

The economic costs of care to family/friend caregivers:

A synthesis of findings

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Preamble

Findings reported here are based on a synthesis of results from a three-year program of research (2010-2013) on the economic costs of care directed by Dr. Janet Fast at the University of Alberta. Embedded within this interdisciplinary research program were five projects led by co-investigators Dr. Janet Fast (University of Alberta), Dr. Norah Keating (University of Alberta), Dr. Donna Lero (University of Guelph), and Dr. Karen Duncan (University of Manitoba). This synthesis report integrates findings from five projects that:

- Provided a framework and literature review of the economic costs of care to caregivers
- Examined Canadians' caregiving trajectories across the life course and risk factors for experiencing care-related employment consequences
- Estimated the monetary costs of eldercare-related labour market accommodations,
- Documented the prevalence, correlates, and social and economic consequences of care-related out-of-pocket expenses, and
- Documented the availability, accessibility and effectiveness of workplace supports for Canadian caregivers.

Methodology used:

- Systematic scoping review of 116 articles was used to examine the extent, range and nature of research on the economic costs to family/friend caregivers, to explore major influences on the magnitude of those costs, and to produce a synthesis of the existing literature.
- Analysis of Statistics Canada, General Social Survey, 2007 on family, social support, and retirement. Impacts of caregiving on employment are based on a sub-sample of 4,129 caregivers aged 45 and older.
- Analysis of Statistics Canada, Labour Force Survey (1997-2008) panel data on work interruptions of 4,870 caregivers to older adults (aged 65 and older).
- Analysis of General Social Survey, 2007, sub-sample of 6,306 family/friend caregivers to determine the incidence of and risk factors associated with care-related out-of-pocket expenses.
- Analysis of Hidden Costs Invisible Contributions (HCIC) 2007 national telephone survey of 260 family members/friends supporting individuals aged 19-65 who have high care needs to examine caregivers' out-of-pocket expenditures in greater detail than 2007 GSS permits.
- Comprehensive on-line voluntary survey of 291 employers and senior HR managers from across Canada in a diversity of workplaces (across size, sector, and industry); workplaces were sampled from all provinces.
- 25 semi-structured telephone interviews (conducted in English or French) with managers who had experience supervising employees with caregiving responsibilities, representing workplaces in a variety of industries and across sectors.

The Economic Costs of Care to Family/Friend Caregivers: A Synthesis of Findings

Families are a central feature in the debate about how societies will face the challenges of population aging. In much of the contemporary discourse, families are viewed as largely responsible for the care and support of their members with a chronic illness/disability. Yet increasingly, researchers and policy makers have expressed concern about threats to the caring capacity of families given changes in family size, composition and structure (such as later marriage and childbearing, and divorce, remarriage and blended families), more geographic mobility (including greater global mobility for work), high labour force participation rates of women and men (including later retirement), increasing longevity and below replacement birth rates, and proximity/distance to provide care (including trans-national migration). These socio-demographic trends, in combination with less access to formal health and continuing care services and a sustained global economic recession, have led to escalating economic and time constraints for family/friend caregivers and a spillover of costs onto employers since most caregivers are employed full time. These challenges make it imperative that we better understand the economic costs of care both to caregivers and to their employers in order to support and sustain family/friend care.

This first of two synthesis reports¹ focuses on *family/friend caregivers* of adults with chronic illness or disability, the economic costs they experience, and the factors that increase the likelihood and/or magnitude of risk. This synthesis report begins by setting the context, noting the increasing prevalence of family/friend care in Canada and demonstrating that caregiving is becoming a normative experience across the life course. We present a framework illustrating three distinct domains of economic costs for family/friend caregivers and integrate findings related to sub-categories of consequences within each domain. We discuss the short- and long-term economic outcomes in each domain and summarize the risk factors associated with employment consequences, out-of-pocket expenses, and caregiving labour. We conclude by identifying those caregivers who consistently are at greatest risk based on a synthesis of the literature and an integration of findings across projects in this research program.

1 in 4 Canadians is a family/friend caregiver

More than 1 in 4 Canadians (26% of men, 31% of women) or 3.8 million people aged 45 or older provided assistance to an adult with a long term health condition or physical limitation in 2007. While most (76%) cared for relatives, 24% cared for friends and neighbours. Between 2002 and 2007, the *proportion* of Canadians over age 45 who were caregivers grew by nearly 10% (from 19.5% to 28.9%), but their *numbers* increased by 65% (from 2.2 million to 3.8 million).

¹ The second synthesis report focuses on *employers* of family/friend caregivers, yet caregiving also has consequences for other stakeholders: care receivers, families of caregivers, communities and society.

