 (77.0-81.0)	1,916,241	84.0 (82.0-85.0)	
Total	1,237,776	100.0	2,295,450	100.0	

Table 14: Out-of-Pocket Spending by Complementary Sources of Funding

Complementary Sources of Funding	Out-of-Pocket Spending				X ²
	Yes		No		
	N	Percent (95% CI)	N	Percent (95% CI)	
General Social Survey					
Financial support from family or friends					111.16***
Yes	105,378	8.0 (7.0-10.0)	59,774	3.0 (2.0-3.0)	
No	1,138,226	92.0 (90.0-93.0)	2,235,676	97.0 (97.0-98.0)	
Total	1,243,605	100.0	2,295,450	100.0	
Hidden Costs/Invisible Contributions					
Financial support from family or friends					17.622***
Yes	121	65.05	27	36.49	
No	65	34.95	47	63.51	
Total	186	100.0	74	100.0	
Private sources					7.89**
Yes	50	26.88	8	10.81	
No	136	73.12	66	89.19	
Total	186	100.0	74	100.0	

Table 14: Out-of-Pocket Spending by Complementary Sources of Funding

Complementary Sources of Funding	Out-of-Pocket Spending				χ^2
	Yes		No		
	N	Percent (95% CI)	N	Percent (95% CI)	
Hidden Costs/Invisible Contributions					
Public sources					0.65
Yes	65	34.95	22	29.73	
No	121	65.05	52	70.27	
Total	186	100.0	74	100.0	
*** p < .001, ** p < .01, * p < .05					

Table 15: Factors Associated with the Probability of Consequences^a of Caregiving

Variables	Odds Ratios		
	Total	Women	Men
Caregiver Characteristics			
Age 65 or older	.901	.819	1.046
Female	1.561***		
Education			
Less than secondary	.741**	.668**	.822
Secondary school	.873	.951	.726
Some post-secondary	.816	.834	.719
PS degree/diploma (omitted)			
Employment status			
Not in labour force	.935	.897	1.686
Retired	1.117	1.183	1.066
Long-term illness	.722	.851	.519
In labour force (omitted)			

^a Experiencing one or more of: reduced social activities, cancelled holiday plans, postponed enrolment in an educational or training program, turned down a job offer or promotion, or moved in with the care receiver

*** p < .001, ** p < .01, * p < .05

Table 15: Factors Associated with the Probability of Consequences of Caregiving, continued

Variables	Odds Ratios		
	Total	Women	Men
Caregiver Characteristics			
Born outside Canada	1.039	.945	1.185
Household income			
Less than \$50,000	.959	.871	1.106
Missing	1.049	.993	1.112
\$50,000 and more (omitted)			
Health status			
Very good	1.080	1.167	.981
Good	1.126	1.274	.923
Fair	.977	.966	.939
Poor	1.195	1.154	1.349
Excellent (omitted)			
Daily limitations due to health			
Often	1.106	1.237	.976
Sometimes	1.070	1.235	.877
No (omitted)			

Table 15: Factors Associated with the Probability of Consequences of Caregiving, continued

Variables	Odds Ratios		
	Total	Women	Men
Level of stress			
Rarely	1.061	.997	1.105
Sometimes	1.440*	1.315	1.615*
Often	1.709**	1.810**	1.543
Always	2.748***	2.188*	3.824***
Never (omitted)			
Separated, divorced, widowed or single	1.437***	1.454**	1.377*
Care Receiver Characteristics			
Female	.848*	.838	.938

Table 15: Factors Associated with the Probability of Consequences of Caregiving, continued

Variables	Odds Ratios		
	Total	Women	Men
Care Receiver Characteristics			
Age			
20 to less than 45 years	1.514	.847	3.770*
45-64	.937	.529	2.334
65 or above	.740	.461	1.522
Deceased	2.258	1.460	5.297*
Less than 20 years (omitted)			
Reason for care			
Mental health problem	1.073	1.267	.835
Both physical and mental health problems	1.615***	1.681***	1.557**
Something else	.824	.962	.675
Physical health problem (omitted)			

Table 15: Factors Associated with the Probability of Consequences of Caregiving, continued

Variables	Odds Ratios		
	Total	Women	Men
Caregiver-Care Receiver Dyad Characteristics			
Relationship between caregiver and care receiver			
Ex-Spouse/Partner	.339*	.369	.305*
Parent	.744	.713	.876
Child	.345***	.353**	.388*
Sibling	.315***	.374**	.248***
Uncle/Aunt	.481**	.451*	.548
Grandparent	1.270	.404	3.222
Other relative	.266**	.190**	.390
Friends and others	.191***	.164***	.255***
Spouse/Partner (omitted)			

Table 15: Factors Associated with the Probability of Consequences of Caregiving, continued

Variables	Odds Ratios		
	Total	Women	Men
Caregiver-Care Receiver Dyad Characteristics			
Proximity to care receiver			
Same area	.629***	.588**	.682*
Less than 1/2 day	.565***	.524**	.628
More than 1/2 day	.410***	.553*	.282***
Co-residence (omitted)			
Caregiving Context			
Complementary sources of financial support			
From government programs	1.852*	2.886**	1.223
From tax benefits for care expenses	1.554*	1.271	2.068**
Gifts from care receiver	1.413***	1.437***	1.409*
Financial support from family/friends	1.442*	1.246	1.723
Rural	.811*	.743**	.921
Years provided support	1.000	1.000	1.000

Table 15: Factors Associated with the Probability of Consequences of Caregiving, continued

Variables	Odds Ratios		
	Total	Women	Men
Caregiving Context			
Number of people caregiver has supported	1.002	1.003	1.000
Incurred out-of-pocket expenses	5.772***	5.586***	6.332***
Constant	.623	1.705	.235
F	21.42	12.42	9.39
Goodness of fit	5.99	4.01	2.63
N	3,407,558	1,936,951	1,470,607

*** p < .001, ** p < .01, * p < .05