INFORMAL CAREGIVING: WHAT ARE THE FINANCIAL COSTS FOR CAREGIVERS?

Evidence, Policy Implications and Knowledge Gaps

By Janet Fast, Jacquie Eales and Norah Keating
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Informal Caregiving: What Are the Financial Costs to Caregivers?

Summary

The family care sector is a key pillar of Canada’s long term care system. In 2012, over 25%, or an estimated 8.1 million, Canadians aged 15 or older provided care to a chronically ill, disabled or aging family member or friend. In fact, caregiving has become a common experience for most Canadians since almost 50% of all Canadians aged 45 and over report that they cared for at least one family member since they were 15 years old.

This sector is currently under stress due to changes in demographic, socio-economic and public policy contexts, and its sustainability increasingly is raising concerns; its failure would have implications for the caregivers’ workplaces, the health care and community service sectors, as well as for the labour force.

Care giving has considerable health, social and financial consequences. Yet, public support to alleviate these costs is still quite modest, in part because the data needed to better appreciate these costs have been lacking until relatively recently.

The purpose of this report is to synthesize the Canadian evidence to date on the financial costs of care to adults with long term health conditions, physical or mental disabilities, or needs associated with aging. It provides a comprehensive but critical review of this body of literature to inform evidence-based policy and practice, and insights to develop a strategic plan to fill knowledge gaps. By identifying the short and long term financial costs incurred by family caregivers it helps make these costs visible, and it is meant to contribute to a broader public discourse on the sustainability of family care.

The report first describes trends in family caregiving in Canada, summarizing the prevalence, magnitude and nature of the financial consequences of care in three broad domains of costs: employment consequences, out-of-pocket expenses, and care labour. The following section reviews findings related to risk factors for incurring these costs. The report examines predictors of financial costs of caregiving in relation to the characteristics of caregivers, care receivers, the caregiver-care receiver relations and the nature of care. These findings are based on multivariate analyses (ranging from OLS and logistic regression to pooled and fixed effects models). We conclude the report by highlighting those caregivers at greatest risk of incurring significant financial costs, and by discussing the policy implications of findings and the knowledge and data gaps that remain.

Although we are just beginning to understand patterns of risk, being female, caring for an immediate family member, and being employed stand out as critical for being at risk for significant financial consequences.

The conceptual and empirical work on domains of costs in this report provides a framework for a much needed national debate, and the information presented provides a state of data, of knowledge and of policy upon which to build a sound program toward containing costs and thus allowing this sector to thrive. Policy discussion needs to focus on Canada’s reluctance to provide financial compensation to family caregivers; whether employers should bear responsibility for enhancing the balance of employment and care; and how to address out-of-pocket costs that may be incurred for a diverse set of products and services only some of which might be amenable to public sector interventions.
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Introduction

Families have long been the main source of care for their members (Baker, 2006; Chappell, 2011). Yet we are at an historic crossroads where changes in demographic, socio-economic and public policy contexts are converging to threaten families’ caring capacity.

Increased life expectancy, population aging, and higher rates of chronic illness and disability are increasing the demand for family care (Busque & Légaré, 2012; Carrière, Keefe, Légaré, Lin, & Rowe, 2007; Denton & Spencer, 2010), but the availability of care may be affected by proximity of family members and changes in family structure and roles, such as later marriage and childbearing, higher rates of divorce and remarriage, and later retirement (Vanier Institute of the Family, 2010). Older adults with no potential support from a child or spouse are also predicted to increase, but at a slower rate than the total population, with the bulk of expected increases occurring after 2020 (Gaymu, Busque, Légaré, Décarie, Vézina & Keefe, 2010; Keefe, Vézina, Légaré, Décarie & Lefrançois, 2012). At the same time, retrenchment and limited resource allocations in the health and continuing care service sectors (Bhatia, 2010; Bryant, Raphael, Schrecker & Labonte, 2010; Chappell, 2011) constrain the ability of the formal care sector to meet projected population needs, ceding further responsibility to the already beleaguered family care sector (Special Senate Committee on Aging, 2009).

In light of these trends, there is increasing concern about the sustainability of the family care sector. Caregiving has become a normative experience that has been shown to result in considerable health, social and financial consequences (Fast, Dosman, Lero & Lucas, 2013; Keating & Eales, in press; Mental Health Commission of Canada, 2015; Turcotte, 2013). Further, there is increasing concern about the accumulation and intensification of caregiver consequences over their life course (Carers UK, 2007; Fast & Dosman, 2013; Keating, Fast, Lero, Lucas & Eales, 2014; Turcotte, 2013). These consequences in turn may threaten caregivers’ ability to meet care and job obligations, and prepare for their own later years (OECD, 2011). These consequences and their impact on caregivers and on society are beginning to receive national and international attention.

In Canada, there has been recent policy concern about the potential for reduced economic well-being of caregivers. The 2013 Throne Speech and priorities of the Federal/Provincial/Territorial Ministers Responsible for Seniors demonstrate awareness of caregiver costs, noting the need to “assist older workers balancing the competing demands of work and care” (Canadian Intergovernmental Conference Secretariat, 2014; Government of Canada, 2013a, 2013b). Yet legislation such as increasing the age of eligibility for Old Age Security as well as incentives to defer uptake of Canada Pension Plan benefits as late as age 70 (Service Canada, 2013) may keep Canadians working longer, even beyond what many may choose as a result of living longer in good health.

Box 1 Family caregiving

Family caregiving is the unpaid assistance provided by family members or friends because of that person’s long term health condition, physical or mental disability, or problems related to aging. (Statistics Canada, 2012)

Such task oriented definitions of care are bounded in the sense that they do not acknowledge other elements of care such as the quality of the connection between caregiver and recipient. However, they have two advantages. The first is that care is positioned as work that has a job description. The second is that care is distinguished from everyday household or family labour, and from supportive exchanges resulting from ongoing relationships with friends or family.

There is no overall agreement on what comprises the complete set of caregiving tasks (Keating et al., 2014). However, common care tasks included in Canadian research are:

- indoor domestic tasks (meal preparation and clean-up, housecleaning, laundry);
- household maintenance and outdoor work;
- transportation and errands (driving, shopping, banking, paying bills);
- personal care (bathing, toileting, brushing teeth, dressing, hair or nail care);
- medical treatments or procedures;
- care management (scheduling and coordinating care tasks, making appointments, managing, finances); and
- emotional support (checking up, visiting).
Human rights cases are emerging that may oblige employers to accommodate workers’ caregiving obligations (British Columbia Law Institute and Canadian Centre for Elder Law, 2010; Canadian Human Rights Commission, 2014). But there has been limited discussion of other financial costs to caregivers such as their unpaid care labour and expenses incurred on behalf of the care receiver. To date, Canadian public programs to reduce caregiver financial costs are modest in their reach and effectiveness. The Compassionate Care Benefit and associated workplace leave are limited to those caring for relatives who are dying and to a maximum of 6 weeks coverage (Service Canada, 2014). The program has been viewed as a good first step but limited in its ability to ameliorate caregiver costs given low levels of compensation, a lengthy application process, required unpaid wait period and limit to those at significant risk of death (Williams, Crooks, Giesbrecht & Dykeman, 2010). Caregiver tax credits (Canada Revenue Agency, 2015) have been criticized because of their low value; because they benefit only 1% of tax filers (mostly high income and male); and because they are not set up to benefit the person engaged in caregiving (British Columbia Law Institute and Canadian Centre for Elder Law, 2010).