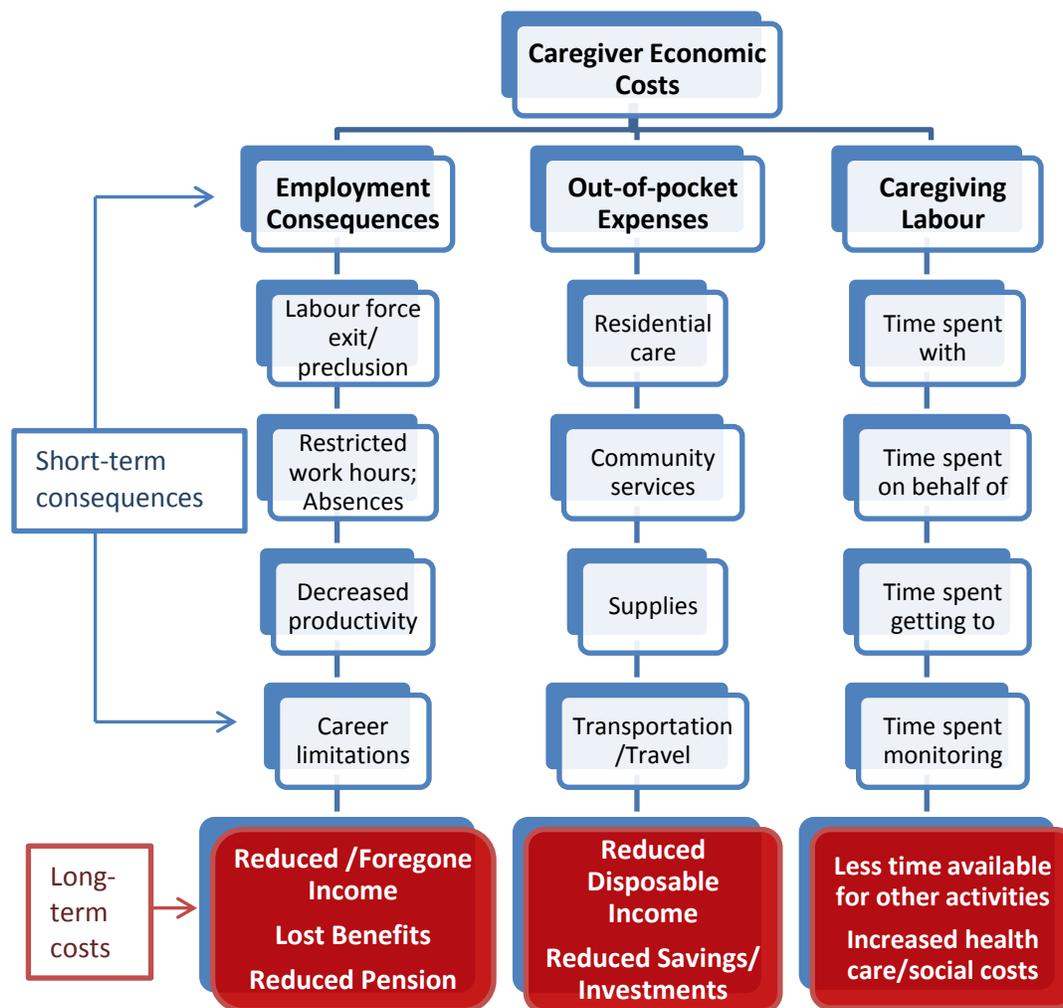
Caregiving across the life course is a normative experience: People often have 'caring careers'

Caregiving is increasingly a normative experience. More than half (52%) of all women and 40% of all men aged 45 and older have provided care to at least one family member or friend with a long-term health problem or disability at some time since they were 15 years of age. Both the mean number of episodes of care by those who experienced them (2.7) and the range (1 to 30) were identical for men and women. However, women spend more of their lifetimes (5.8 years on average) providing care than men (3.4 years on average).

Family/friend care has short and long term economic costs

As illustrated in Figure 1, there are three domains of economic costs for caregivers (employment consequences, out-of-pocket expenses, and caregiving labour) with sub-categories within each domain. Each of these three domains of costs (indicated by blue boxes) leads to a different set of immediate and longer-term economic outcomes for family/friend caregivers (indicated by red boxes), including reduced/foregone income, lost benefits, reduced pension, reduced savings/investments and increased health care costs. The identification of short and long term economic costs incurred by family/friend caregivers is key to making these economic costs visible, and part of a broader public discourse on the sustainability of family/friend care.