The family care sector is a key pillar of our long term care system; its failure would have implications for the sustainability of caregivers’ workplaces, the health care and community service sectors, as well as for the labour force (Canadian Institute for Health Information, 2010; Duxbury, Higgins & Schroeder, 2009; Hermus, Stonebridge, Theriault & Bounajm, 2012). Identifying the short and long term financial costs incurred by family caregivers will make these costs visible, and contribute to a broader public discourse on the sustainability of family care. Knowledge of the prevalence and magnitude of caregiver costs can provide evidence to inform the development of public programs to sustain it.

The purpose of this report is to synthesize the Canadian evidence to date on the financial costs of care to adults with long term health conditions, physical or mental disabilities, or needs associated with aging. Our aim is to provide a comprehensive but critical review of this body of literature to inform evidence-based policy and practice, and provide a strategic plan for the research community to fill knowledge gaps. Our method for selecting the studies included in the synthesis is summarized in Box 2 below.

We have limited our attention to care to adults aged 18 and over because both the nature and consequences of the care, and the policy responses to it, differ substantially when the care receiver is a child. As per the taxonomy developed by Keating and her colleagues (2014) based on a systematic scoping review of national and international literature, we examine three broad domains or sources of financial costs for family caregivers: employment consequences, out-of-pocket expenses; and care labour (see Figure 1 next page).

### Box 2 Selection of studies included in the synthesis

We began our literature search with the Canadian Research Data Centre Network (CRDCN) bibliography, looking across data sets and publication years since 2000 using selected key words. Based on our knowledge of Canadian scholars working in the topic area, we also searched by author surname.

From this search we identified 40 papers and reports based on work conducted in the RDCs. Of these 40, 16 were read and subsequently excluded: three were not directly relevant to the focus on the financial costs of care to caregivers of adults; and 13 focused on care receivers and their unmet needs, care networks, or home care use. The remaining 24 (indicated by * in the reference list) were included in the synthesis.

The majority of studies reviewed for this synthesis drew on nationally representative data and were peer reviewed. Some were based on national data but were reported in the form of research briefs (such as Fast et al., 2010 and Fast, Lero, DeMarco, Ferreira & Eales, 2014).

This body of publications was supplemented with relevant Canadian and international studies to set the context around families and care, and where appropriate, to highlight useful lessons that may inform Canadian research going forward.
Source: Keating, Fast, Lero, Lucas, & Eales (2014)

Sources of data in Canada

The body of knowledge about caregiving in Canada has grown substantially in recent decades, thanks in no small measures to the development of relevant sources of data. In 1996 Statistics Canada's General Social Survey (GSS) had as one of its core topics the issue of social support to older adults, allowing for the first time in-depth investigation of family caregiving to older adults (aged 65 and older). A monograph produced for the 1999 International Year of Older Persons provided the first Canadian documentation of the nature, extent and consequences of family care to seniors who require help because of a long-term health problem or activity limitation (Keating, Fast, Frederick, Cranswick & Perrier, 1999).

Since then, the inventory of nationally representative data files with content on family caregiving has grown. For example, the GSS Cycle 16 (2002) and Cycle 21 (2007) focused on aging, social support and retirement among Canadians aged 45 and older. The 2009 Canadian Community Health Survey (CCHS) had questions about both receipt and provision of care as well as out-of-pocket expenses. Since 1997, the Labour Force Survey (LFS) has included questions that allow respondents of working age (20-64 years) to report that they were absent from paid work, reduced their paid work hours to part time, or were not working during the reference week because they were providing eldercare (that is, care to adults aged 60 and older because of his/her long term health problems or disabilities). The newest addition to the collection is the GSS Cycle 26 (2012) which focused entirely on caregiving and care receiving and covered the full age range of givers and receivers, making available much more detailed information about the employment, out-of-pocket, and direct labour consequences of caregiving.
These datasets have provided the grounding for much of the current state of knowledge of the financial consequences of family care in Canada. The development of the Canadian Research Data Centre Network (CRDCN) has been vitally important in providing researchers with access to the full versions of these data files, and much of the Canadian work that is synthesized in this report was actually produced in one of the Research Data Centres.

Other entries to the data pool are emerging. Baseline data from pilot and early waves of new longitudinal surveys such as the Longitudinal and International Study of Adults (LISA), and the Canadian Longitudinal Study on Aging (CLSA) are now available. Both surveys include information about whether respondents are providing care, at baseline and in all subsequent waves. Thus it will be possible to track transitions into and out of caregiving, as well as transitions into and out of paid work as a result of caregiving. In time, these data will also become useful in answering some of the key questions related to the financial consequences of care.

Looking forward

The rest of the synthesis is organized as follows. We begin by describing trends in family caregiving in Canada, summarizing the prevalence, magnitude and nature of the financial consequences of care in the three domains of costs. We also describe the long-term impact on caregivers of each of these consequences. These findings are mainly descriptive, drawn from studies that set out the broad terrain of financial consequences of care.

In the following section are findings related to risk factors for incurring these costs. We examine predictors of financial costs of caregiving in relation to the characteristics of caregivers, care receivers, the caregiver-care receiver dyad and the nature of care. These findings are based on multivariate analyses (ranging from OLS and logistic regression to pooled and fixed effects models). Only statistically significant differences at the .05 level or greater are reported.

We conclude the report by highlighting those caregivers at greatest risk of incurring significant financial costs, and by discussing the policy implications of findings and the knowledge and data gaps that remain.

Trends and financial consequences of caregiving

More than 1 in 4 (28%), or an estimated 8.1 million, Canadians aged 15 or older, provided care to a chronically ill, disabled or aging family member or friend in 2012 alone (Sinha, 2013). While there were methodological differences between GSS cycles in 2007 and 2012, Sinha (2013) estimated that the number of caregivers aged 45 and over likely increased by 760,000 to 4.5 million between 2007 and 2012, representing a 20% increase in the number of mid-life and older caregivers.

The data on care histories, available for the first time in the 2007 GSS, also demonstrated that caregiving is an even more common experience when examined from a life course perspective. More than half of all women and almost 40% of men aged 45 and over reported that they had provided care to at least one family member with a long-term health problem or disability at some time since they were 15 years of age (Fast, Dosman, Lero & Lucas, 2013). Data indicate that 10% of women caregivers and 7.5% of men started their caring careers early, reporting first providing care as a young adult under age 25 (Fast, Dosman et al., 2013). In 2012, 15% of all caregivers were aged 15 to 24 years, typically caring for grandparents (48%) or parents (25%) (Sinha, 2013).

In 2012 there was an almost equal gender split in proportions of employed caregivers (51% women, 49% men), a gender gap that has narrowed over time. Reporting findings from one of the first Statistics Canada surveys on family caregiving, Keating et al. (1999) estimated that women comprised 61% and men 39% of all Canadian caregivers in 1996 (Keating et al, 1999).

In 2012 most caregivers of employment age were in the paid labour force (82% or 5.6 M), and most of them worked full time (Fast et al., 2014). Most were caring for a parent or parent-in-law (Sinha, 2013), and were less likely to be caring for non-kin, or to be living with the person for whom they were caring. Analysis of the 2007 and 2012 GSS showed that employed caregivers were systematically different from non-employed caregivers: they were younger, better educated, more likely to be married and to have
young children at home (Fast, Dosman et al., 2013). They were more likely to have multiple competing demands and to spend less time on care tasks overall (Fast, Dosman et al., 2013; Sinha, 2013).

**Employment consequences**

Most of the literature available on the financial costs of care addresses employment-related consequences, including restricted work hours, absences and leaves; labour force exit and preclusion; career limitations; and reduced productivity.

Employment consequences were common among employed caregivers and especially so among women. According to synthetic cohort analysis of twelve years of Labour Force Survey (LFS) panel data, three times as many women as men adapted their paid work to meet eldercare demands in two different time periods: 1997–2002 (273,762 women v. 86,061 men annually) and 2003–2008 (521,881 women v. 175,830 men) (Fast & Dosman, 2013).

Absenteeism was the most common employment consequence amongst those who were employed (Fast et al., 2014; Sinha, 2013). In 2012, 44% of employed caregivers, or 2.4 million employed Canadians, reported that they had arrived to work late, left early, or taken time off during the day to care for their ill family member or friend (Fast et al., 2014; Sinha, 2013). This figure increased to 54% for those providing 20 or more hours of caregiving per week (Sinha, 2013). On average, caregivers were absent for between 8 and 9 days, accounting for 9.7 million days of absenteeism in Canada per year (Fast et al., 2014). Overall, employed caregivers worked 256 million fewer hours per year than those without caregiving responsibilities (Fast et al., 2014).

Data on the prevalence of leaves of absence to provide care are not available in national caregiving surveys. However, in an on-line survey of 291 Canadian employers, more than one-third (39%) of respondents reported having employees who had taken stress leave or disability leave, at least in part as a result of their caregiving responsibilities (Lero, Spinks, Fast, Hilbrecht & Tremblay, 2013). Almost half (47%) of employers also reported that employees with caregiving responsibilities had reduced their output, quality of work or performance level. About one third reported that employed caregivers seemed uncharacteristically distracted, made errors, became injured or put someone else at risk. These findings reflect the degree to which employers see caregiving as having a negative effect on workplace productivity, often referred to in the business literature as “presenteeism” (Burton, Chen, Conti, Pransky, & Edington, 2004).

We don’t know employees’ perspectives on their performance level since questions about reduced productivity were not asked in national surveys that address caregiving consequences. However, we know that most employed caregivers were satisfied with their current work-life balance, although they were significantly less so than non-caregivers (Sinha, 2013).

In 2012, 15% of employed caregivers (828,739 Canadians) stated that they cut back their work hours because of caregiving responsibilities, often changing from full to part-time employment (Fast et al., 2014). Women and men were almost equally likely to report reducing work hours; however, on average, women reported cutting back on their hours of work significantly more than men (10 hours per week v. 9 hours per week) (Fast et al., 2014). These changes are likely to be longer term than the temporary absences resulting from juggling work schedules.

In 2012, fully ten percent of employed caregivers (557,698 Canadians) also reported that they had retired early, quit or been fired from a job because of caregiving during the previous 12 months (Fast et al., 2014). Significantly more women (12%) than men (8%) exited, in one way or another, the paid labour force to provide care, and the numbers were higher among those who retired to provide care. Among all caregivers aged 45 and older who reported that they had ever retired and who attributed that retirement to caregiving, almost 13% of women gave caregiving as a reason for retirement (Fast, Dosman et al., 2013). Similarly, Humble, Keefe and Auton (2012) found that in 2002, 21% of women caregivers aged 45 and older and 8% of men caregivers retired for caregiving purposes. Although there were also other reasons that factored into their decisions to retire, many employed caregivers (69%) who retired “voluntarily” because of eldercare responsibilities wished to have remained in the labour force. This was particularly true among men caregivers who were more likely than women to view their retirement as involuntary (Humble et al., 2012).
Care responsibilities can also influence the overall career planning of some caregivers. Based on analysis of the 2012 GSS, 10% of employed caregivers turned down or did not pursue a new job or promotion because of their caregiving responsibilities (Sinha, 2013). Furthermore, 40% of caregivers sought a less demanding job because of their caregiving duties (Sinha, 2013). Such decisions have significant implications for future employability, advancement and earning power.

Impact of employment consequences

Being absent from work, reducing paid work hours or leaving the labour force altogether can have immediate and long-term effects on caregivers’ benefits, pensions entitlements and income. But we are just beginning to learn about the actual impact of such employment disruptions.

The lost wages associated with eldercare-related employment disruptions as reported by LFS participants were modest for some caregivers ($100-$1,000/year), but much more substantial for others (more than $16,000/year) (Fast & Dosman, 2013). Estimated annual lost wages varied across age cohort, with higher losses experienced by caregivers at mid-life or closer to retirement, and higher individual losses for men than for women (Fast & Dosman, 2013), consistent with the persistent gender wage gap (Vincent, 2013). Based on synthetic cohort analysis of twelve years of LFS data, the estimated aggregate annual income losses from not working attributable to eldercare were $81.9 million for women and $53.8 million for men (2003-2008) (Fast & Dosman, 2013).

Among employed caregivers who reduced their hours of work in 2012, 14% reported losing some or all of their benefits, such as extended health and prescription drug benefits, dental benefits, employer-provided pension, and life insurance (Sinha, 2013).

Income losses, in mid or later life when earnings would normally be increasing or at their peak, compromise caregivers’ ability to save for retirement and to accumulate CPP and other pension benefit entitlements. At the other end of the age spectrum, caregiving at an early age can also have a powerful impact by limiting participation in education and work, thereby affecting the development of job skills and future earnings (Lero, Keating, Fast, Joseph & Cook, 2007). However, whether the cumulative wage losses would be greater for those who began their “caring careers” at younger ages than for those who enter the caregiver role later in life is unknown.