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



Employment consequences are common among the 2.3M employed caregivers

Most family/friend caregivers are employed. More than three-quarters, or 2.3 million Canadian caregivers of employment age (45-64 years), are in the labour force and most are employed full time (79% of women and 90% of men). Employed caregivers are systematically different from non-employed caregivers: they were younger, better educated, more likely to be married and to have young children at home. In other words, they have multiple competing demands. They also were less likely to be caring for non-kin, were less likely to co-reside with the person for whom they were caring, and spent less time on care tasks. Even so, employed caregivers devoted a substantial amount of time to providing care, averaging between 6 and 11 hours per week of caregiving (for men and women, respectively), the equivalent of $\frac{3}{4}$ to $1\frac{1}{2}$ normal work days, on top of their paid jobs and other responsibilities.

Employment consequences are common and reflect accommodations caregivers make in labour force participation, work scheduling and productivity, or career progression to meet their care demands. There are four subcategories of employment consequences: labour force exit/preclusion, restricted work hours and absences, decreased productivity, and career limitations.

Labour force exit/preclusion affects women more than men

Labour force exit/preclusion includes withdrawing from the labour force due to job loss, quitting a job or taking early retirement. Those who do not enter the labour force because of caregiving responsibilities assumed in early adulthood are considered to be precluded. A noteworthy minority of caregivers start their 'caring careers' early: 10% of women and 7½% of men caregivers, or 338,881 Canadians, first provided care as an adolescent or young adult (under age 25). According to the systematic literature review, caregiving at an early age can limit one's participation in education and work, affecting the development of job skills and future earnings.

Quitting or losing a job because of care was reported by only 2% of employed women caregivers aged 45 and older and 0.5% of men. Similarly, only 4% of all women and 1% of all men caregivers reported that they had retired early in order to provide care to a family member or friend. However, among all caregivers who reported that they had ever retired, a substantial minority (almost 13%) of women had retired in order to provide care. Although uncommon, these decisions have significant economic costs associated with them, especially for women.

Restricted work hours and absences are common

Restricted work hours/options include working fewer hours, missing days of work, working part time, rearranging schedules, or changing jobs or positions in order to reduce pressures or increase flexibility in paid work. Taking a leave of absence (paid or unpaid) is also included in this category. In fact, 39% of employers surveyed reported that one or more employees had taken stress leave or disability leave, at least in part as a result of their caregiving responsibilities.

The most commonly reported employment consequence is absenteeism. Thirty percent of women and 21% of men caregivers aged 45 and older had missed at least one full day of work to provide care in the previous year. Women who missed days of work were absent for more days than men (3.1 days per month on average compared to 2.4 days for men), and women who were employed full-time were more likely to be absent from their jobs to provide care than those who worked part-time. Indeed, over 520,000 employed caregivers missed one or more days of work per month to provide care. Collectively they missed nearly 1.48 million days of paid work in 2007.

The next most common employment consequence was reducing hours of work. Women and men were almost equally likely to report cutting back on their paid employment because of

unpaid caregiving responsibilities at 17% and 15%, respectively. However, women who reduced their hours of work once again reported a greater impact than men, reducing their hours by more than a full work day (8.3 hours) each week on average while men reduced their hours of work by an average of almost $\frac{3}{4}$ of a work day (5.8 hours) each week. In 2007, over 313,000 employed caregivers reduced their work hours to accommodate care responsibilities; collectively reducing their paid employment by over 2.2 million hours per week. Self-employed women were 4.7 times more likely than those working for an employer to have 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 reduce their work hours because of caregiving.

Decreased productivity

Decreased productivity can result from the absences noted above, but even those who remain on the job can be distracted by worry about the person for whom they are caring or by care management tasks that have to be squeezed into regular office hours. Many employers we surveyed reported that employees with caregiving responsibilities reduced their output, quality of work or performance level (47%), or seemed uncharacteristically distracted, made errors, became injured or put someone else at risk (33%), reflecting the degree to which caregiving negatively affects productivity while at work.

Career limitations: Employed caregivers sometimes turn down job opportunities because of caregiving

Career limitations are opportunity costs that caregivers may experience due to their care responsibilities, such as declining a job offer or promotion, turning down or postponing job-related training opportunities, and declining work-related opportunities such as work travel and relocation. Among those aged 45 and older, almost 5% of employed women caregivers and 3% of their male counterparts turned down a job offer or promotion because of caregiving responsibilities. Women caregivers who were employed part-time were more likely than those working full-time to forego job offers or promotions, or to lose a job because of their caregiving responsibilities.

Long-term outcomes of employment consequences: Caregivers' current and future incomes are reduced

Employment consequences result in two major types of economic outcomes: reduced current income and foregone future income, such as that associated with foregone job-related benefits and reduced employment-related pension benefits. Both current and past caregiving experiences matter when it comes to the likelihood and extent of employment consequences. Taken as a whole, findings suggest that the more extensive and demanding the caregiving experience, the more extensive the employment consequences. More caregiving episodes that encompass more years of caregiving across the caregiver's life course were associated with

both care-related employment consequences during the 12 months previous to the 2007 General Social Survey and with labour force participation and usual hours of paid work at the time of the survey. Women are more likely to accommodate their paid work to meet care demands, so they are more likely to experience the biggest economic impact, jeopardizing future income and pension entitlements.

Those caring for community-dwelling adults with high needs shared their experiences of the long-term outcomes of care-related employment consequences.

The hidden cost to me was the loss of my job. (Caregiver to non-senior veteran with service-related disability)

Our income is dramatically reduced: I would be making \$100,000 at the job lost due to it. His disability lump sum is no where near the salary he would have had, and he's lost the opportunity for another salary after military retirement. (Caregiver to non-senior veteran with service-related disability)

I had to retire early, lost \$70,000 in yearly earnings. (Caregiver to adult with spinal cord injury)

Number of employees who experienced lost wages because they were providing eldercare has nearly doubled

We had intended to utilize Statistics Canada's LifePaths microsimulation model to monetize the cumulative cost of care-related employment consequences. However, in the end we were unable to implement this plan due to unexpected data limitations. Instead, twelve years of Labour Force Survey panel data (1997-2008) were used to estimate the annual income losses associated with *eldercare* (care to adults aged 65 and older) across the adult life course.

The number of employees who experienced lost wages because they were providing eldercare has nearly doubled, from 359,823 per year during the period 1997-2002 to 697,711 during the period 2003-2008. Three times as many women as men reported accommodating their paid work to meet elder demands in both periods 1997-2002 (273,762 women v. 86,061 men (and 2003-2008 (521,881 women v. 175,830 men).

The patterns of employment consequences also differ for men and women. Men most commonly accommodated their eldercare responsibilities by taking part or whole days off from their work. Part- or full-day absenteeism also was the most common accommodation made by women (2003-2008), but women were much more likely than men to attribute their part-time paid work or lack of employment to their eldercare responsibilities.

Estimated annual income loss associated with eldercare-related employment disruptions is \$336.8 million

Estimates² of the lost wages associated with eldercare-related employment disruptions were modest (\$100-\$1,000 per year) for some individual caregivers, but much more substantial (more than \$16,000 per year) for others. Income losses from absenteeism were highest for both men and women between the ages of 55-64 (about \$400/yr). Income losses due to not working are highest for men between the ages of 45-54 (about \$12,500/yr), and for women between the ages of 55-64 (about \$4,000), at a stage of life when earnings would normally be at their peak, thus limiting women's ability to save for retirement and accumulate pension benefit entitlements. Overall, men's estimated lost wages were higher than women's in mid-life, consistent with the general observation that the gender wage gap increases with age (Drolet, 2001). Wage losses were higher for those with the least education. Those who were self-employed were more likely to report absenteeism and working part-time because of eldercare, but those working in the private sector lost more time when they made these adjustments. Collectively, the estimated annual income losses attributable to eldercare is high, ranging from \$220.5 million for women to \$116.3 million for men (in 2002 dollars) annually during the period 2003-2008. These losses were substantially higher than during the previous six year period (\$219.3 million between 1997-2002), almost doubling for women and increasing by 40% for men.

Risks associated with higher employment consequences

Caregivers at greatest risk of care-related employment consequences are: women (especially those caring for a child with disabilities); men caring for a spouse; those approaching retirement age (46-64 years); those in poorer health; those spending more years caregiving, and those spending more time performing care tasks. There is evidence of a threshold effect: it is the most intense caregiving situations that are likely to result in employment consequences. There also is evidence that the threshold may be different for men and women: 20 hours per week spent on care tasks for women; as few as 10 hours per week for men. Crossing the intensity threshold triggers a cascade of employment consequences, including missing work days, reducing work hours, and exiting the labour force.

Being self-employed was also associated with higher odds of experiencing at least one employment consequence. Men caregivers, and those who became caregivers at a young age (less than 25 years) were more likely to be self-employed, and self-employed caregivers were more likely to experience employment consequences, in particular taking full or part days off from their jobs and reducing their hours of paid work from full to part time. This restriction compounds the impact of caregiving on employment income.

² Results from analysis of the Labour Force Survey should be considered to represent lower bound estimates.

Education appears to be a protective factor in that those with higher levels of education are the least likely to be out of the work force and they lose less time when they take partial absences. Women and men caregivers with a high school education or less were the most likely to be out of the labour force entirely due to eldercare responsibilities.

Out-of-pocket expenses are extra expenses incurred because of caregiving

Out-of-pocket expenditures are those made by the caregiver that s/he would not have made in the absence of care responsibilities. They occur in four main categories: residential care, care-related community services, supplies, and transportation costs. Typically, these are expenditures for care, services or supplies for the care receiver, but they may also include out-of-pocket expenses for services that allow the caregiver to provide hands-on care, such as child care or housekeeping services for themselves that frees up their time to spend on care-related tasks.