Out-of-pocket expenses

Care-related out-of-pocket expenses have been much less studied than employment consequences. Yet these costs may be an indication of the increasing privatization of care for older adults. Prevalence rates indicated that more than one-third of Canadian caregivers (35%), or over 1.2 million people aged 45 and older, had care-related out-of-pocket expenses (Duncan, Shooshtari, Roger, Fast, & Han, 2016). This rate based on the 2007 General Social Survey is similar to two other nationally representative Canadian surveys conducted in 2002, in which it was estimated that between 38% (Habtu & Popovic, 2006) and 44% (Decima Research, 2002) of family/friend caregivers incurred extra expenses associated with caregiving.

Current evidence suggests that out-of-pocket expenditures were modest for most caregivers, but substantial for others. Nationally, out-of-pocket expenses (for those reporting them) varied widely in 2012, from a median of $300 in the last 12 months for caregivers of extended kin and non-kin to between $1,900-$2,300 for those caring for immediate family members (Turcotte, 2013). Other studies also have documented Canadian caregivers’ out-of-pocket expenses. Estimates varied widely by health condition of the care receiver (Chai, Guerriere, Zagorski & Coyte, 2014; Duncan et al., 2016; Longo, Fitch, Deber & Williams, 2006) and type of setting (Chappell, Havens, Hollander, Miller & McWilliam, 2004; Miller, Hollander, Corbett & van der Valk, 2008; Miller, Hollander & MacAdam, 2008).

Results of national surveys indicated that the most common out-of-pocket expenses were transportation, travel and accommodation costs. These were reported by more than half of caregivers to close kin and friends (Turcotte, 2013). Data on costs to purchase supplies is limited to medications and some assistive devices, leaving a gap in our understanding of other expenses.

Estimates of the proportion of caregivers who purchase care receivers’ prescription and over-the-counter medications varied widely depending on the type of medication purchased, caregiver-care
receiver relationship and type of chronic condition, but consistently showed that these are another common expenditure for caregivers.

A 2002 national survey by Decima Research suggests that 71% of caregivers purchased non-prescription medications and 43% purchased prescription medications (Decima Research, 2002). Estimates based on the 2012 GSS ranged from 11% among children caring for a parent to 52% among spouse caregivers (Turcotte, 2013). There are few Canadian estimates of the amount spent specifically on medications. One study of Canadian caregivers for non-senior community-dwelling care receivers with high needs reported average annual spending on prescription and non-prescription drugs of $1,027 per year (Fast, Keating et al., 2013).

Some caregivers also purchased specialized devices or equipment. Estimates based on the 2012 GSS ranged from approximately 8% of children caring for a parent or parent-in-law to 22% of caregivers to immediate family members (Turcotte, 2013). A Canadian study of caregivers to high needs non-senior adults found that more than one-quarter had expenses for specialized aids and devices, as well as clothing and footwear, spending on average $1,755 and $594 per year respectively for these items (Fast, Keating et al., 2013).

There is also some evidence that some caregivers purchased professional or rehabilitation services, and other assistance with daily activities that were not otherwise funded or available through public programs, but we are only beginning to track these costs.

The prevalence and magnitude of expenditures on these services vary across samples and types of services. The 2002 national survey by Decima reported that 19% of caregivers who had out-of-pocket expenses paid for respite services and 20% paid for professional services such as physiotherapy for the care receiver (Decima Research, 2002). Estimates based on the 2012 GSS ranged from 5% among those caring for a parent to 20-23% among caregivers of immediate family members (Turcotte, 2013) who incurred non reimbursed expenses for professional or rehabilitation services. Estimated average expenditures by caregivers to community dwelling high needs non-senior family members were $2,733 for assistance with personal care alone (Fast, Keating et al., 2013).

In 2012 expenses for dwelling modifications were incurred by 10-12% of children caring for parents or parents-in-law, and 13-16% of those caring for immediate family members (Turcotte, 2013). The amount spent on dwelling modifications can be substantial. For example, Fast and her colleagues found that caregivers of community-dwelling non-senior adult care receivers (aged 19-64) with high needs spent $11,354 on average per year for home modifications (Fast, Keating et al., 2013).

Impact of out-of-pocket expenses

Because of the limited data available on out-of-pocket expenses, it is difficult to estimate with any certainty the long term impact of such expenditures. Available evidence from the 2012 GSS indicates threats to financial security of some caregivers: 20% of those caring for a spouse experienced financial difficulties associated with caregiving, a significantly higher proportion than those caring for a parent or parent-in-law (6-7%) (Turcotte, 2013). Caregivers of immediate family members also were significantly more likely than those caring for other relatives or friends to report that they changed spending habits, depleted or deferred savings, borrowed from a bank or financial institution, or borrowed money from family or friends (Turcotte, 2013).

Care labour

Caregivers represent a formidable work force, collectively performing an immense amount of care labour that represented a substantial economic contribution to Canadian society. There is tremendous individual variability in care workloads across caregivers (as indicated by number of persons cared for and amount of time spent). In 2012, more than half of caregivers (57%) provided care to one person. However, assisting more than one care receiver was not uncommon. More than one in four (27%) caregivers cared for two people and 15% cared for three or more (Sinha, 2013). In the last 12 months of life, caregivers’ unpaid care labour accounts for the largest proportion of total palliative care costs (Chai et al., 2014).
Based on analyses of the 2012 GSS, the majority of caregivers spent time checking up on (96%) or providing emotional support to (88%) the care receiver (Sinha, 2013). Among more instrumental types of assistance, 73% of caregivers provided transportation and 52% helped with household work, such as preparing meals, cleaning or laundry, and often at least once a week. Assistance with home maintenance and outdoor work, scheduling and coordinating appointments, and managing finances was also provided, but such assistance typically occurred less than once a week. While providing personal care and medical assistance were the least common types of care, when they were provided, these tasks were most likely done regularly, at least once a week, and often on a daily basis (Sinha, 2013).

Overall estimates of the magnitude of time spent caregiving underestimated care labour by not including time spent monitoring and providing emotional support or commuting to and from the care receiver. Rather, current estimates focused solely on time spent with or on behalf of care receivers providing instrumental tasks. In 2012, caregivers spent a median of three hours per week caring for a family member or friend with an illness, disability or needs associated with aging (Sinha, 2013). However median amounts varied widely from 2 hours per week for those caring for grandparents or friends to 14 hours per week for those caring for a spouse. One in ten caregivers spent 30 or more hours per week providing care (Sinha, 2013) – the equivalent of a full time job.

Gender differences in the amount of care provided were common. In 2012, the median number of hours spent providing care was similar for women and men (4 and 3 hours per week, respectively) although women were more likely than men to spend 20 or more hours per week providing care (17% versus 11%) (Sinha, 2013). Conversely, men were more likely than women to spend one hour per week or less providing care (29% versus 23%).

While the frequency of tasks provided by caregivers in Canada has been documented (Fast et al., 2010; Sinha, 2013), detailed information about the time spent by caregiving task is not available. One can infer that the greater intensity of care among women may be due in part to the types of tasks they commonly perform. Women were more likely than men to provide personal care, assist with medical treatments, and look after housework (Sinha, 2013) – tasks that must be completed on a set or frequent schedule. In contrast, men were more likely to assist with house maintenance and outdoor work (Sinha, 2013), tasks that occur less frequently and are easier to schedule around other commitments.

Impact of care labour

Using data from the 2002 GSS and unit cost data for hourly wages for different categories of workers from the 2007 LFS, Hollander and his colleagues (Hollander, Liu & Chappell, 2009) calculated the market replacement costs (the cost of hiring substitute services from the labour market) for unpaid caregivers aged 45 and older providing care to those aged 65 and older; they estimated the overall market value of this unpaid care at $25 billion in 2008-09.

More recent estimates of the care labour of Canadian caregivers’ aged 15 and older were not available.

Predictors of financial costs of caregiving

In the previous section we summarized the literature on the prevalence and magnitude of the three main domains of costs. These descriptive findings of the extent and magnitude of the monetary costs of care provide an overview of our state of knowledge of these consequences. They help make visible the magnitude of the contributions of Canadians to the care of adults with chronic conditions, and they point to differences across caregivers in the extent of costs based on characteristics of the caregiver and of the care receiver, caregiver-care receiver dyad, and the nature of care.

We will now further examine these risk factors. Understanding which caregivers are at increased risk of one or more financial costs is essential to inform development of policies and practices that might reduce these risks toward sustaining the family/friend care sector. Findings reported in this section come mainly from studies employing multivariate analytic techniques intended to isolate the influence of individual risk factors by controlling for others. Different data sources and definitions contributed to one of the challenges of understanding the predictors of financial costs.
Table 1 Factors that predict the financial costs of care for family/friend caregivers

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<th>Out-of-pocket Expenses</th>
<th>Caregiving Labour</th>
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Main sources of findings for predictors of financial consequences of care
10. Fast and Dosman (2013). Data source; FFS data (Monitizing the Cost...)
11. Magee (2004). Data source: SLID (one mention overall)
12. Fast and al. (2014). Data source: ?? (Combining Care Work and Paid Work...)
Risk factors are summarized in Table 1 for the three types of costs. The table reflects significant findings across all of the literature reviewed for this report and can serve as a guide to researchers as to what explanatory factors should be considered for inclusion in their own studies.

**Caregiver characteristics**

Descriptive findings foreshadowed some of the caregiver characteristics that are associated with risk for financial consequences: gender, age, health status, marital status, parental status, and education were important risk factors.

Gender was an important risk factor across all financial consequences. Women were more likely than men to be caregivers (Sinha, 2013); to have more episodes of care that occupied more years of their lives (Fast, Dosman et al., 2013); to spend more time providing care (Sinha, 2013); to experience greater employment consequences (Fast, Dosman et al., 2013); and to incur care-related expenses (Duncan et al., 2016). Women caregivers who were employed part-time were also more likely than those working full-time to forego job offers or promotions, or to lose a job because of their caregiving responsibilities (Fast, Dosman et al., 2013).

These findings were corroborated in analysis of Labour Force Survey data which showed that women were three times more likely than men to experience lost wages, to work part time, or be out of the labour force altogether in order to provide eldercare (Fast & Dosman, 2013). Given the fact that women in Canada have lower average incomes than do men, are less likely to have job-related pension plans, and contribute less to the Canada Pension Plan (Vincent, 2013), caregiving represents a much greater threat to women’s income security throughout their life course than it does for men (Fast, Dosman et al., 2013), suggesting a new double jeopardy of being female and a caregiver.

For the most part, age increases risk of financial consequences. Age was positively related to most employment consequences, with the rate of increase greater for women than for men (Fast, Dosman et al., 2013). Caregivers aged 45 to 64 were more likely than those aged 65+ to incur care-related out-of-pocket expenses (Duncan et al., 2016). In contrast, older caregivers were at higher risk of care labour. Those aged 65 years and older spent the most time on care labour (20 hours or more per week) (Sinha, 2013).

Women also were less likely to be in the labour force and more likely to experience higher employment-related costs closer to retirement (age 56+) when they may be caring for either their parents or their spouse (Fast & Dosman, 2013; Lilly, Laporte & Coyte, 2010).

There is substantial evidence that health is a risk factor for employment consequences. Caregivers in fair or poor health were almost three times more likely to exit the paid labour force than those in good or better health based on analyses of the 2007 GSS data (Fast, Dosman et al., 2013), LFS data (Fast & Dosman, 2013), and the Survey of Labour and Income Dynamics (SLID) data (Magee, 2004). Similarly, caregivers without activity limitations were three times more likely than those with activity limitations to be in the labour force at the time of the LFS survey (Fast & Dosman, 2013). Men in poor to fair health were between 4.6 and 5.1 times more likely to reduce paid work hours and miss days of work respectively than those in better health (Fast, Dosman et al., 2013). One study found that mental health was a risk factor for out-of-pocket expenses. Caregivers aged 45+ who felt stressed often or always by their care responsibilities were between 2.2 and 2.8 times more likely to incur care-related out-of-pocket expenses than those who never felt stressed (Duncan et al., 2016).

Marital status is a risk factor for care labour consequences. Those caregivers who were no longer married (either widowed or separated/divorced) were more likely than those who were married or living common-law to spend the most time on caregiving labour (20 hours or more per week) (Sinha, 2013). However, marital status or number of unions did not predict the probability of ever experiencing a care episode, number of care episodes ever experienced, or duration of caregiving (Fast, Dosman et al., 2013). No relationship was found between marital status and employment consequences (missing work days, reducing work hours or exiting the labour force because of care) (Fast, Dosman et al., 2013; Fast et al., 2014); nor for incurring care-related out-of-pocket expenses (Duncan et al., 2016).
Being a “sandwich generation” caregiver increased the odds that women (but not men) were absent from work because of caregiving (Fast, Dosman et al., 2013). Parental status had no effect on reducing paid work hours or exiting the labour force (Fast et al., 2014). However, those caregivers who were not raising children under the age of 18 spent more time on care labour than those with childrearing responsibilities (Sinha, 2013). This may imply that those without this competing demand had more time to allocate to care tasks.

Employment status of the caregiver is also a risk factor for employment consequences, incurring expenses and care labour. While self-employment is often seen as a strategy for increasing flexibility so as to better combine paid work and care work (Vosko & Zukewich, 2006), the evidence suggests instead that self-employment may increase the risk of some employment disruptions. Self-employed women caregivers were 4.7 times more likely than those working for an employer to report having reduced the hours they spent working at their own business because of their care responsibilities, while self-employed men were only about half as likely as men working for someone else to report reducing their work hours because of caregiving (Fast & Dosman, 2013). These accommodations compound the impact of caregiving on employment income.