More than 1/3 of Canadian caregivers incur out-of-pocket expenses

Out-of-pocket expenses are common. Nationally, more than one-third of Canadian caregivers (35%), or over 1.2 million people aged 45 and older, reported having care-related out-of-pocket expenses in 2007. This proportion rises as care demands increase or intensify. Among those caring for community-dwelling adults with high needs, a large majority (71%) reported incurring extra expenses because of their caregiving responsibilities.

Caregivers spent over \$12.6 million on care-related out-of-pocket expenses

Of those caregivers who reported incurring care-related out-of-pocket expenses, more than $\frac{3}{4}$ (80%) spent \$6,000 or less per year on average. One in six (17%) spent between \$6,000 and \$24,000 per year, and 3% spent more than \$24,000 in the year prior to the 2007 General Social Survey. Collectively, Canadian caregivers aged 45 and older spent approximately \$1,049,600 per month on care-related out-of-pocket expenditures in 2006, or almost \$12.6 million. In comparison, caregivers of community-dwelling adults with high needs spent on average \$7,599 per year, although there was considerable variability observed (range \$15-\$120,000 per year).

Out-of-pocket costs have the greatest consequences for low-income caregivers

Out-of-pocket costs have the greatest consequences for low-income caregivers. In 2007, nearly one-third of caregivers aged 45 and older who had care-related expenses (30%) had annual household incomes of less than \$30,000 per year, and of these, 82% spent less than \$500 per month on average, 14% spent \$500-\$2,000 per month, and 4% spent over \$2,000 per month on care-related out-of-pocket expenses. Similarly, low income caregivers of community-dwelling care receivers with high needs spent \$7,610 annually on average on care-related expenses, while those with annual household incomes of \$60,000 or more spent \$9,326 on average. Thus it seems that caregivers with low incomes who have care-related out-of-pocket expenses spend

proportionately more of their annual income (25% or more) on care-related expenses than those with higher incomes (15% or less), likely causing financial strain or hardship. Cycle 26 (2012) of the General Social Survey contains more detailed questions on out-of-pocket expenses, including whether respondents have experienced financial hardship because of their caregiving responsibilities.

Residential care

Residential care includes costs associated with a variety of supportive housing settings from nursing homes to lodges. In most cases, residential care is the responsibility of individuals, except for those who qualify for provincial subsidies on the basis of poor health and/or low income; co-payment rates vary across provinces. We found in our systematic literature review that when a care receiver co-resides with their caregiver there are also housing costs in terms of additional expenditures for utilities, regular household supplies, and home purchase, maintenance or modification to accommodate care receivers' needs. At least one in seven caregivers (15%) of community-dwelling care receivers with high needs spent additional money on home purchase and maintenance (\$2,913 on average) and home modifications (\$11,354 on average).

Care-related community services

Care-related community services includes fees or other costs related to accessing services provided by specialized health care providers and professionals on either an ongoing or occasional basis (physical therapist, geriatric assessment, lawyer, etc.), as well as for acute care services (ambulance fees, hospital stays or emergency room visits). Home care services, respite services, day support, and household help are other services that caregivers may pay for. These services often are not covered by our universal Canadian health care insurance system, and while they may be subsidized, typically a co-payment is required. Only those with very low incomes may be eligible for subsidies.

Nearly 20% of caregivers of community-dwelling care receivers with high needs incurred expenses for professional services for care receivers' health or rehabilitation, spending \$1,154 on average. Nearly one in seven of these caregivers spent \$2,050 on average for additional supports for the family (13%) and \$2,733 on average for personal assistance (12%). Six percent spent \$790 on average for animal assistance.

Supplies

Supplies includes food, clothing and personal items for the care receiver, as well as health and medical supplies such as medication (including supplements and vitamins), equipment (walkers, wheelchairs, etc.), and health supplies (incontinence products, wound care, pressure stockings, etc.). Medications were among the most common out-of-pocket expenses of caregivers of community-dwelling care receivers with high needs. Nearly half (44%) incurred costs for prescription and non-prescription drugs, spending \$1,027 on average. More than ¼ had expenses for specialized aids and devices, and clothing and footwear, spending on average \$1,755 and \$594 respectively for these items.

Transportation/travel

Transportation/travel consists of expenses for taxis, parking, gas, airfare, accommodation and meals that caregivers incur in travelling to, with, or for the care receiver. Transportation was

the most common out-of-pocket expense, reported by almost 60% of caregivers of community-dwelling care receivers with high needs. Those who incurred transportation and travel-related expenses because of their caregiving spent nearly \$4,000 a year on transportation alone.