Employed caregivers aged 45+ spent substantially less time providing care than their non-employed counterparts, for both women and men (Fast, Dosman et al., 2013). Similarly in 2012, Sinha (2013) found that those caregivers who were not currently employed (whose main activity in the last 12 months was retired or caring/household work) were more likely to spend the most time on caregiving labour (20 hours or more per week) than those working at a paid job or business (or looking for paid work).

Compared to caregivers in the paid labour force, retired women were 1.3 times more likely and retired men were 1.7 more likely to incur out-of-pocket expenses (Duncan et al., 2016). Caregivers with lower levels of education were least likely to miss days of work, reduce paid work hours or exit the labour force (Fast & Dosman, 2013). Education also was a predictor of duration of caregiving. The more education beyond high school that caregivers had the more years they spent providing care (Fast, Dosman et al., 2013; Fast et al., 2014) found that among caregivers aged 45+, those with some post-secondary education were at greater risk of incurring care-related out-of-pocket expenses than those caregivers who had not completed high school. Having post-secondary education may act as a resource to caregivers who are able to make changes to their employment and purchase services and supplies to accommodate their caregiving.

**Care receiver characteristics**

Two characteristics of the care receiver were associated with increased risk for all three domains of financial cost of care: severity of their health conditions and disease/disability type.

Caregivers with high demanding care situations (such as those caring for people with more severe impairment, or at end-of-life) reported more changes to their employment (Fast, Dosman et al., 2013; Fast et al., 2014), were 1.6 to 2 times more likely to incur out-of-pocket expenses (Duncan et al., 2016), and spent more time providing care (Sinha, 2013).

Care receivers’ disease or disability type increased risk of each domain of cost. Certain health conditions require more hours of care (Sinha, 2013). Conditions requiring at least 10 hours of care a week involved developmental disabilities or disorders, accident-related injuries (43%), cancer (36%), diabetes (33%), Alzheimer’s disease or dementia (32%) and respiratory problems (31%). The probability of reducing paid work hours was higher for those providing care to someone whose main health problem was cancer compared to those whose main health problem was other conditions (Turcotte, 2013). Similarly, those caring for someone with a cognitive condition were 2.8 times more likely to reduce paid work hours than those caring for a person with age-related conditions (Fast et al., 2014). However, caring for someone with an age-related condition did not, in itself, increase the likelihood of employment consequences except in the case of cognitive conditions.
The caregiver–care receiver relationship

Relationship has been found to be a main determinant of financial costs for both men and women. Those who cared for an immediate family member spent the most time caring (Sinha, 2013; Turcotte, 2013), had the highest total annual caregiving-related expenses (Turcotte, 2013), and were substantially more likely than those caring for other relatives and non-kin to have arrived late, left early, or missed days of paid work because of their caregiving responsibilities (Fast et al., 2014; Turcotte, 2013). For example, women and men caring for a parent (in-law) were between 2.9 and 3.7 times more likely to miss days of work than those caring for non-kin (Fast et al., 2014). Men caring for a spouse were 15.2 times more likely than those caring for friends or neighbours to miss days of paid work (Fast et al., 2014), while women caring for a spouse were 6.8 times more likely to miss days of work and 4.9 times more likely to reduce paid work hours because of their caregiving than those caring for non-kin (Fast et al., 2014).

Geographic proximity also influenced the type of financial costs incurred. Caregivers who lived with the person for whom they cared spent more time providing care (Keating et al., 1999) and were more likely to leave the workforce when caregiving demands were onerous (Fast et al., 2014). For example, those who lived with the care receiver were 3.2 times more likely than someone living at a distance (3 hours or more by car) to quit, be fired, or retire early from their jobs because of their care responsibilities (Fast et al., 2014).

In contrast, caregivers who lived at a distance were more likely to incur extra expenses (Duncan et al., 2016). Women who lived more than a half-day away from their care receivers were 2.6 times more likely to incur care-related expenditures than those who lived with the care receiver (Duncan et al., 2016). Compared to those who co-resided, men who lived more than a half-day away were 2.5 times more likely to incur out-of-pocket expenses and men who lived less than a half-day away were 1.9 times more likely. Yet for women only, those who lived in the same area were 32% as likely as those who lived with the care receiver to incur care-related out-of-pocket costs.

The relationship among distance, amount of out-of-pocket expenses, and hours of care provided warrants further investigation to clarify the effect.

The nature of care

Two characteristics of the nature of care influenced the likelihood of experiencing one or more financial costs: intensity of care and care history.

Intensity of care has been measured in several ways: hours per week of care; primary v. secondary caregiver status; provision of personal care; co-residence with the care receiver and number of types of tasks performed (Fast et al 2014; Fast, Dosman, et al, 2013; Lilly, Jacobs, Ng, & Coyte, 2011a; Turcotte, 2013). Regardless of how the concept is operationalized, intensity of care is typically found to be a key determinant of financial consequences of care.

Spending more time caregiving, providing a greater number of tasks, and caring for two or more people increased the likelihood of and amount spent on care-related out-of-pocket expenses (Turcotte, 2013). Similarly, those providing high intensity care were more likely to report experiencing employment consequences including disrupted work routines (Sinha, 2013), missed days of work (Fast et al., 2014), reduced paid work hours (Fast, Dosman et al., 2013; Fast et al., 2014; Sinha, 2013; Turcotte, 2013), and being out of the labour force entirely (Coyte, Jacobs, Ng & Lilly, 2012; Fast, Dosman et al., 2013; Fast et al., 2014; Jacobs, Lilly, Ng, & Coyte, 2013). The probability of reducing paid work hours was higher for those providing five or more hours of care per week, those providing five or more tasks, and those caring for at least one other person (Turcotte, 2013).

There was some evidence that the tipping point or threshold of intensity was different for employed men and women caregivers (Fast, Dosman et al., 2013; Jacobs et al., 2013). The likelihood of experiencing employment consequences was spending 20 hours per week on care tasks for women, and as few as 10 hours per week for men (Fast, Dosman et al., 2013). Crossing the intensity threshold triggered a cascade of employment consequences, including missed work days, reduced work hours, and labour force exit (Fast, Dosman et al., 2013; Lilly, Laporte & Coyte, 2010).
Interestingly though, former caregiving status was not significantly associated with the likelihood of current labour force participation, hours of work or wages. There was, however, considerable evidence that the periods in which individuals provided care were associated with transitions into and out of the labour force (Lilly, Jacobs, Ng and Coyte, 2011b).

Fast and her colleagues (2013) also found that having a more extensive care history increased the odds of care-related employment consequences. Each additional episode of caregiving that women experienced across their life course increased the odds that they had reduced their work hours during the previous 12 months by 5% and men were 5% more likely to report a recent care-related absence for each additional care episode they reported over their lifetime (Fast, Dosman et al., 2013).