Long-term outcomes of out-of-pocket expenses: Caregivers have less disposable income and fewer opportunities for saving/investing

Care-related out-of-pocket expenditures reduce caregivers' disposable income and opportunities for saving or investing. Over the long-term, these can threaten the economic security of some caregivers. Some caregivers may receive government program subsidies or tax credits that can offset some of their care-related expenses, however, these benefits are not always readily available or accessible. In all cases payments must be made immediately and reimbursement can be delayed. Many caregivers of community-dwelling adults with high care needs mentioned cost as a chief reason for lacking needed supports – either they were too expensive (60%) or not covered by insurance (67%).

Those caring for community-dwelling adults with high needs shared their experiences of the long-term outcomes of care-related out-of-pocket expenses.

In the last year, we've had to purchase a new house to accommodate (Care Receiver). The house had to be built with wide doorways, specialized bathrooms, and various other features. The additional cost to build all of these custom features into our new house did cost about \$50,000. (Caregiver to adult with cerebral palsy)

My daughter is living in one of my other properties and doesn't pay rent. This loss of rental income is about \$875 per month. (Caregiver to adult with mental health disorder)

We had to put out a considerable amount of out of pocket money to build our new home; to modify and make it comfortable for him; he's in a wheelchair. If you have money, then you have quality of life; otherwise, no good quality of life. (Caregiver to adult with spinal cord injury)

Risks associated with higher out-of-pocket expenses

Caregivers most at risk of incurring care-related out-of-pocket expenses were: those with post-secondary education, those with their own health limitations, those who are middle-aged or retired, and those who felt especially stressed by their care responsibilities. Also at higher risk were caregivers to someone with both physical and mental health problems, as well as those caring for a child or adolescent with a long term illness or disability, a spouse, and someone caring at a distance. Most of these risk factors are beyond anyone's control.

Caregivers, particularly women, who receive some type of financial assistance, from either public (through tax benefits) or private sources (from family and friends, or gifts from care receivers) are more likely to make care-related expenditures. Caregivers are not benefitting personally from these financial supports. Rather, they reinvest them in supporting care receivers.

Caregiving labour is valuable time

Caregiving labour refers to time spent by family and friend caregivers performing tasks and providing services to a care receiver because of that person's long term disability or chronic illness. Caregiving labour involves time, energy and engagement on the part of the caregiver, and includes four main categories: time spent with the care receiver; time spent on behalf of the care receiver; time spent getting to/from the care receiver; and time spent monitoring the care receiver.

2.2 billion hours of care is a significant contribution

Collectively, caregivers aged 45 and older in Canada provide an estimated 2.2 billion hours of care annually or the equivalent to 1.17 million full-time employees. The amount of time spent on care varies across caregivers and tasks. Women caregivers spend significantly more time than men providing care (13.6 hrs/wk vs 8.2 hrs/wk respectively). Non-employed caregivers spend more time than employed caregivers (17.4 hrs/wk for non-employed women and 12.0 hrs/wk for non-employed men vs 10.9 hrs/wk for employed women and 6.4 hrs/wk for employed men).

Time spent with the care receiver

Time spent with the care receiver involves face-to-face activities that are important to the quality of life, or even the survival, of the care receiver. They include: providing personal care (feeding, dressing, bathing and toileting), household help (such as housekeeping, meal preparation, laundry and home maintenance), transportation (for shopping, recreation and/or medical appointments) and attending medical appointments with the care receiver.

Time spent on behalf of the care receiver

Time spent on behalf of the care receiver includes activities done by the caregiver for the care receiver. These include tasks such as managing finances, coordinating care and services, shopping for the care receiver and crisis management. Nearly half of women caregivers aged 45 and older (48%) and almost 40% of men (39%) spent time on care management, such as scheduling or coordinating care tasks, making appointments, and managing finances.

Time spent getting to/from the care receiver

Time spent getting to/from the care receiver is the travel time involved in providing care. This category has only recently been recognized as having potential for significant amounts of time spent and likely will become increasingly important with high rates of geographic mobility in Canada. Two-thirds of caregivers aged 45 and older had a relatively short commute to provide care, living proximate to their care receivers. However, 15% of caregivers had a long commute, traveling up to half a day (10%) or more (5%) to provide care. Nearly half of employers surveyed (45%) knew of employees who were providing care or support to a family member in another province or country.

Time spent monitoring the care receiver

Time spent monitoring the care receiver involves checking in with the care receiver, problem solving with or for them, and monitoring the care receiver to ensure their health and safety.

Long-term outcomes of caregiving labour: Caregivers have less time available for other activities (including paid work) and risk negative impact on health

The two cost domains of caregiving labour and employment consequences are inter-related in that more time spent on caregiving labour can result in less time spent in paid work. This has implications for caregivers' current and future income and benefits. Time spent in caregiving also reduces the amount of time available for other activities that are important to caregivers, such as spending time with other family members or friends, and pursuing leisure and recreational interests. This has implications for caregivers' health and social well-being in the long term, which may in turn increase public or private expenditures on health care and other services for the caregiver. Those caregivers providing more intense care were more likely to report care-related health consequences. Further examination of the interactions between amount of care provided and social, health and economic consequences over the long term are warranted.

Those caring for community-dwelling adults with high needs shared their experiences of the long-term outcomes of care labour.

When he is laid up in bed, everything needs to be done for him, everything, bowel care, everything. I have to take off work because you can't leave him alone. I have to be there to train workers. It would be helpful if I could be compensated for this so there would be some money coming in. I work on contract, and if I'm not there I'm not paid. (Caregiver to adult with spinal cord injury)

The main cost for me is that instead of working outside the home I work at home. Because of the downturn of her health (Care receiver) has become my full time job. So the only cost is the loss of income. (Caregiver to adult with cerebral palsy)

Sometimes I need respite or a break but there is limited support for such activities. Supporting (Care receiver) daily for 30 years takes its toll and sometimes I wish that I could just have a break. (Caregiver to adult with developmental disabilities)

There is no affordable disability insurance for myself, and there is no compensation for caregivers who give up their careers to provide support. (Caregiver to adult with cerebral palsy)

Risks associated with increased caregiver labour

Family and friends who spend the most time on caregiving labour included: women, middle aged caregivers, not employed caregivers, caregivers with lower incomes, those caring for someone with more severe health conditions or disabilities (especially dementia) and living in the community. Primary caregivers, those caring for a close relative, living with the care receiver, and caring at a distance also were at higher risk.

Economic costs of care are interrelated

There is evidence of interrelationships among the three domains of costs. For example, spending more hours on care tasks is associated with a higher likelihood of experiencing care-related employment consequences for both men and women. Furthermore, women who provided more than 20 hours of care per week were 60% less likely to be in the labour force than women who had not recently provided care. Those incurring care-related out-of-pocket expenses were 5.6 times more likely for women and 6.3 times more likely for men to experience other employment and social consequences as well, such as turning down a job offer or promotion, postponing enrolment in an educational or training program, reducing social activities, cancelling holiday plans, or moving in with the care receiver.

Who is at greatest risk of economic costs?

There are several risk factors that increase the prevalence and magnitude of incurring employment consequences, out-of-pocket expenses or care labour. These risk factors are summarized in Table 1 and reflect characteristics of the caregiver, care receiver, caregiver-care receiver dyad or broader context (caregiving, workplace, community or policy). Based on a synthesis of the literature and integration of findings across all five projects in this research program, we identified several risks factors that have the most consistent pattern and the greatest impact on caregivers' short- and long-term economic outcomes. Although age was a risk factor in all three domains, the pattern of effects is not consistent, likely confounded with other factors. Below we identify those caregivers who consistently are at greatest risk of

experiencing economic consequences in all three domains: women, those with demanding care situations (intense amounts of care or care receivers with complex health conditions), those caring for close kin (children, spouses or parents), those living with the care receiver, and those caring at a distance.

Table 1. Factors that impact the economic costs of care for family/friend caregivers by cost domain

	Employment consequences	Out-of-pocket Expenses	Caregiving Labour
Caregiver characteristics	<ul style="list-style-type: none"> • Gender • Age • Education • Health • Employment status 	<ul style="list-style-type: none"> • Gender • Age • Education • Health limitations • Retired • Stressed • Low income 	<ul style="list-style-type: none"> • Gender • Age • Employment Status • Low income
Care receiver characteristics	<ul style="list-style-type: none"> • Disease/disability type • Severity of condition 	<ul style="list-style-type: none"> • Disease/disability type • Severity of condition • Age of care receiver 	<ul style="list-style-type: none"> • Disease/disability type • Severity of condition
Characteristics of the caregiver-care receiver dyad	<ul style="list-style-type: none"> • Relationship • Geographic proximity 	<ul style="list-style-type: none"> • Relationship • Geographic proximity 	<ul style="list-style-type: none"> • Relationship • Geographic proximity
Caregiving context	<ul style="list-style-type: none"> • Intensity of care provided • Care history 	<ul style="list-style-type: none"> • Receiving financial support from other sources (public or private) 	<ul style="list-style-type: none"> • Intensity of care provided • Care history • Care network size
Workplace context	<ul style="list-style-type: none"> • Availability of workplace flexibility and other supports 		<ul style="list-style-type: none"> • Availability of family leave programs
Community context	<ul style="list-style-type: none"> • Access to community services 	<ul style="list-style-type: none"> • Home or residential care setting 	<ul style="list-style-type: none"> • Home or residential care setting
Policy context		<ul style="list-style-type: none"> • Health care system 	<ul style="list-style-type: none"> • Availability and affordability of formal services