The effect of spending more years providing care in total across the life course (whether in a small number of long episodes of care or a larger number of short ones) was also statistically significant, but the effect was small. Each additional year spent providing care decreased the odds of women currently being in the labour force by 3% (Fast & Dosman, 2013).

Evidence suggested also that beginning one's caregiving career in early adulthood (age 25-44) increased the odds of being in the labour force at the time of the LFS survey for both men (by 1.5 times) and women (by 1.4 times), but starting in mid-life (age 45-64) depressed the likelihood of current labour force participation for women by a third (Fast & Dosman, 2013). Men who were under 25 years of age at the first caregiving episode were 3.4 times more likely to be self-employed than those who never provided care (Fast, Dosman et al., 2013). Perhaps the early onset of care responsibilities requires caregivers to make long term life choices (such as not marrying, not having children, or limiting career paths) related to caregiving and work while those who acquire care responsibilities for the first time as an older worker struggle to make that transition.

Analyses of risk factors for financial consequences of caregiving provide the basis for our understanding of groups of caregivers who are likely to incur the greatest costs of care. These findings also give some direction to the areas of policy that might be most relevant to the reduction of costs for these high-risk groups. Discussion of the strengths of these findings and important gaps is presented in the next section of the report.

**Advancing knowledge of financial consequences of care**

The results presented in this synthesis illustrate the growth in our knowledge of the costs of family/friend caregiving from the first publications based on nationally representative Canadian data to current multivariate analyses of risk factors across domains of financial cost. This growth is due largely to the development of surveys that provide nationally representative data on these costs.

The knowledge gained from this research, however, is uneven. We know most about employment consequences and much less about out-of-pocket expenses. Despite great concern about the sustainability of the family care sector, we also know relatively little about care labour. Findings and their limitations are driven in part by available data. Topics chosen for surveys always are contested as survey length and cost are important criteria. The unevenness of findings also may reflect current policy priorities as government departments both support and draw upon these data to inform their agendas.

Given these constraints, it is not surprising that we have most knowledge about employment consequences of care. Labour force engagement is important to the financial well-being of individual caregivers, to workplace efficiency, and to the overall productivity of the economy. Descriptive findings suggest that there is some cause for concern about sustaining employment and care. The majority of Canadian caregivers are in the labour force. Differing frequencies of employment consequences suggest they try to manage with the least intrusive workplace adaptations: absenteeism, followed by reducing hours of work (e.g. going from full time to part time), or leaving the labour force. Employer surveys are beginning to find concern about caregiver distraction, poor performance and overall negative effect on workplace productivity.

Out-of-pocket expenses are reported by between 30% and 40% of caregivers. Estimates of expenses they incurred vary widely. One reason for such differences is that demands on caregiver financial resources will differ based on such things as needs of the care receiver (e.g. assistive devices such as
motorized wheel chairs are relevant to some disabilities; or types of living situations (e.g. housing adaptation costs will differ depending on current configuration of the home). A second reason is that until recently, data on these costs were collected at a high level so that detailed breakdown of costs is difficult. For example, in the GSS 2007, out-of-pocket expenses were 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. Amount of expenses was an ordinal variable with categories from less than $500 per month to more than $2,000 per month.

Although out-of-pocket expenses seem the most tangible/measurable of caregiving costs, there has been relatively little research activity around tracking care-related expenditures. This data gap is unfortunate since such out-of-pocket costs reduce caregivers’ disposable income and opportunities for saving or investing.

The GSS Cycle 26 (2012) is a step forward in providing data to conduct this research. It included more detailed data on out-of-pocket expenses including a breakdown of expenses by type: home purchase, maintenance and modification, professional services for care receivers health care or rehabilitation, hiring people to help with care receivers’ daily activities, transportation or travel related to care responsibilities, specialized aids or devices, prescription or non-prescription drugs and other (open ended question). For each category the respondent was asked to estimate expenses. If they were unable to give a precise estimate, they could respond with categories from under $200 through $5,000+. Respondents also were asked whether they have experienced financial hardship (reduce savings, sell assets, declare bankruptcy, etc.) because of their caregiving responsibilities. Further research on care-related out-of-pocket costs and the financial outcomes of these extra expenses using this nationally-representative dataset is warranted.

Most puzzling of all is the lack of focus on care labour—surely the focal point for understanding the sustainability of the family care sector. While there is a large body of research on caregiving and caregivers, the vast majority of studies of the consequences of caregiving assess the social and health impacts of caregiving. As a result, we have surprisingly little information on the financial consequences of time spent in caregiving labour.

We know from studies reviewed for this synthesis that Canadian caregivers are a large and growing workforce, often caring for more than 1 person across a variety of tasks. Like out-of-pocket expenses, we have overall estimates from caregivers of time spent in care labour with median amounts of 2 hours per week for those caring for grandparents to 14 hours per week for spouses. And there are indications of tipping points of amount of care labour that can lead to a cascade of other consequences. It’s time to collect data on time spent across each of the caregiving tasks.

Given the uneven nature of knowledge about the three domains of costs, it is not surprising that little is known about the interrelationships among these costs (Shooshtari, Duncan, Roger, Fast & Han, in press). We don’t know for example the circumstances under which caregivers might substitute caregiving labour for labour force participation. We don’t know whether caregivers who have left the labour force substitute care labour for the purchase of assistance which is no longer affordable. Nor do we know how long term caregiving influences employment trajectories or long term retirement and pension benefits in Canada. We know little about whether employed caregivers incur more out-of-pocket expenses for the care recipient than those who are not employed, or whether the latter reduce their standard of living in order to afford the best possible care. We don’t know the extent to which more distant members of care networks take on the main out-of-pocket expenses while nearby members do more direct labour. These questions are the new frontier of knowledge on the costs of care.

Transitions into and out of caregiving can occur across the life course, and caregivers often have multiple caring episodes across their lives. Evaluation of life course factors that influence cumulative caregiving costs could move forward our understanding of the balance of care labour, out-of-pocket and employment costs at different lifecycle stages. We know for example that transitions into parenthood increase out-of-pocket expenses and caregiving time and often lead to employment consequences such as reduced labour force participation. Similarly, career stage or type of employment of one or more members of care networks may influence the ways in which they negotiate who will shoulder costs in each of the three domains.
There are relatively few Canadian studies that estimate the financial value of lost wages and benefits in part because of a notable gap in information about cumulative losses of people who have foregone employment or left the labour force early because of long-term care responsibilities. Nationally representative Canadian surveys often restrict questions to labour force participation within the past 12 months, resulting in exclusion of those who have left the labour force or never entered the labour force and who consequently may have the highest long-term employment-related costs. Those who had left the labour force more than 12 months previously to provide care were not captured in the 2007 Cycle 21 GSS survey. However, the problem of exclusion of those who have withdrawn from the labour force (e.g., retired early to provide care) and employment consequences for those who are self-employed has been resolved in the 2012 GSS Cycle 26.