Women are at greatest risk of being financially disadvantaged

Taking on caregiving represents a much greater source of risk to income security throughout the life course for women than it does for men for a number of reasons:

- They are more likely than men to be a caregiver at some point in their life course
- They experience more episodes of care that occupy more years of their life
- They spend more time performing care tasks, particularly tasks that require their presence on a regular basis and that are less easily scheduled around other commitments such as paid work
- They are more likely to be caring for a child with a disability, which has the biggest impact on employment consequences and out-of-pocket expenses
- They are three times more likely than men to experience lost wages, to work part time, or be out of the paid labour force altogether in order to provide care
- They experience greater employment consequences than men, and the intensity threshold for employment consequences is higher for women than men, likely due to the type of care provided
- They incur higher care-related out-of-pocket expenses

Given the fact that in Canada women have lower average incomes than do men, are less likely to have job-related pension plans, and contribute less to the Canada Pension Plan, caregiving represents a much greater source of risk to women's income insecurity throughout their life course, particularly in their later years, than it does for men, suggesting a new double jeopardy of being female and a caregiver.

Those with demanding care situations are at-risk: intense amounts of care or care receivers with complex health conditions

Caregivers with demanding care situations, such as those caring for people with high care needs (more complex disabilities, greater severity of impairment, or at end-of-life) report more changes to their employment, have a higher likelihood of incurring out-of-pocket expenses, spend more on care-related expenditures, and provide higher amounts of care. The most intense caregiving situations are likely to result in care-related employment consequences, including being absent from paid work, reducing hours of paid work, and being out of the labour force entirely. Men and women were almost equally disadvantaged by intense caregiving responsibilities with respect to their labour force participation. Yet the intensity threshold is different for men and women: 20 hours per week spent on care tasks for women; and as few as 10 hours per week for men.

Those caring for close kin (children, spouses or parents) are at-risk

The relationship between caregivers and care receivers is another common factor across all three economic cost domains. Almost half of caregivers aged 45 and older cared for their parent or parent-in-law (46% of women and men) and 10% cared for spouses (10% of women and 11% of men). Overall those who care for a close relative (spouse or parent) spend the most time caring. Caregivers who are caring for a spouse or partner are more likely to retire, and more likely to incur care-related out-of-pocket expenses.

Women caring for a child or adolescent with a disability were most likely to reduce their work hours, experience absenteeism, and incur care-related out-of-pocket expenses. Caring for a child with a disability — a lifelong commitment — has been shown to affect family income and the capacity to purchase additional care supports (Statistics Canada, 2008).

Co-residential caregivers are at risk

Geographic proximity between the caregiver and care receiver is a contributing factor across all three economic cost domains. Caregivers who co-reside with the person they care for spend more time providing care, are more likely to leave the workforce when caregiving demands are onerous, and in the case of women, are 1.3 times more likely to have care-related out-of-pocket expenditures.

Those caring at a distance are at risk

Commuting time and travel expenses are most sensitive to the geographic proximity between caregivers and care receivers. Caregivers who live at a distance are more likely to make accommodations to their work schedule, have more absences to meet the needs of care receivers, are twice as likely to incur extra expenses and spend more on care-related expenses. Men living a half day's commute from their primary care receiver were most likely to reduce work hours. Findings on the relationship between distance and hours of care provided are inconsistent; additional exploration needs to be done to clarify the effect.

Those who are self-employed are at risk

Men caregivers were more likely to be self-employed, and self-employed caregivers were more likely to experience employment consequences, Taking full or part days off from their jobs and reducing their paid work from full to part time to accommodate eldercare demands was far more commonly reported among men and women who were self-employed than those

working in the private or public sectors. These work interruptions compound the negative impact of caregiving on employment income for those who are self-employed.

A multipronged and flexible approach is required

Findings clearly debunk the assumption that family/friend care is 'free' when provided by caregivers whose rewards lie in their fulfillment of family obligations and reciprocity to spouses or parents. Caregivers incur significant employment, out-of-pocket, and labour costs – costs that may jeopardize some caregivers' current or future economic security. Those at particular risk are women, those with demanding care situations, those caring for close kin, those living with the care receiver, those caring at a distance and those who are self-employed. Given the diversity among caregivers and among the persons to whom they provide care, a multi-pronged and flexible approach is needed to address the needs of caregivers at greatest risk economically. This includes increased awareness of the 'hidden' costs of family/friend care, effective workplace practices, informed public policies, and responsive community supports. The caregivers of today should not be the poor of tomorrow.

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