Across Statistics Canada surveys, information on care labour is not structured to allow for detailed analyses of consequences. There is some information about how much time is spent on different care tasks in the Participation and Activity Limitations Survey (PALS), Canadian Community Health Survey (CCHS) and GSS Cycles 21 and 26. PALS has a module on care tasks received and amount of time the caregiver spends from the perspective of the respondent care receiver collected through a post-censal survey of people identified in the census as having an activity limitation. In the 2009/2010 CCHS there is a module on ‘home care and care receiving’ but only 1 or 2 questions about whether any of the ‘home care you received was provided by a family member or friend’ and thus no option for costing care labour. In GSS Cycles 21 and 26 there are questions about time spent in general categories of care tasks. Estimates of time spent are crude because they are based on recall questions for the last 12 months.

The GSS time use surveys have the most detailed information on all activities throughout the day, although these data sets (the last one was 2009) have not been used extensively to estimate care time. There are questions about time spent on care tasks in the recall diary in which the respondent is asked to report on activities during the last 24 hours starting at 4am and there are some stylized estimates of time spent providing care to someone who lives outside of your household. Questions are asked about two different groups of people. There are activity codes for ‘personal care’ and ‘medical care’ provided to someone inside the respondent’s household. When a respondent reports doing housework, meal preparation, home maintenance/repair, etc., they are asked whether or not they did these things for someone outside of their household. In some of the surveys they were then asked whether that person was over age 65 and whether they had a disability. The advantages in this survey of detailed information on daily use of time must be balanced with disadvantages including the fact that many care tasks are not done daily and these may be underestimated in a 24 hour recall diary. Attempts are made to address this issue through the stratification of the sample by day of the week and month. Perhaps a more important disadvantage is that only personal or medical care to someone in the household are coded. Thus care tasks such as meal preparation, laundry and transportation are excluded. Coverage of care tasks for recipients outside the household is broader but nothing is known about the care recipients.

Informing policy to support family caregiving

Canadian findings reported here point the way to the need for broad policy/values discussions relevant to the sustainability of the family care sector. At the broadest level, discussions are needed about the place of both public and private sector programs in ameliorating the financial costs incurred by family caregivers.

A point of departure is the longstanding debate about the place of the state in family affairs. Family caregiving is now part of the public discussion though as yet there has been little national debate about whether the public benefits that accrue from family care (in areas such as unpaid labour or out-of-pocket costs incurred by family caregivers) should be compensated.

In 2010, the British Columbia Law Institute and the Canadian Centre for Elder Law have undertaken a comprehensive review of international programs on caregiver compensation (such as care allowances, family caregiver wages, and transferrable payments to care recipients). In so doing, they raised provocative questions concerning what approaches to compensating care labour in Canada are most appropriate to Canada’s values, policy goals and existing policy infrastructure. They concluded that the most direct way to recognize and compensate care labour was through direct payment (British
Columbia Law Institute and Canadian Centre for Elder Law, 2010). In terms of care labour, a key question is why Canada has been so reluctant to provide financial compensation to family caregivers? Different questions arise in relation to employment consequences — a financial cost to caregivers that is receiving considerable national attention, although the discussion is focused on the ways in which employers might help family caregivers be more productive. Increasing recognition by employers of the need to maintain and support employed caregivers is admittedly a promising development. The 2015 release of the Employer Panel for Caregivers report by Alice Wong, Minister of State (Seniors), (Employer Panel for Caregivers, 2015) is illustrative of the approach to engaging labour market players in reducing caregiver costs.

Yet workplace policies to date are piecemeal and discretionary. The national debate that needs to occur is whether paid employment should trump family care. Data in this report suggest that many caregivers have few choices but to compromise their labour market involvement in order to ensure that their relatives are cared for. The resulting costs to caregivers in lost income and benefits, to employers in reduced productivity, and to Canadian society in lost income tax revenues and increased demand for public assistance need to be addressed.

Policy directions to address out-of-pocket costs are less coherent and have been virtually absent from public discourse. This absence may be a result of lack of data on these costs so that their magnitude or long-term impact on caregiver sustainability is unknown. It also may be because these costs may be incurred for a diverse set of products and services only some of which might be amenable to public sector interventions. For example, knowledge to date of the main sources of these costs include prescription medications (covered in part by some provincial legislation such as BC Pharmacare); home adaptation (covered from time to time by various homeowner grants from federal programs such as Canadian Mortgage and Housing Corporation); or transportation (sometimes supplemented through municipal transportation programs for persons with disabilities). Areas of out-of-pocket costs need to be better identified so that policy interventions can be targeted to specific cost areas.

Finally, at the individual level, a key concern for policy makers and service providers is identifying which caregivers are at highest risk for financial consequences that might render them unable to sustain their caregiving activities or their employment. Findings from Canadian research reported here indicate that a mix of caregiver characteristics, care-receiver relations and care contexts affect the magnitude and prevalence of financial costs. Despite limitations on the data available to construct our understandings of domains of costs of care, we are beginning to understand patterns of risk for these consequences. Three stand out as important across all consequences: gender, caring for an immediate family member, and employment status.

Findings that women are at higher risk of financial consequence are congruent with our longstanding knowledge of women as the key family caregivers. Women also earn lower wages than men on average (and in many cases even at the same jobs) and so face lower opportunity costs of time. This situation can mask the inequities in the financial impact of caregiving: women are more likely than men to experience all of the financial consequences of care and, because they earn less than men on average, the implications of lost earnings and higher out-of-pocket expenditures may appear to be less severe when examined at the population level. New findings noted in this synthesis illustrate that caregiving places Canadian women at much higher risk than men of income insecurity across the life course. Such indicators of financial risk resulting from the gendered work of family care are another example of the societal costs of leaving unpaid work outside of the Canadian GDP.

Caring for close family members, especially spouses and parents, was another important risk factor. It was associated with more hours of care, highest out-of-pocket expenses and all employment consequences compared to caring for more distant kin or friends and neighbours.

Our understanding of how employment status is a risk factor is still tentative. Those who are self-employed experience more consequences. However, we don’t know whether self-employment itself is a strategy to handle care responsibilities. Longitudinal data would provide opportunities to tease out causal relationships such as those between employment status and care.
Conclusion

This synthesis is a tribute to the progress made by those who produce Canadian data sets to inform our understanding of the costs of care, by those who use these data to create knowledge of these costs and by those charged with developing policies and programs to support caregivers and reduce costs.

While much has been accomplished, we are at the threshold of an era of critical need to sustain the family care sector. Forecasts of increasing need for care along with uncertainty about its availability mean that these debates about costs of care need to be placed at the forefront of national policies related to population aging. The conceptual and empirical work on domains of costs in this report provides a framework for that debate, and the information presented provides a state of data, of knowledge and of policy upon which to build a sound program toward containing costs and thus allowing this sector to thrive.
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